SAVVY CAREGIVER™

KNOWLEDGE. SKILLS. MASTERY.

Trainer's Manual

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Icons – Quick Reference

The Trainer's Manual uses several icons to provide you with guideposts through the text.

This icon is used when the manual is providing information about your task.

This icon will provide you with an overview of each session.

This icon signals an exercise, which are used extensively in this training program.

The specific directions for each exercise are enclosed in an area highlighted like this.

This icon signals a brief talk by the group leader (intended to be interactive).

This icon alerts you to a transition or a time to shift gears in the program flow.

This icon refers *to the home activities and assignments*.

You will learn more about all of these icons in the Introduction.

Introduction

Remember:

“You are the leader of this training program.”

Program Overview

The Savvy Caregiver Program and Your Key Role in It

What the Savvy Caregiver Program Seeks to Accomplish

Family caregivers occupy a critical place in the healthcare system for persons living with a form of dementia illness (PLWD) produced by Alzheimer's disease or similar illnesses. In fact, they are the center of the system. They provide the care, in all its dimensions, that enables the PLWD to remain in the community for as long as possible. Caregivers are often invisible in the larger system. Depending on the awareness and sensitivity of healthcare clinicians, a family caregiver may or may not be present when the person living with the illness is being examined or questioned. They may or may not be brought into care plan deliberations. They may or may not be given information about what is happening to the person or about how to provide care.

While a positive relationship with the care recipient is often the motive for caregiving, not all caregivers take on the role willingly or fondly. Not only do family caregivers go through their "unexpected career" as caregivers with mixed amounts of help and support, the overall experience tends to be very harmful to their physical and emotional health. Stigma still exists, so social isolation may ensue, and family conflict is not uncommon. Research indicates caregivers are terrible at taking care of their own health and wellbeing. As a result of all this, family caregivers are in the paradoxical situation of providing help that greatly benefits the person being cared for and contributing to society by keeping costs down, but doing all this while paying a high price for doing so and not attending to self-care needs.

Savvy Is a Training Program for Caregivers

The Savvy program is based on the notion that family members who become caregivers assume a caregiving role for which they are unprepared and untrained. The role is usually built on their relationship with the person for whom they care, but the role is different from the relationship. The role is a way of describing the work that they will undertake to care for the person. That role can be understood in terms of the **knowledge, skills, and attitude** that it takes to be able to do the work, to be successful at it, and to go through the experience with as much reward and as little distress as possible. As the name implies, the program is meant to enable and empower caregivers to be savvy as they go about the work of caregiving. As we use the term, being savvy means being "street smart" about caregiving, being confident about being able to scope out situations and develop informed plans or responses to them. It also means being ready to learn and grow in competence from whatever happens when the plan is put in play.

It is important to recognize – and to make the point clearly and explicitly with caregivers – that while we understand that a dementia illness can produce issues in relationships, the program is not going to deal extensively with these issues. Caregivers may face devastating losses in their relationship with care recipients, and the program acknowledges that caregivers need to attend to these relationship issues. However, our focus in this program is primarily about enhancing caregiving skills – the "how to" of taking on, doing, and succeeding in the daily work of caregiving. In the course of the program, part of the instruction will involve describing and encouraging a caregiving attitude or outlook that is based on the caregiver's ability to stand back from their person and caregiving situation, coolly analyze what is going on, and develop a plan of action to address the situation. This is a work skill. It is not meant to suggest a distancing in the relationship. Caregivers should be encouraged to acknowledge these emotional issues and to look elsewhere for help with them; the Alzheimer's Association support groups or personal counseling are excellent options to look for that.

You are the leader of this training program. The course is built on earlier versions of the program that were tested in research trials and that successfully increased caregiver confidence and reduced the adverse effects of caregiving. Savvy, itself, has undergone extensive field-testing and has likewise shown itself to improve caregiving confidence and sense of mastery and to reduce caregivers' sense of distress. Since its launch and over the past 20 years, the Savvy Caregiver Program has been delivered throughout the United States. It is promoted by the United States Department of Health and Human Services as a leading evidence-based dementia caregiver training intervention.

The unique contribution of Savvy is the angle it takes on caregiving and caregiver education. The many clinicians and educators who have contributed to the development of the program take the perspective that caregiving is a form of clinical work, and so caregivers need a form of clinical training. Throughout the program – and laced through the various program materials, like the Savvy Caregiver's Manual – the central concept that is emphasized is the notion of **strategy**. Over and over in the program, caregivers will be urged to learn, develop, and modify strategies that they will use to accomplish the goal of their caregiving, namely that caregivers will be able to guide their persons through days that are as safe, calm, and pleasant as possible. There is a parallel goal that caregivers can and should also have rewarding days as well; there is satisfaction in work well done, and, on occasion, the gratification of moments of connection with the person. These goals that the program asserts are manifested in the **Contented Involvement** of the person living with the illness in their daily life. In order to help caregivers develop such strategies, the program presents ideas that come from many disciplines and points them to information that comes from many sources. We don't claim these ideas or this information as our own; we provide citations and web addresses that both acknowledge the sources of these ideas and encourage the caregivers to explore further in the work and disciplines cited.[*] The program offers distillations of these ideas and pursues a particular teaching technique (termed, by some, psychoeducation) that emphasizes active involvement in learning, independent practice of the ideas presented in group sessions, and very interactive debriefing and coaching that reflects on the practice and experiments that caregivers do at home with their persons.

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[*] Thus, for example, the theory we use as the basis for Savvy and similar programs relies on the work of a number of psychologists. See, for example:

Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review, 84*(2), 191–215. https://doi.org/10.1037/0033-295X.84.2.191

Bandura, A., Adams, N. E., & Beyer, J. (1977). Cognitive processes mediating behavioral change. *Journal of Personality and Social Psychology, 35*(3), 125–139. https://doi.org/10.1037/0022-3514.35.3.125

Lazarus, R. S., & Folkman, S. (1984). Coping and adaptation. In W. D. Gentry (Ed.), *The handbook of behavioral medicine* (pp. 282-325). Guilford.

Core Savvy Principles

As you focus on trying to develop participants' mastery of the caregiving role, it is important to keep in mind the key ideas and values on which the program is based:

- ***Personhood persists***. The person living with Alzheimer's or a similar illness is always there, never eradicated. The illness progressively erodes the person's thinking capacities, behavioral and emotional control, and ability to do everyday things. It makes it progressively harder to be in touch with him- or herself and to make connections with the caregiver and with others. Nevertheless, the person's life story is still there. The person's interests and accomplishments are still there. The person's habits of speech and gesture are still there. The likes and dislikes – still there. Peculiarities and mannerisms – still there. They are there, but harder for the person to find and connect with. And, harder for the caregiver to see and tap into.

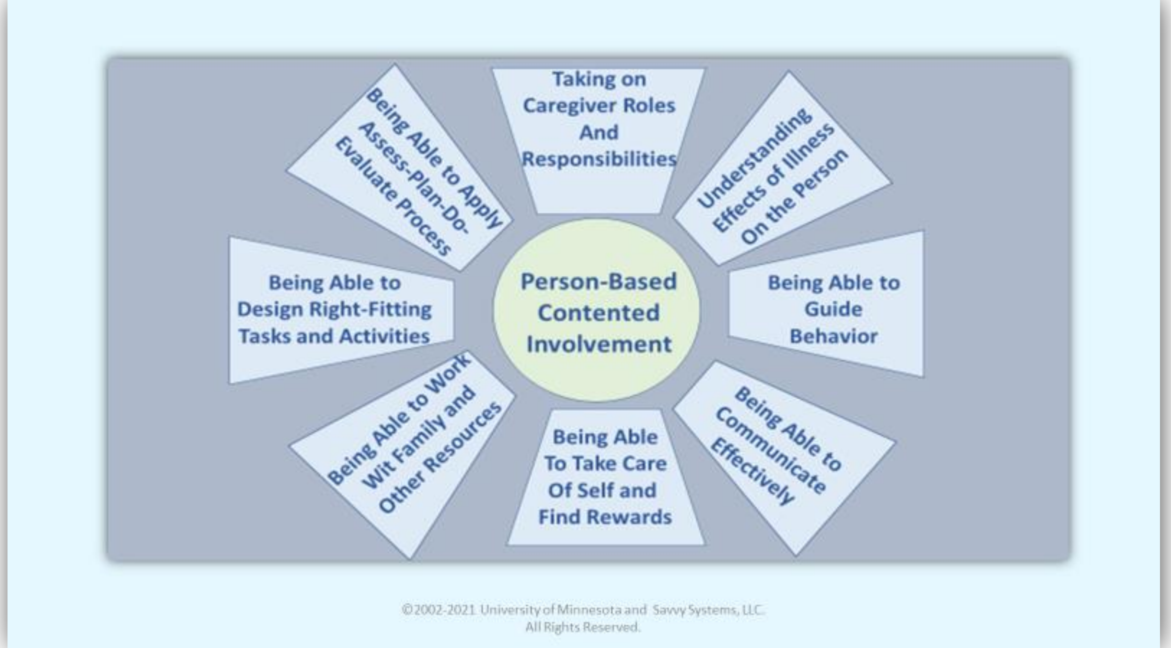
- ***Engagement is always possible***. The ability to become engaged in some activity – to zero in on something, become engrossed in it – is a very human capacity. Neurocognitive illnesses do not eradicate this capacity. They make it harder for a person to get to and stay in these zones of engagement, but it is still possible. A skilled caregiver – a Savvy caregiver – can learn how to use what s/he knows about the person and about what the illness has taken away from him or her to design tasks and activities that fit for the person. The Savvy Caregiver learns to promote Contented Involvement throughout the day.

- ***Caregiving is a role***. While individuals are motivated in a variety of ways – often based on relationship – to take care of a person living with a neurocognitive illness, caregiving is a role that can be described in terms of a set of activities the effective performance of which requires appropriate skills, knowledge, and outlook. Savvy is a training program for that role.

- ***Self-care is essential***. The caregiver is the instrument of the care recipient's wellbeing, and the instrument must be cared for. It is a basic rule for clinicians, like nurses and physicians and social workers, that the work is demanding, and ensuring one's own wellbeing is critical for effective performance in the role. This is true for caregivers as well.

- ***The Savvy curriculum is intentional and non-negotiable***. The program is designed to unfold in a way that both introduces material in an intentional sequence and expects participants to practice the material as an integral part of their learning. While adaptation of terms and ideas to fit the culture or capacity of learners is reasonable and advised, adding or deleting material or changing the order of presentation fails to maintain fidelity to the intent of the program and risks compromising its effect on the learners.

It's important to keep these principles in mind because the Savvy curriculum is so emphatic about ensuring that caregivers develop a clinical, objective perspective and become adept at developing and refining caregiving strategies. Words and notions like "objective" and "strategies" can seem very impersonal – and depersonalizing. Keep in mind that these enhanced capacities are meant to help the caregiver guide the person through days that are as safe, calm, and pleasant as possible. That is a core caregiving goal.



Person-Based Contented Involvement

Taking on Caregiver Roles And Responsibilities

Understanding Effects of Illness On the Person

Being Able to Guide Behavior

Being Able to Communicate Effectively

Being Able To Take Care Of Self and Find Rewards

Being Able to Work Wit Family and Other Resources

Being Able to Design Right-Fitting Tasks and Activities

Being Able to Apply Assess-Plan-Do-Evaluate Process

The Savvy program proposes that the best day-to-day indicator that that goal is being attained is that the person is contentedly involved in tasks and activities. The idea of Contented Involvement is quintessentially person-centered. It embodies the principle of enduring personhood in that it asserts that the human capacity to become engaged with something – a task or activity – remains throughout the course of the person's life with a dementia illness. As the slide here illustrates, all of the Savvy training is designed to keep the person at the center of care and to emphasize the importance of aiming for Contented Involvement.

The curriculum provides information about Alzheimer's and similar illnesses. It teaches about the illness-produced cognitive, behavioral, emotional, and performance losses that proceed through the stages of the illness may. In-group exercises and assigned home activities emphasize practice in designing and implementing engaging tasks and activities. All of these curricular components are aimed at promoting the caregiver's ability to implement daily tasks and activities that are grounded in who the person is and that promote Contented Involvement. Other elements of the curriculum – those aimed at self-care, family issues, and decision making – are meant to further equip the caregiver for this difficult role.

This slide is one that can be used to introduce the program, and variations of the slide will be used throughout the program as a way of reminding participants what they have learned, alerting them to the content of a particular session, and pointing the way ahead, in terms of content. Here and in its other appearances, the slide emphasizes the centrality of the person in the caregiving task. The program stresses engagement, and the set of skills it develops in caregivers is intended to enable them to design and provide engagement opportunities that are well matched to the strengths of their persons even as the illnesses with which they are living are shrinking those strengths.

Recurring Savvy Mantras

There are four messages that you will find yourself repeating across all of the sessions in one form or other. These are key take-away messages that we hope caregivers will take for their own and use to remind themselves of the mastery they've acquired and the techniques they've learned.

You're it! You're responsible; you're in control. You are central to your person's care. You are increasingly responsible for and in control of the person's daily life. Taking charge, giving directions, making decisions for another person as the illness progressively impedes the person's ability to do these things for him/herself are all actions that make us uncomfortable. Perhaps we even find them repugnant – because of the profound sense of respect for personal autonomy that we hold as a fundamental cultural value. To be successful in the role, a caregiver gradually has to take control of the situation and the person – while still affirming the persistent personhood of the individual. This is a progressive process, one propelled by the progress of the disease in the person. But in order to meet the modest caregiving goal this program proposes (calm, safe, pleasant days marked by Contented Involvement) and in order to retain his/her own sense of wellbeing, the caregiver has to recognize that the disease at work forces him/her to cross this line and to be in control.

Don't just do something…Stand there! Every part of the Savvy Caregiver program relates to the impact of Alzheimer's and dementia diseases on the person's thinking, feeling, behavior, and ability to do daily tasks and activities. The core message to caregivers throughout is: Watch carefully and methodically before giving a name to a behavior or trying to do something about it. The "Don't Just Do Something" mantra is shorthand for the "Assess-Plan-Implement-Evaluate" Savvy Process that is taught in the program.

All behavior has meaning. Watch the behavior and try to figure out what the person is trying to "say" by the behavior, because it does mean something. Deciphering the behavior isn't always easy, and the caregiver – as often as not – won't get at the meaning on the first try. But forming a response based on the best sense of what the person is expressing by whatever it is that s/he is doing gives the caregiver the best chance of restoring order to the world. Likewise, considering the meaning of positive responses (what worked?) allows the caregiver to guide the moment in that direction more often.

***Let it go!* (Curb expectations).** Alzheimer's and similar progressive illnesses affect everything. They progressively affect how people with the diseases look at and make sense of what's in front of them. These illnesses progressively affect persons' abilities to do things in the world, including how long it takes them to do things and how well they do them. They will never again be as good at doing things as they once were. They will never again do things well that they used to excel at. Caregivers have to recognize this, and they have to accept the fact that, as these diseases progress, the pace of the day will slow, and the quality of performance will diminish. To avoid frustration, their own and the frustration they will transmit to (and therefore provoke in) their persons, caregivers have to let go of expectations based on what the person used to be able to do. The caregiving goal – safe, calm, pleasant days marked by Contented Involvement – only means that the person has times during the day when s/he is doing something that is keeping him/her occupied and that s/he is deriving some kind of enjoyment from doing that. The goal has nothing to do with speed, accuracy, or excellence of performance. Caregivers will be happier and more relaxed if they can let go of those expectations and focus on the experience and the process instead.

A Word About Language

"Demented," and "dementing" are loaded terms, words that can be perceived as stigmatizing of the person living with Alzheimer's or similar illnesses. In some settings and cultures, the term suggests mental illness or that the person is "crazy." Although these are terms very much in common use, we have tried to be careful to limit their use in the program.

In order to assert the principle of persistent personhood and avoid subsuming the person beneath the illness, we emphasize that a person is **living with a dementia illness** (or with Alzheimer's or a similar illness), and we never refer to the individual as "the demented person." "Dementia" is certainly a familiar term, referring to a set of symptoms produced by Alzheimer's and other **neurocognitive disorders** (the term used in the most recent Diagnostic and Statistical Manual [DSM-5] of the American Psychiatric Association), so we continue to use "dementia" when appropriate to do so. We raise this point because you, as a Savvy program leader, may encounter caregivers who have run into difficulties with (or being stigmatized by) these terms.

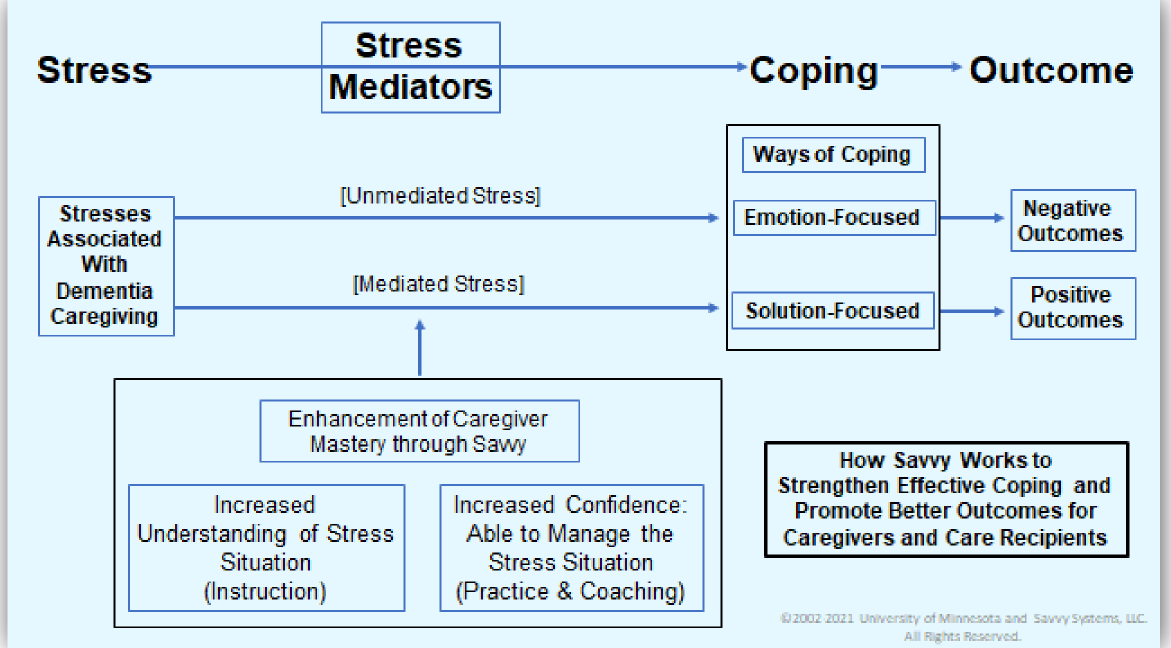
The Theoretical Basis of the Savvy Caregiver Program

The Savvy Caregiver program rests on the belief that caregiving is, essentially, a situation that places the caregiver under great stress. Not only do family caregivers have to deal with the day-to-day reality of the situation – making sure the person gets safely, securely, and pleasantly through the day – they are also dealing with their own struggle to accept the reality of the situation and with the feelings of sadness, loss, disappointment, etc. that go with this struggle.

Caregivers typically take on added responsibilities within the family. They become, de facto, the conflict manager and chief financial officer, as well as the full-time laundry and housekeeping staff. Beyond the home, the caregiver must also manage all the boundaries between the person and the various institutions with which they interact. They organize and manage medical care, financial and legal responsibilities, and family and social relationships. Caregivers are often faced with added financial pressures, having now to consider spending their own or the person's assets on care-providing services. They also have to manage all this from the center of the cyclone of a family system trying to deal with a situation they don't want and don't necessarily understand.

The ways caregivers handle the caregiving situation – how they cope with it – plays a critical part in how the situation turns out for both the caregiver and care recipient. Caregiving research shows that how well a family caregiver is able to manage their care demands will influence the quality of care, their own wellbeing and that of the person living with a dementia illness.

The cognitive/stress process framework upon which the Savvy program is based asserts that positive or negative outcomes of a stressful situation – such as dementia illness caregiving – are affected by the person's coping behaviors. The kinds of practical, solution-focused caregiving behaviors that the Savvy program hopes to promote contribute to more positive outcomes. The program likewise hopes to guide caregivers away from more emotion-focused coping behaviors, like wishing the situation wasn't happening or could somehow go away. These behaviors can contribute to more negative outcomes.



In relation to this conceptual framework, the Savvy program is built around two ideas:
(1) caregiving mastery – the sense of confidence the caregiver feels that s/he can handle things – is essential to successful coping (and, therefore, positive outcomes); and (2) caregiving mastery can be developed or strengthened. The "choice" of coping behaviors is influenced by a person's understanding of the stress situation (What exactly is happening?). Coping options are also influenced by an individual's assessment of his/her ability to manage the situation, or how well they feel they can master and manage the situation effectively.

The Savvy program provides instruction, practice, debriefing, and coaching activities to strengthen caregiving mastery and promote a more effective, solution-focused coping approach to caregiving and the development and enactment of a richer repertoire of appropriate and relevant caregiving strategies and skills. In dementia illness caregiving, strengthening a caregiver's knowledge and understanding of the disease and its effects is a critical component of managing caregiving successfully. To promote better outcomes for persons living with dementia illnesses and their caregivers, the Savvy curriculum provides clear, accessible information about the progressive nature of dementia cognitive diseases. Moreover, we describe the elements of thought that are affected by dementia illnesses in the associated changes /losses that result in the person's thinking, emotional and behavioral control, and everyday performance. The stress framework we use indicates that mastery is developed through instruction, successful enactment of suggested caregiving behaviors, and the witnessing of such successful enactments by caregivers in comparable situations.

The home activities and the debriefing and coaching segments built into the program are targeted to mastery development in equal measure with the instruction the program provides. In each session, the Savvy Trainer provides caregivers with the opportunity to report their efforts to successfully apply their increased knowledge and skills. The home activities are designed so that participants can apply what they are learning in every session to their everyday caregiving situations. Debriefing with participants will enable them to receive feedback on their efforts. Overall, an enhanced sense of caregiver mastery will promote Savvy Caregiver participants being able to effectively assess caregiving situations and plan and implement their own solution-focused caregiving coping behaviors to address these situations.

Gains in knowledge and skill, along with improvements in mastery and implementation of more effective caregiving strategies empower caregivers and provide them with a greater sense of competence in their new role. Ideally, both the caregiver and care-recipient will experience improved wellbeing (i.e., less distress; better quality of life for both; reduced behavioral and psychological symptoms of stress). Most caregivers will still experience distress, but as most studies have shown, it should be significantly reduced as a result of these new skills and outlook. Moreover, we expect that caregivers will also feel a greater sense of accomplishment and reward for their efforts as a caregiver. Similarly, the outcome for the person living with a dementia is also improved; more effective caregiving provides the person living with the illness with a higher quality of life, one in which they will feel greater comfort and less confusion.

The Savvy Evidence Base

The curriculum of the Savvy Caregiver program derives from research conducted at the University of Minnesota on family caregiver education programs. These programs all focused on providing training to family members caring for persons living with Alzheimer's disease or other related dementias. In both trials, the psychoeducation program produced significant improvements in participating caregivers' levels of depression and caregiver burden and in caregiving mastery.

The Savvy Caregiver program was similarly tested in a randomized multi-site trial. It produced results similar to the earlier trials; caregivers participating in Savvy showed significant improvements in depression, burden, and mastery compared to those who did not take part. [1]

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[1] Further information and research results can be found in the following publications:

Hepburn, K., Lewis, M., Sherman, C. W., & Tornatore, J. (2003). The Savvy Caregiver Program: Developing and testing a transportable dementia family caregiving training program. *The Gerontologist*, *43*(6), 908-915. https://doi.org/10.1093/geront/43.6.908

Hepburn, K., Lewis, M. L., Tornatore, J., Sherman, C. W., & Bremer, K. L. (2007). The Savvy Caregiver Program: The demonstrated effectiveness of a transportable dementia caregiver psychoeducation program. *Journal of Gerontological Nursing, 33*(3), 30-36. doi.org/10.3928/00989134-20070301-06. Posted 2007 Mar 1.

Kally, Z., Cote, S. D., Gonzalez, J., Villarruel, M., Cherry, D. L., Howland, S., Higgins, M., Connolly, L., & Hepburn, K. (2014). The Savvy Caregiver Program: Impact of an evidence-based intervention on the wellbeing of ethnically diverse caregivers. *The Journal of Gerontological Social Work, 57*(6-7), 681-693. doi.org/10.1080/01634372.2013.850584. Accepted author version posted online 2013 Oct 30, Epub 2014 May 12.

Samia, L. W., Aboueissa, A., Halloran, J., & Hepburn, K. (2014). The Maine Savvy Caregiver project: Translating an evidence-based dementia family caregiver program within the RE-AIM framework. *The Journal of Gerontolgical Social Work, 57*(6-7), 640-661. doi.org/10.1080/01634372.2013.859201. Epub 2014 May 15.

Sherman, C. W., & Steiner, S. C. (2018). Implementing sustainable evidence-based interventions in the community: A fidelity-focused training framework for the Savvy Caregiver Program. *Journal of Applied Gerontology, 37*(12), 1450-1471. doi.org/10.1177/0733464816684623. Epub 2016 Dec 25.

The Savvy Caregiver Training Program

The Savvy program focuses on informal caregivers (family members or friends) to help them acquire and strengthen knowledge, skills, and attitudes that are appropriate for the community-based caregiving role they have undertaken. [Of note: Savvy is not aimed at professional paid caregivers. Although paid caregivers might benefit from some portions of the training, the program is not specifically designed for them.] How informal caregivers understand and interpret the situation they're in, the kind of knowledge they have about what the disease is doing to their persons, the strategies they can bring to bear on the situation (strategies are skills and techniques that are informed by knowledge and honed through practice), and how competent or masterful they feel in the situation (how confident of their ability to manage the situation) all play big parts in determining how much the stress of the situation will result in negative or positive outcomes for caregivers and their care recipient. In essence, the Savvy program aims to empower caregivers to be more intentional, strategic, and responsive in their care role.

While the major program emphasis is on the family caregiver's acquisition of knowledge, skills, and attitude for caregiving, some sections of the training call attention to more than just the caregiver's personal resources (mastery). These sections focus on enhancing the caregiver's decision-making skills and on strategies for strengthening the family as a caregiving resource (involving other family members in the Savvy training can be useful as long as big family groups do not interfere with the group process or inhibit others' participation). In some cases, a Savvy participant may be in a solo situation; there is no family or friend network to which to turn. Savvy will help that person to clarify this situation. Caregivers are directed to websites (such as those maintained by the Alzheimer's Association and the Administration for Community Living) where they might find help identifying community-based resources for caregiving. Ideally, local Savvy sponsors provide information about relevant local resources available to caregivers.

Below are the areas of knowledge, skill, and outlook (attitude) taught or developed in the program:

✓ ***Information and Knowledge*.** Many caregivers simply do not have the facts straight about what it is they are dealing with. The program is designed to help them understand that:

- They are dealing with a real disease; there is actual pathology that is affecting the person's brain.
- Virtually all of these illnesses are progressive, irreversible, and terminal.
- Alzheimer's and most other neurocognitive diseases can be characterized as progressing in broad stages; the disease stage has great relevance for designing caregiving strategies.
- Much of their caregiving work will entail dealing with behavior.
- All behavior has meaning and represents a form of communication.
- Caregiving can and does have its rewards, but it almost always takes a big toll on caregivers.

Caregiving occurs in context. Savvy teaches many key ideas, but the program's words and ideas are heard, filtered, and made use of within the context of a caregiver's cultural, ethnic/racial, and social background. For example, Savvy uses "dementia" to describe the process of the illnesses affecting care recipients, but the program never uses “demented” to describe the person who is living with a dementia illness.

Likewise, the program never identifies those who are being cared for as a “loved one” because, while many care recipients are in fact loved ones, there are many for whom the caregiver would not apply this term. In consequence, be prepared to engage with caregiver participants in conversations to enable them to absorb and enact the Savvy key ideas within their own personal and familial contexts.

Skills. Caregiving is a complex job and entails many tasks. Since the principal task of the caregiver is to manage day-to-day life with the person, these are the skills on which the program focuses. There is one “meta-skill” the program seeks to develop: a basic process for planning tasks and activities or for responding to behaviors that seem difficult or disturbing. It is useful for you, as a trainer, to understand that the root skill Savvy is teaching is a process – illustrated in the slide on the next page – that is common to most clinical professions. This process includes: Sizing up a situation (Assess); Using the assessment and one’s fund of knowledge to settle on a way to handle the situation (Plan); Moving forward with confidence (Implement): and Seeing how it works out (Evaluate). The evaluation adds to the individual’s fund of knowledge (that worked, so keep it; that didn’t quite work, so tinker with it – or don’t try it again). Thus, as the process continues with the next situation, the assessment is strengthened by the prior experience and evaluation.

In particular, the program is designed to develop the following skills:

- How to consider the person’s disease-produced losses – in cognition, behavioral and emotional self-control, and the performance of everyday activities – in the manner in which they interact with the person
- How to understand that “behavior” is neither good nor bad. It represents a form of communication by a person whose illness is progressively limiting this ability.
- How to take the person’s disease stage into account in developing caregiving strategies, including communication strategies
- How to choose and design – and help the person become and remain involved in – daily tasks and activities that allow the person to be contented throughout the day
- How to avoid and/or handle difficult situations

The program also provides instruction in:

- Important self-care skills – especially those related to understanding and managing caregivers’ own feelings
- Skills for making decisions as they continue their caregiving career
- Skills for navigating family issues that come up while providing care – including asking for help

✓ ***Outlook or Attitude***. The program aims to foster an increased sense of self-acknowledged caregiving mastery. There are at least three areas of attitude that the program tries to affect:

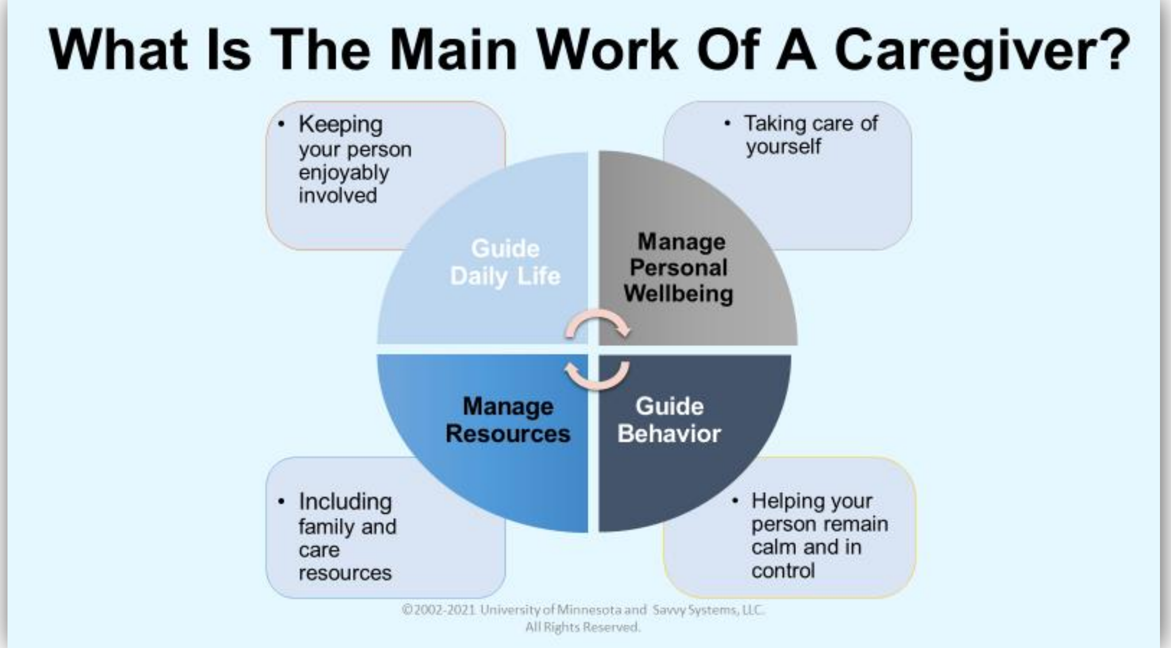
- **Objectivity.** Caregivers have to learn to become less emotionally involved – at least when they are trying to figure out a caregiving problem – and more “clinically detached.” This attitude is embodied in the program’s use of “savvy” in its title. The idea of being savvy implies something like being “street smart.” It is meant to evoke an image of someone leaning a bit back, head tilted a bit to the side, reading the scene in front of him or her with an air of assurance that this is a situation that can be sized up and managed. With this in mind:

  - We want caregivers to become more analytical and experimental in their caregiving – like a detective or a scientist, like a nurse or a physician.
  - We want them to be able to step back from the person and the situation and to examine – objectively and dispassionately – just what they are seeing. This ties in especially with the message that all behavior has meaning and is a form of communication.
  - We want them to be able to put that observation together with other knowledge they gain from the program to be able to create a plan for what they want to have happen and how they will get it to happen.

- **Self-Confidence (Mastery).** Caregivers have to believe they can do the work of caregiving. The program fosters growth in self-confidence through the home exercises and in-group coaching that constitute most of what happens in the latter part of the program. Caregivers learn new skills through trying them. They become increasingly confident of their abilities through the successes they experience in practicing the new skills using their newfound knowledge.
- **Self-Value.** We want caregivers to appreciate their own work and worth.
  - They should be clear about why they have undertaken this role (motives), be able to state the objectives they have in mind for it (what they hope to accomplish), and be able to say what it is they want to get out of it (rewards and satisfactions).
  - They should recognize the vital importance of self-care; they have an obligation to preserve their own health and wellbeing.
  - They should recognize their right and need to ask for – and expect – help with their caregiving.

The Focus of the Savvy Caregiver Program

The diagram below portrays what the Savvy Caregiver program is about. At the center of the program is the assertion that caregiving is work – a task or role – and that (for almost all who fill the role) it is work for which most caregivers are unprepared and untrained. The Savvy Caregiver program provides training for the caregiving role.



What Is The Main Work Of A Caregiver?

- Keeping your person enjoyably involved

Guide Daily Life

- Taking care of yourself

Manage Personal Wellbeing

Manage Resources

Guide Behavior

- Including family and care resources

- Helping your person remain calm and in control

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The four quadrants represent the main content of the program. Each area of content is described briefly below.

1. **Manage Daily Life.** This area of content makes up the majority of the content of the program. The first four sessions of the program deal, in sequence, with the impact of Alzheimer's and similar progressive illnesses on the person living with the illness. The idea is to take caregivers through the ways in which these illnesses affect cognition, behavioral and emotional control, and the ability to do things in life. Each of these four topics is presented in the same way and with the same objective in mind:

   - First, the content of instruction – and this material is typically provided both in the form of talks that you will give and in written information in the Caregiver's Manual – concentrates on how the disease affects one of four areas. Basically, the instruction unpacks for the caregivers the ways in which these diseases gradually erode the person's abilities to: (1) use normal thinking powers; (2) maintain emotional balance; (3) direct his/her own actions; and (4) do everyday things.

   - Next, each of the losses presented is looked at from the perspective of the caregiver. The basic question that is addressed is: as the illness erodes this capacity in the person, what should you expect? How should you prepare yourself for what you are likely to see happening?

   - Finally, each section on losses ends with a focus on the development of caregiving strategies: if this is what's happening to the person, and if this is what you can expect, what might you do to make this situation as positive as possible?

   The idea is that caregivers acquire greater and greater responsibility for getting themselves and their persons through each day as successfully and effortlessly as possible. The program teaches that the caregiver is responsible for guiding and managing the day and that, as the disease progresses, s/he becomes more influential in this process. In order to succeed in this task, the caregiver has to develop a caregiving repertoire – a set of strategies (a tool kit; a “bag of tricks”) s/he can call on both to structure the day and to respond when things don’t go as planned (and to protect him/herself from the possible emotional damage – and even physical harm – that can occur). In all of this, it is useful to have a general caregiving goal in mind, and ***the program suggests that an appropriate and feasible caregiving goal is to help the person have days that are as calm, safe, and pleasant as possible***. ***The indicator that this goal is met is that the person becomes and remains content and involved in everyday tasks and activities.***

The program teaches a number of techniques for enabling the caregiver to help his/her person experience this calm and engagement. The core technique involves designing tasks and activities that are likely to reflect the person’s likes and preferences, that are structured in ways that fit the person’s current capacities, and that are initiated and maintained through methods of communication that likewise fit the person’s current capacities. Tasks and activities include all the daily activities of living like bathing or washing up, dressing, toileting, etc.; they also include doing things in the hours between breakfast and lunch, lunch and dinner, and dinner and bedtime.

To help caregivers get a handle on their person’s current capacities, the program teaches a **staging system** that helps caregivers understand how a dementia disease like Alzheimer’s affects the person’s ability to do things. The system uses a simple four-stage system (Early/Early-Middle/Late-Middle/Late) drawn from the occupational therapy-based Allen Cognitive Levels.[2] As part of the program, participants may arrive at a working (“ballpark”) estimate of their person’s disease stage. The program then links this estimate to strategies of **Structure** (the design of and environment for tasks and activities) and **Support** (methods for communicating with the person to help him/her begin and stay with a task) that help caregivers design tasks, activities and events appropriate to their person’s strengths and likely to help them become engaged. The program encourages the development and/or strengthening of daily routines to promote comfort and familiarity.

2. **Guide Behavior.** Behaviors exhibited by persons living with dementia that caregivers perceive as difficult or disturbing are strongly linked to caregiver distress and burden. The program attempts to give caregivers a basis for understanding behaviors that likely represent an effort by the person living with the illness to communicate his/her own distress or discomfort. Moreover, it provides strategies for avoiding, subduing, and/or responding to such behaviors.
   Responsive strategies help stop or reduce behaviors in intensity so that the caregiver is less troubled by them. The program encourages caregivers to develop strategies – reliable or routine responses to frequently occurring situations that they find troubling. A common example is developing one or two standard answers to their persons’ repetitive questions.

3. **Manage Personal Wellbeing.** Caregivers often experience feelings associated with caregiving that can be overpowering and even incapacitating. The program examines the socio-emotional impact of caregiving on caregivers and provides tools for caregivers to examine their own feelings and to do something about them. Savvy especially focuses on those feelings that are negative and/or reinforce

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[2] See: Allen, C. K. & Blue, T. (1998). Cognitive disabilities model: How to make clinical judgements. In N. Katz (ed.), Cognitive rehabilitation: Models for intervention in occupational therapy. Bethesda, MD: American Occupational Therapy Association.

a sense that they are powerless in the situation. The program also urges caregivers to examine their own personal interests – hobbies, social ties – in order to have a repertoire of things that they will do *for themselves* when they have free time to do them.

The focus on promoting caregivers' conscious management of their own wellbeing ties in with the program's emphasis on this being a form of clinical training. Becoming aware of the impact of the caregiving work on one's own self is a part of the training of every kind of clinician. For example, nurses and physical therapists, doctors and counselors are explicitly trained that the people and the conditions they're dealing with in their clinical role can affect them emotionally and physically, and that these can "get to them." This is often referred to as "burnout" or "compassion fatigue," and includes both physical and psychological effects. We train health clinicians both to recognize that this can happen, what to do to avoid it, and how to deal with it if and when it does happen.

If we acknowledge that caregivers are playing a similar clinical role, we have to help them deal with the emotional impact of the role, just as we do with other clinicians. Caregivers – like nurses or doctors – are the instrument of their person's wellbeing; they have to keep the instrument in tune. They have to attend to their own physical and emotional wellbeing.

4. **Manage Resources.** Content about this topic is in two parts. The first centers on the family as a resource for caregiving. The program provides a description of five types of family caregiving systems and encourages caregivers to figure out in which kind s/he finds him/herself – and which kind s/he would like to have. The program provides a structure for strengthening family involvement in caregiving. As part of this process, we also ask caregivers to assess and "map" their social and community resources. We sometimes refer to this as an "environmental scan" – and it helps illustrate whether and where caregivers have resources to turn to for support in their care role.

   The second area of content regards decision-making. Regardless of their previous role in the family, the caregiver is now thrust into a more prominent decision-making role. They, and other family members, will become increasingly responsible for decisions on behalf of the person living with a dementia illness. Whether it is deciding what to do with the day or whether and when to sell the family home, the caregiver has to make decisions. The program provides a technique for processing information and making decisions.

A Key Savvy Goal: Caregiver Mastery

Savvy seeks to develop and enhance **caregiving mastery – caregivers' own sense that they can be effective in their role as caregivers**. From a theoretical perspective, the program builds on the work of those studies referenced above (Bandura, Folkman, Lazarus) that indicates that mastery is condition- or situation-specific: that is, being masterful in one area – like baking or math – does not mean one is masterful in another area, such as caregiving. The theory also indicates that mastery is developed in three main ways:

1. *Successful Performance.* When a person succeeds at something about which he or she was uncertain or timid, the person grows in confidence in his/her ability to perform that action in the future. Trying something and having it not work out is also a kind of success. It signals the

person's willingness to apply what's being taught, and the analysis of why it didn't work out can provide a roadmap for future success.

2. *Surrogate Performance.* Observing another person succeed in a situation about which we have doubts about our own ability bolsters our confidence that we can succeed in that situation as well.
3. *Expert Guidance.* A person gains mastery through instruction – for instance, the instruction and coaching provided by a Savvy trainer.

The assigned home activities are an integral part of Savvy training, a part explicitly designed to promote caregiving mastery. Caregivers are given assignments after every program session. They will be asked to read sections of the Caregiver's Manual. ***More importantly, they will be asked to apply what they have learned in the session in their work with the person at home***. They will be asked to develop and try out strategies based on materials from the manual and the in-person sessions. These strategies should be based on an appreciation of disease-produced losses and should represent an effort to compensate for those losses.

> The strategies will mainly be directed at attempting to design a task or activity that is: (1) grounded in an appreciation for the person's likes and dislikes; (2) based on an appreciation for illness-produced losses and retained abilities; (3) facilitated by communication methods geared to the person's capacity for receiving the messages; and (4) the structuring or set up of the task to take best advantage of the person's abilities to focus on it. For example, after Session 1, caregivers will be asked to adjust their own responses to the person based on their newly acquired appreciation for the cognitive losses produced by a dementia illness. They will be asked as part of Sessions 4 and 5 to design and structure tasks and activities the person might find involving and contenting and to apply behavior management principles to guide the person away from troubling behaviors.
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> The root reason for these home assignments is that participants will not achieve a sense of mastery about their new skills and knowledge unless they try them and experience comfort and success in their use – or see others like them experience success. Thus, it is important that participants are encouraged – and held accountable, within reason – to practice. The other important thing that practice accomplishes is to provide caregivers with a sense of comfort in experimentation, a skill and a sense that they need to carry forward after the program ends (keeping in mind the "Don't Just Do Something" mantra and the Savvy Process).[3] Many caregivers are extremely cautious about trying anything new or different with their person. The program gives them direction and permission to do so. One of the big lessons from the program should be that caregivers will develop a bigger repertoire – and a greater sense of mastery – if they try new things – and that even a failed experiment provides information that eventually leads to something that works and that can be added to the bag of tricks.

Your role as Savvy leader in the debriefing and coaching portion of each session after Session 1 is essential to the development of caregiver mastery. Increasing amounts of time are allocated in each

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[3] As the Savvy Caregiver coach, as well as instructor, recognize that coaches hold their clients accountable for practicing what is taught. This is the only way they can be prepared for the role.

session, beginning with Session 2, to coaching activities. Coaching combines active listening and on-going teaching. It involves:

- Encouraging participants to report on their efforts – whatever they were. Even if they did not try anything; eliciting a response reinforces the notion that this is a serious expectation. Some may take several weeks before they actually try to apply the lessons to their actual caregiving.
- Providing positive reinforcement for any reported successes, no matter how large or small and linking those successes to the material taught in previous sessions. Seize on any opportunity to make the connection between the content of the program and the success a caregiver experiences in applying that material.
- Listening carefully for an opportunity to suggest ways in which a caregiver's efforts could be strengthened by a closer application of the lessons taught. This is a time to suggest how some lesson from Savvy could be better understood and put into action.
- Eliciting comment on a caregiver's report from other caregivers. Having others respond is reinforcing for the caregiver, but it is also a way for these individuals to develop confidence in their own ability to try things out. This process builds collaboration within the group.
- Pointing out the commonalities among the successes that caregivers report; this is a chance to reinforce a teaching point from one of the prior sessions.
- Providing encouragement for further or continued efforts to apply Savvy lessons to day to day caregiving.

Home assignments may pose problems for some caregivers. For some, making time to come to the sessions may use up all the free time they have. For others, it may prove difficult to find time and place at home where they can be away from the person they care for. They may have a hard time being able to do the home activities. This is a reality of caregiving. You can offer some suggestions that might help:

- ✓ Encourage family participation. Have other family members help out while caregivers do their home activities. Alternatively, have the home activities be a group activity with the other family members.
- ✓ Encourage them to follow along carefully in class and to keep the home activities material handy – someplace where they can get to it quickly and easily. Then, do it when they get the time.
- ✓ Encourage them to remember the assignments. Even if they can't do the reading or fill out the forms right now, they should keep them in mind. Remember they are there and are meant to be a resource. They should make a deal with themselves to get these materials out when they feel the need for them.

A Last Word on Mastery. Mastery should promote positive outcomes. It should help the caregiver to experience a sense of success and accomplishment in the work of caregiving. Promoting Contented Involvement may also produce situations in which there is an experience of a strong sense of connection with the person. But mastery does not eliminate the grief and loss that many caregivers experience, and the Savvy program is not built to address these issues. Support groups and counseling can and should be encouraged for those who are struggling emotionally.

The Savvy Caregiver Weekly Program Structure

The program generally entails six two-hour meetings, held weekly.[*] The chart on the next page provides an overview of the material covered in each session. You will note that, beginning with the second session, each week begins with a review of the previous week's materials and with the home assignments that were given. This coaching time is key. It gives participants a chance to ask questions about material you covered in the previous week(s) or in the readings and to take credit for their accomplishments. It also makes it clear that they know a great deal about caregiving – they are experts and are getting even more expert at their role.

The home assignments are not meant to be oppressive, and there is no expectation that you, as program leader, will "enforce" the completion of home activities (no grades are given). Nonetheless, home application and practice of caregivers' new knowledge, skills, and outlook is an important component of the program's success. As noted, the debriefing and review segments will be an important time for you to assess participants' comprehension and to provide feedback and coaching related to caregivers' experiences trying out the ideas and strategies presented in the program.

Having caregivers try to apply their learning at home is, again, a strategy that is used in clinical training. It isn't enough to read about a skill, or even just attend the six sessions. The learner only acquires both the skill and the outlook that goes with the skill by putting it into use over and over and having someone – here, you and the group – with whom to debrief and be coached to ensure their ultimate success and effectiveness.

The first four weeks of the program are very content laden. The sessions – through exercises, handouts, and talks – are meant to give participants a great deal of information and a great deal to try out and think about. The Caregiver's Manual will reinforce and add to this information; material from websites can also add to the content. The design of the program is such that the expectation for caregiver performance – for the demonstration that they are taking all this information in and are "getting it" in such a way that they are able to put it into use in their caregiving – is deferred. While you urge and prod them to do their home activities, keep in mind that the real payoff doesn't usually come until the fourth, fifth or sixth weeks. That is when most caregivers begin to show that they have integrated at least the main ideas of the program.

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[*] This is a pattern that has worked, historically. Meeting every week and covering a lot of material creates group connectedness and underscores the importance of the program and caregivers' need to acquire this knowledge and skill. We recommend staying with the pattern unless there is a *compelling* reason to change it.

Week	Savvy Caregiver Program Training Curriculum Content
1	✓ Introduce the program and program material. ✓ Introduce yourself and then have participants introduce themselves. ✓ Teaching Topics: ▪ Talk about the role of the caregiver – and the toll caregiving can take. ▪ Explore neurocognitive illnesses – facts about dementia disorders. ▪ Look at the impact of Alzheimer's and other progressive dementia-related illnesses on thinking and the implications of these losses for Savvy caregiving. ✓ Introduce the resource materials for the program.
2	✓ Coaching: Review of last week's materials, readings, and home activities ✓ Teaching Topics: ▪ Caregiver Self-Care (recognizing and dealing with feelings) ▪ Confusion – the central problem in dementia conditions (inc implications for Savvy Caregiving) ▪ A Simple Model of Behavior ▪ Communicating with Confusion (including dealing in "emotional truth") ▪ Taking control and guiding responsibly
3	✓ Coaching: Review of last week's materials, readings, and home activities ✓ Teaching Topics: ▪ Contented Involvement: An indicator of effective caregiving ▪ The Concept of "Fit": Matching tasks and activities to abilities ▪ Performance – the important elements ▪ A Staging System for neurocognitive illnesses
4	✓ Coaching: Review of last week's materials, readings, and home activities ✓ Teaching Topics: ▪ Anchors of Contented Involvement – Person, Structure, and Support ▪ Linking disease stages to structure and support ▪ Basic communication techniques ▪ Developing strategies for common behavioral problems
5	✓ Coaching: Review of last week's materials, readings, and home activities ✓ Teaching Topics: ▪ Applying Savvy Caregiver principles to day-to-day life: Using the Anchors to design daily tasks ▪ Introducing The OOVL Decision-Making Guide (Options, Outcomes, Values, Likelihoods)
6	✓ Coaching: Review of last week's materials, readings, and home activities ✓ Teaching Topics: ▪ Types of caregiving families ▪ Strengthening families as resources of care ▪ Review of the Savvy Caregiver Program

This can be challenging, from your perspective as a leader. In our experience, there may be times when the group seems to be floundering during its early weeks. Participants might seem confused or unconvinced. Some will tell you that they "get it," but, when you hear them talking, it is clear that they don't yet understand the main idea. You've got to rely on the material and be patient. Don't be concerned if the group seems flat, even in the middle weeks. Just keep at it. They will get it and will show you they get it – even if it's only in the sixth week that they do so.

Interaction with Family[4]

A number of exercises specifically expect caregivers to interact with other family members. However, there is no intent to limit interaction to these specified times. Caregivers should be encouraged to share the readings with them and/or bring one or two family members to the program, but only if this doesn't interfere with group dynamics.[5]

The Savvy Caregiver program is often the first opportunity caregivers have had to see that there is a great deal they can learn and that they can access resources to help them. As the program progresses, and as caregivers become more comfortable with and confident in it, more and more questions will arise. The material itself will stimulate questions. For example, the material on staging in Session 3 will likely involve a way of thinking (i.e., staging) and/or a method of staging that most people have not heard of before. Similarly, the linkage between stages and strategies for designing tasks and activities (Session 4) is probably something they have not considered before.

The Role of the Program Leader

The program proceeds through a series of exercises you will lead and brief talks you will provide. The program has been designed to take advantage of your experience with caregivers, caregiver support groups, and/or other group and teaching situations. The major skills you need to lead the program are those of group facilitation. We envision Savvy Caregiver group leaders as a knowing "coach" for the program participants. You assess each one's capacity and encourage and motivate them to integrate and implement the new Savvy content and skills. If you bring expertise in the area of Alzheimer's and dementia illnesses, that is a plus. If you don't, you will learn enough basic information about dementia illnesses and the Savvy approach from your training and this manual to successfully guide the program. You may want to supplement this with more extensive information available online.

Because you are the group leader, questions will be addressed to you. Group leaders will be expected to follow four guidelines in addressing questions from caregivers.

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[4] We define family very broadly, and basically accept whatever definition of family caregiving participants use. Relatives by blood or marriage, partners, fictive kin, friends: the family is whoever the caregiver says is part of it.

[5] Sometimes multiple members of a family wish to attend a Savvy program. While there is no hard and fast rule, ensuring that all participants feel comfortable and that they have equal standing in the group is essential. If too many family members from a single family group attend, it can crowd out others. We recommend only one or perhaps two other family members besides the principal caregiver attend. Having people drop in and out of the group should be discouraged; it interferes with the continuity you are hoping to develop within the group.

1. **Validate (and clarify) the question.** Process the question. Be sure the person (as well as you) understands what s/he is asking. Recognize the importance of the question – encourage questions and the search for information. That, in itself, is an important caregiving strategy and is one mark of a Savvy caregiver.

2. **Stay within your own expertise.** Give the best answer you can from your own knowledge – but, if there are limits to that knowledge, make them known. (For instance, if asked about the effectiveness of Alzheimer's drugs, you might respond, "Well, I'm not a physician, but we do hear about new drugs all the time, so this is definitely an important question to direct to your/your person's doctor.") Don't guess, and don't try to" wing it." If you are trying to reason through to something, based on your knowledge, let the group know this.

3. **Try to find answers.** Recognize and acknowledge when you don't know an answer and – if you think it feasible – take it on yourself to search out the answer outside of the group. If you do say you'll look for information, make note of this so that you can hold yourself accountable for seeking the answer and then reporting back on it.

4. **Refer to appropriate disciplines.** Make it clear that some answers might best come from experts in various fields. Physicians, nurse practitioners, and pharmacists can be sources of information about Alzheimer's medications and medications that can be useful with some of the behaviors that can manifest themselves in Alzheimer's and other diseases. The occupational therapy-based staging system presented in the Savvy Caregiver program allows caregivers to estimate their person's approximate stage; if they want a professional assessment that can provide an exact staging, they should be referred to an occupational therapist who knows the Allen Cognitive Level assessment process (see Session 4 , which relies heavily on OT and nursing). Additionally, many caregivers may need additional case management or counseling to deal with caregiving. If this comes up, refer participants back to their healthcare experts.

As the leader, you will need to be able to "read" the participants and to manage the dynamics of the sessions. You can expect great variability among those who take part in the program. A fairly large portion will be clear about what the program is intended to do and what they are expected to do as participants. A smaller proportion will come expecting an education-tinged support group. You may have to regularly remind those expecting a support group of the explicit training and education purpose of the program.

In practical terms, you may need to develop strategies to gently stop "talkers," participants who want to tell their stories at length and who would, in so doing, dominate the group and take time away from the core training program. On the other end of the spectrum are those who learn quietly and are not willing to or interested in participating in group activities. Such individuals may not wish to report, for example, on activities carried out at home. It is important to continue to provide such individuals with the opportunity to share with the group when and if they become so inclined. In some cases, participants will show up for whom a more intense intervention is likely needed. In these cases, providing suggestions discreetly about resources like counseling may be the best option.

Program and Session Materials

The program materials supply the information participants need about dementia illnesses and other covered topics. The amount that you will be called upon to "lecture" about these things will be minimal. When a talk is called for, the outline is provided in this guide, and the content is fully given in the Caregiver's Manual. Material is included in the Trainer's Manual that may help you provide additional information and guidance or from which you can draw questions to use to help the sessions be more interactive.

Exercises are structured and outlined in this manual, and any handout materials you might need are provided, including **worksheets**. **Slides for the talks** are included in the text of this manual. Program participants should be given a set of the slides in hard copy, so they can follow along and make notes as you use them in the sessions. In some cases, program leaders distribute them as one complete set; in other cases, the slides for a given session are provided at the beginning of the session. These slides, which have room for notes, may be all the participants need to bring to the sessions. No additional materials should be provided without consultation with the program developers.

The Caregiver's Manual is the "textbook" for the program, and most of what happens in the program is covered in the manual. The order of the Caregiver's Manual is intended to follow the same order as the material presented in the sessions. Since the content is covered in the live sessions and in the manual, you can direct caregivers to appropriate sections to review material and to read ahead. You, as leader, will have a copy of the Caregiver's Manual and should read it carefully, use the ideas in it, and refer to it. The Trainer's Manual will provide specific page references to the Caregiver's Manual when these are relevant for exercises or tasks. We don't advise that caregivers bring their manuals to the sessions, but rather keep them at home for their review there.

A video asset accompanies the Trainer's Manual. It contains three video segments.

- The first segment captures persons at various stages of Alzheimer's being directed by an occupational therapy assistant to make a sandwich and fold towels. This segment is viewed in Session 3 when teaching the staging system used in the program, and only the sandwich- making task is shown; the towel-folding clip is there to help trainers better appreciate the progressive effect of these illnesses on persons' performance capacities.
- The second segment of the video portrays a group of persons at various stages of Alzheimer's, led by an occupational therapist, engaged in a common activity. This fits in Session 4 when discussing the Anchors of Contented Involvement. The video can be an effective tool for illustrating the way in which a skilled clinician works to involve persons at varying stages in an activity. This is a segment that trainers will benefit from viewing to provide them with a clearer sense of how fitting the abilities of the individual women to specific tasks the therapist assigns promote Contented Involvement. It also illustrates how the therapist tailors her communication strategies to the ability of each of the women.
- The third segment of the video presents a talk by Dr. Marsha Lewis on the OOVL decision-making model that is taught in Savvy in Session 5. You can use this to replace a brief talk that you would provide on the decision-making model.

Preparing to Lead the Program

We have learned, from feedback from other program leaders, that it is essential to prepare a "lesson plan" for each session. The Trainer's Manual gives you the structure of each session and, together with the Caregiver's Manual, provides content material. However, it doesn't work well to try to use the Trainer's Manual as a sort of cookbook for leading the class. And the manual is not intended as a "script;" it is not meant to be read from. **The best preparation – especially for the first time through the program – is to thoroughly digest each session's intent and structure, read all the material, and then use whatever teaching/leading strategy works best for you (note cards, an outline, etc.).** This should become *your* program. The manuals give you the structure and content; the way you lead is your own.

Icons as Guideposts

The Trainer's Manual uses several icons to provide you with guideposts through the text.

This icon is used when the manual is providing information about your task. Typically, sections marked with this icon are intended *to let you know what's coming in the program and what the intention of the next section is*. These sections give background information on the section ahead and often suggest what you – as the leader – should be aiming at and looking for by way of response from the participants. Exercises and talks typically use slides and/or handouts. As noted above, hard copies of the forms, handouts, slides, and "talking point" notes for each slide are incorporated into the Trainer's Manual.

At the beginning of each session, you will see this icon. It *will provide you with an overview of the session*. The overview will include the main topics to be covered in the session and guidelines for the amount of time to be spent covering each topic.

This icon *signals an exercise*. Exercises are used extensively in the training program, so you'll be seeing this icon frequently. Before each exercise, the manual explains the purpose of the exercise – what learning objectives it is meant to accomplish – and gives you a sense of how to conduct the exercise. It provides a sense of how long the exercise should take and also gives a sense of what kind of response you should expect to see from the participants. When there are slides with the exercise, these are also provided.

The specific directions for each exercise are enclosed in an area highlighted like this. Typically, you are provided with specific directions for the exercise. Often, suggestions are provided for ways to start the exercise and/or prompt participants through it.

This icon *signals a brief talk by the group leader, and even these talks are meant to be interactive* (hence, the "talk bubble" and the "question bubble"). Every effort has been made to keep these parts of the program to a minimum. The material for each talk is provided in the text of the Caregiver's Manual and in slides. The manual is meant to support you in the talks, but you should feel free to search beyond the manual for additional information. Whenever you feel confident that you can provide the group with additional information, you should do so as long as the material remains faithful to the Savvy core principles and content. The limiting factor is the length of the sessions and of the program. On the other hand, if your strength for leading the program is in process rather than content, we want you to feel comfortable that all that you need to give the talks has been provided.

This icon will appear in the middle of the page (like shown here) and *alert you to a transition*, a time to shift gears in the flow of the program. It's like a form of punctuation in talks. Typically, it will appear in sections of the Trainer's Manual in which material for the brief talks is being presented, using slides. Once you get the hang of using the slides for talks, this icon will seem unnecessary. However, it is meant to be helpful for leaders who may have less experience with using slides.

This icon *refers to the home activities assignments*. The Trainer's Manual provides instructions for the home activities, and if any handouts are used, they are provided as well.

Some Final Words

Participation is a key to success in the program. Another key is covering all the material. You may sometimes find these two at odds with each other. ***There is no easy or fixed answer to this problem: cover as much as possible.*** Caregivers may enter the program either passively or reluctantly or think that it is another kind of support group. One of your big jobs will be to clarify the nature and purpose of the program and to draw the participants into it – this is a class, an interactive class, not a support group. Another big job will be to defer questions that are outside the scope of the training until after the session – to keep it from turning into a support group. Thus, your group skills will be paramount to the success of the program.

Keep in mind that much of this material is new to participants, and that most of them are learning a great deal in the program. When you see opportunities to do so, remind participants of things they learned. Also, if you see that something from an earlier session was incompletely understood, circle back to it and review it to be sure participants truly understand it.

Savvy is just one piece of instruction and support from which caregivers can benefit, and completing the program does not, in itself, prepare the caregiver for all that is to follow. From your experience, you may know of other programs that would be of benefit. We encourage you to refer caregivers into those. At the same time, we urge you to recognize the enormous power you have as a program leader, power that would enable you to use Savvy as a platform for other ideas you may deeply believe. ***Keep the Savvy program intact; teach it as it is presented; alter it only in small ways that are consistent with what the program is setting out to accomplish***. If words or ideas seem unclear, work with the participants to "translate" them to make them clearer. But don't change the underlying concept or meaning. This is referred to as "fidelity to the program" and is critical to achieving the positive outcomes the Savvy program can deliver.

We’ve found it is helpful if the medical providers with whom caregivers are dealing know something about the Savvy program. It is helpful for them to understand what caregivers are learning and to see that they, the caregivers, are strengthening their competence, based on a certain way of thinking about strategies for management. If providers and caregivers can share a common language and frame of reference about the disease and how the caregivers are handling it, those clinicians can provide invaluable on-going assistance. So, encourage participants to share the program with their medical professionals.

Be prepared for repetitions in the Trainer’s Manual. You might read straight through the manual once, perhaps as you approach your first solo session. But it is more likely that you will use it, chapter by chapter, to ready yourself for leading each session. With this in mind, there is material in each session chapter that refers back or ahead to material already taught or that will be taught. There is also often material that repeats core principles and ideas. Especially for the leader who is using the manual to prepare session by session, such repetitions are meant to help the leader recall that any given session is part of and contributes to a larger whole and a larger purpose.

The program unfolds through stages of presenting and integrating information in a way that comes fully together only in its fourth session. It is in this session that the program integrates previous materials to introduce a strategy for guiding the person living with a dementia illness into tasks or activities that promote Contented Involvement (a concept introduced in session 3). **This idea – guiding toward Contented Involvement – is the main caregiving strategy that Savvy seeks to develop.** To get to this place, you will find that the program is seeking to build up and weave together a fund of key ideas, and you, as leader, will be in a position to make the relationships among program ideas clear to participants. So, the repetitiveness of material in the manual is both to help you to see the linkages among program concepts and to remind you to make those linkages explicit as you lead the program.

Finally, the slides that are cut into the text of this manual are copies of the slide set you will have for your use in leading the program. In a few cases, if you are reading the manual in print version rather than on a computer, the slides might be difficult to read. As a suggestion, you might open up the main slide set and have them on a screen so you can see them more clearly.

Introduction Notes

Weekly Session 1

"If you can't explain it simply,
you don't understand it well enough."

Albert Einstein

Session Agenda

Savvy Caregiver Program
Weekly Session 1 Agenda

Instructional and Topic Areas	Content Included In Topic Area	Approximate Time
Introductions	• Introductions: You and Participants (15 min) • Introduction to the Savvy Caregiver Program – Program Goals and Expectations (10 min)	25 Minutes
Teaching: Caregiving	• Defining and Exploring the Role of the Caregiver (10 min) • Skills, Knowledge, and Outlook Needed for Effective Caregiving (10 min) • The Toll of Caregiving (10 min)	30 Minutes
Teaching: Alzheimer’s Disease and Other Dementias	• Basic Facts About Alzheimer’s Disease and Other Dementias (20-25 min) • Cognitive Losses in Persons Living with Dementia (30-35 min)	55 Minutes
Home Practice and Program Resources	• Assigned Home Readings and Practice Tasks • The Caregiver’s Manual and Handouts	10 Minutes

Program Leader's Overview of Session 1

The major aim of Session 1 will be to get the participants to begin thinking of this experience as a training program. To accomplish this aim, the session will need to attain several objectives. As the slide below indicates, in terms of developing all of the skills and knowledge that enable the caregiver to design and implement days that promote Contented Involvement for the person living with dementia, this session introduces the participants to the program's overall purposes – but it also begins to focus on three important elements that contribute to this capacity: role acceptance; appreciation for disease impact; and acquisition of a Savvy process for developing caregiving strategies and mastery.

Being Able to Apply Assess-Plan-Do-Evaluate Process

Taking on Caregiver Roles And Responsibilities

Understanding Effects of Illness On the Person

Being Able to Design Right-Fitting Tasks and Activities

Person-Based Contented Involvement

Being Able to Guide Behavior

Being Able to Work Wit Family and Other Resources

Being Able To Take Care Of Self and Find Rewards

Being Able to Communicate Effectively

Note: This overview slide is for you, as a trainer, to grasp the many elements of Savvy Caregiver. However, we recommend not showing this to families at this point as it may be overwhelming. (This graphic does appear in the summary section of the slides, which is an appropriate place to recap these concepts.)

As Program Leader, you will want to watch the participants to see if these objectives are met. Here are the indicators to watch for. As a result of their participation, caregivers should:

- ⇒ Become comfortable with the title of caregiver and with the idea of describing themselves by that title.
- ⇒ Appreciate that caregiving is a "job" – work they have undertaken. It may spring from their relationship with the person – that may be the motivating force – but it is different from the relationship; it is work they have taken on.
- ⇒ Begin to understand that the work of caregiving can be rewarding, but it is often difficult, demanding, and potentially punishing. Caregiving requires an extensive set of knowledge and skills

– and an appropriate outlook – in order to carry it out effectively. This will benefit their person and preserve their health and wellbeing.

- ⇒ Begin to think of themselves as "Savvy Caregivers" – in other words, capable and confident caregivers. Being Savvy is good for their person and for themselves.
- ⇒ Recognize that the program is a *training* program, as opposed to a support group or other health promotion class. It is a program designed to give them the skills, knowledge, and attitude they need to be a Savvy Caregiver. They will apply the lessons to their own care situations; thus, it is quite different from any kind of support group in which they may have participated before.
- ⇒ Begin to develop and acquire caregiving strategies – ways to work day to day with the person for whom they provide care, but also longer range strategies for thinking about and making the decisions they will face as caregivers.
- ⇒ Begin to acquire information – about the disease and about caregiving – in a way they immediately begin applying to shaping themselves as Savvy Caregivers – even in small ways.
- ⇒ Begin to identify more effective ways of interacting with their person, to state the objectives they have for their caregiving, and to recognize and expand the rewards and satisfactions they can derive from it.
- ⇒ Be prepared for the home activities that will be assigned, and recognize that the more they are able to apply the weekly lessons to their life, the more they will get out of the program.
- ⇒ Recognize that the program will point them toward other learning resources (published materials and online resources) and that the process of acquiring caregiving strategies is an ongoing one.

Structure of Session 1

Session 1 involves several interactive exercises. These are designed to draw participants into the content of the program and also into its process. There is one main brainstorming exercise that asks caregivers to draw on their own knowledge and experience of caregiving. The exercise should serve as an icebreaker, but it should also serve to demonstrate that there is a lot of instinctive knowledge and experience in the group.

It is important that participants feel comfortable and be able to share their experiences – particularly those experiences they have in trying out the strategies and techniques suggested in the program. Since the development and reinforcement of their caregiving mastery is a key objective of the program, every opportunity should be provided to encourage participants to interact and to draw on their own expertise to address caregiving problems. Encouraging participation can sometimes lead to awkward silences; your comfort with these moments of silence will help group members to be comfortable and, eventually, to chime in.

Each of the remaining sessions begins with a group debriefing regarding the previous week's session and coaching focused on the "home activities assignments." These debriefings provide the chance for you to reinforce the participants' learning and growing expertise as caregivers and to continue to coach them in developing their caregiving mastery.

In the second hour of this first session you will give a brief talk on Alzheimer's disease and other dementias and then introduce the first set of illness-produced losses (cognitive losses) with which caregivers have to deal. It is possible that participants may have attended an Alzheimer's Association class or read books on the topic. Your brief talk will provide a quick review of such material and is meant to reinforce the idea that caregivers are dealing with a disease. The material for the talk is all in the Caregiver's Manual and is also reinforced in the online materials of the Alzheimer's Association (www.alz.org) and the National Institute on Aging's Alzheimer's and related Dementias Education and Referral Center (ADEAR) (www.nia.nih.gov/health/about-adear-center).   Information about other dementia-producing conditions can be found at websites of the Lewy Body Dementia Association (www.lbda.org/) and the Association for Frontotemporal Degeneration (www.theaftd.org/what-is-ftd/disease-overview/).

Introductions. The first session opens with an exercise in which participants introduce themselves. Kick this off by introducing yourself, your background and experience, and how you came to be a Savvy leader.

Then move to the introductions -- which are meant to serve two purposes:

⇒ Convey a welcoming sense of trust and openness, so that all feel comfortable talking.
⇒ Ensure that all participants meet each other and discover they all have some things in common – including, likely, their situations and reasons for being at the program.

The introductions also provide you with a bit of information about the caregivers and where they are – and what problems they are facing – in their caregiving. But this is not about getting participants' life stories or the complete history of their caregiving. These are meant to be brief. Try to take notes on the introductions – in an effort to tie the content of the program into each person's individual situation.

Ask caregivers to take a minute to think through the questions below.

✓ Who are you helping?
✓ How long have you been providing help?
✓ What is the biggest caregiving issue you're facing right now?
✓ What do you hope to get from this program?

Then give each participant time – but no more than 1 to 2 minutes – to introduce him/herself by first name and then provide answers to those questions (tell the group you'll keep time and keep each to a limit – this can be done playfully, but you should keep the limit)[*].

Once everyone has introduced him/herself, proceed to the introductory talk. No further processing is needed in the introduction.

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[*] You will have to maintain – and "enforce" – a certain amount of control throughout the program in order to cover all the material and avoid having it turn into a support group. You can do this explicitly at moments like this, and it may help reinforce your order-keeping role.

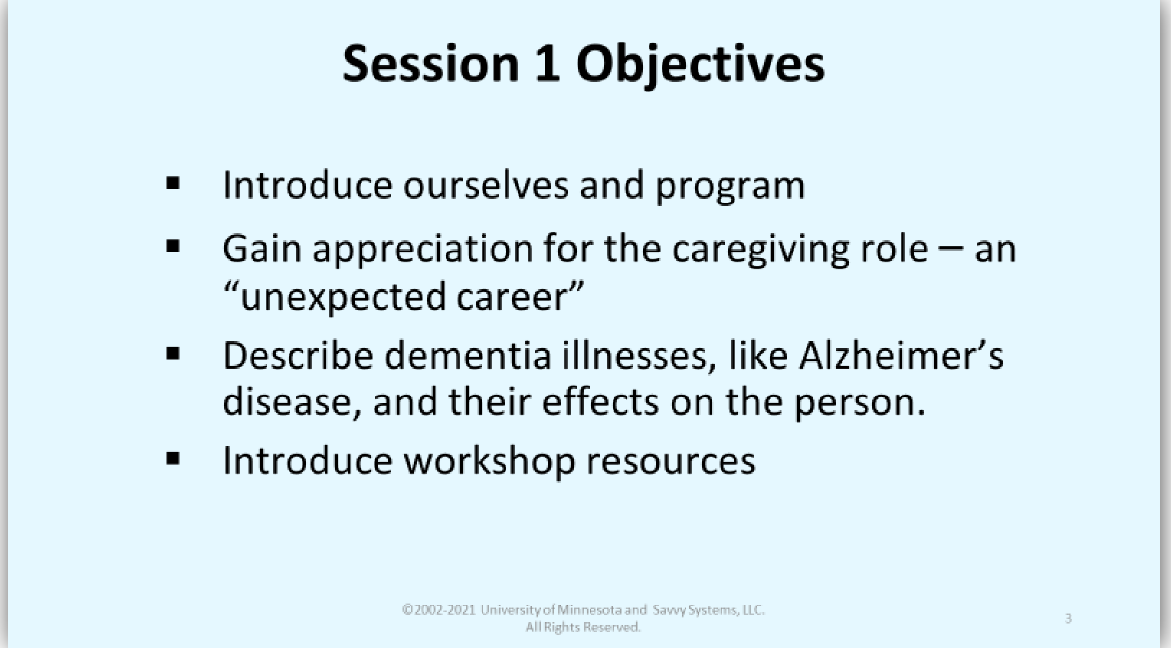
Program Objectives and Materials – and Session 1 Objectives.

This is a brief introductory talk. This is your first opportunity to make clear to caregivers what they have gotten themselves into and what will be expected of them. It is also the first opportunity to bring into view the materials caregivers will use in the program. Be clear with participants that you have two purposes in mind:

1. To set the stage for today's session.

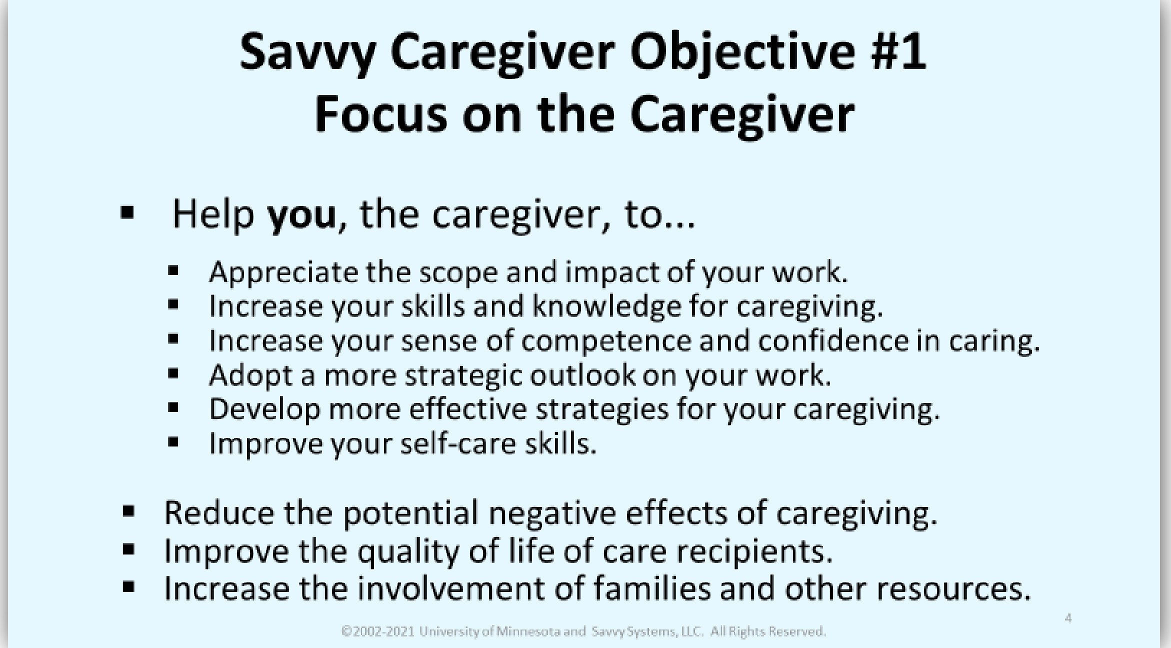
2. To introduce and provide an orientation to the program and materials (the Caregiver's Manual and Workbook fit here), and

Review the overall program objectives during the first part of Session 1. Read each objective and let each sink in – offer comments and reinforce them.



Session 1 Objectives

- Introduce ourselves and program
- Gain appreciation for the caregiving role – an "unexpected career"
- Describe dementia illnesses, like Alzheimer's disease, and their effects on the person.
- Introduce workshop resources



Savvy Caregiver Objective #1
Focus on the Caregiver

- Help **you**, the caregiver, to...
  - Appreciate the scope and impact of your work.
  - Increase your skills and knowledge for caregiving.
  - Increase your sense of competence and confidence in caring.
  - Adopt a more strategic outlook on your work.
  - Develop more effective strategies for your caregiving.
  - Improve your self-care skills.

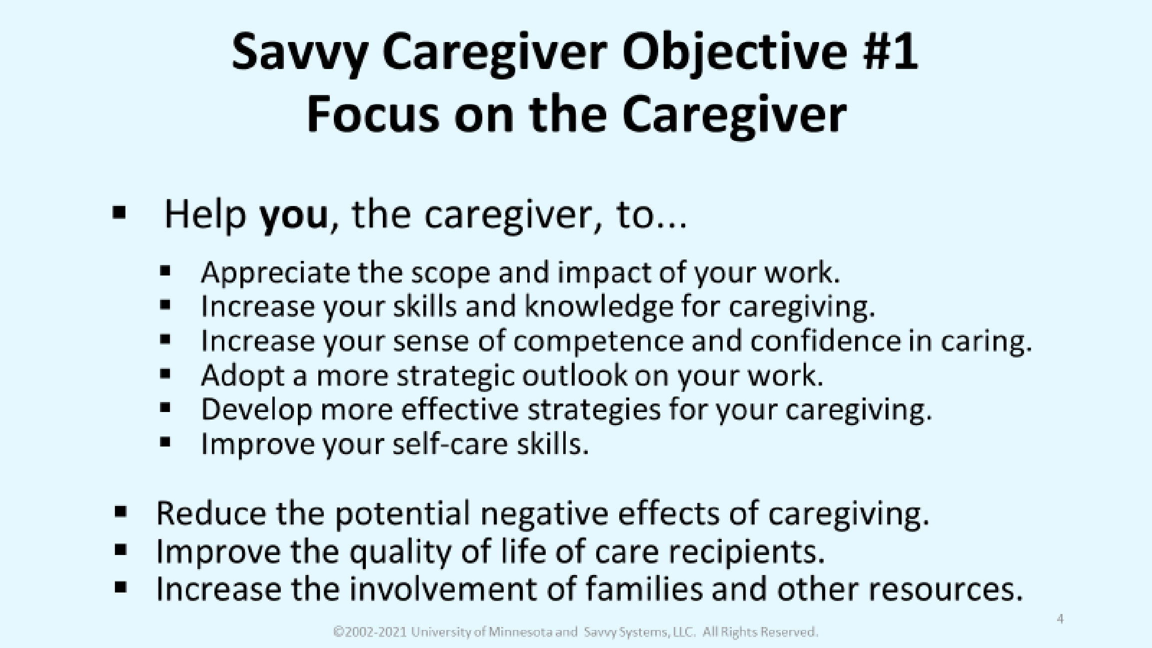
- Reduce the potential negative effects of caregiving.
- Improve the quality of life of care recipients.
- Increase the involvement of families and other resources.

It is important that the point be made that the program is **for the caregiver**. Drive this point home. It is built on a recognition that this is an unexpected role that they have taken on, one that requires lots of skills and can take a lot out of the person. It is not by accident that the main objectives are focused on the caregiver and that it isn't until near the end of the list that the care recipient is mentioned at all. Overall, the thought is that by becoming more skillful – Savvy – caregivers, participants will improve the quality of life of the person for whom they provide care. It is also key to point out that enhanced caregiving skills may also improve the quality of the caregiver's life as well.

The Objectives give the leader a chance to emphasize that Savvy caregiving is a skill-, knowledge-, and outlook-development training program – not a support group. There is a strong expectation that learning and change will occur to enhance their care experiences.

Regarding the last point on families: Families should be encouraged to read the Caregiver's Manual and work with the caregiver as s/he works through it and other resource materials. Having some (one or two) family members attend the program with the caregiver *might* be alright, but concern for the effect on the group should be a higher priority. See the footnote on p. 27 for a discussion about family attendance.

The following slides outline the primary objectives of the Savvy Caregiver program.



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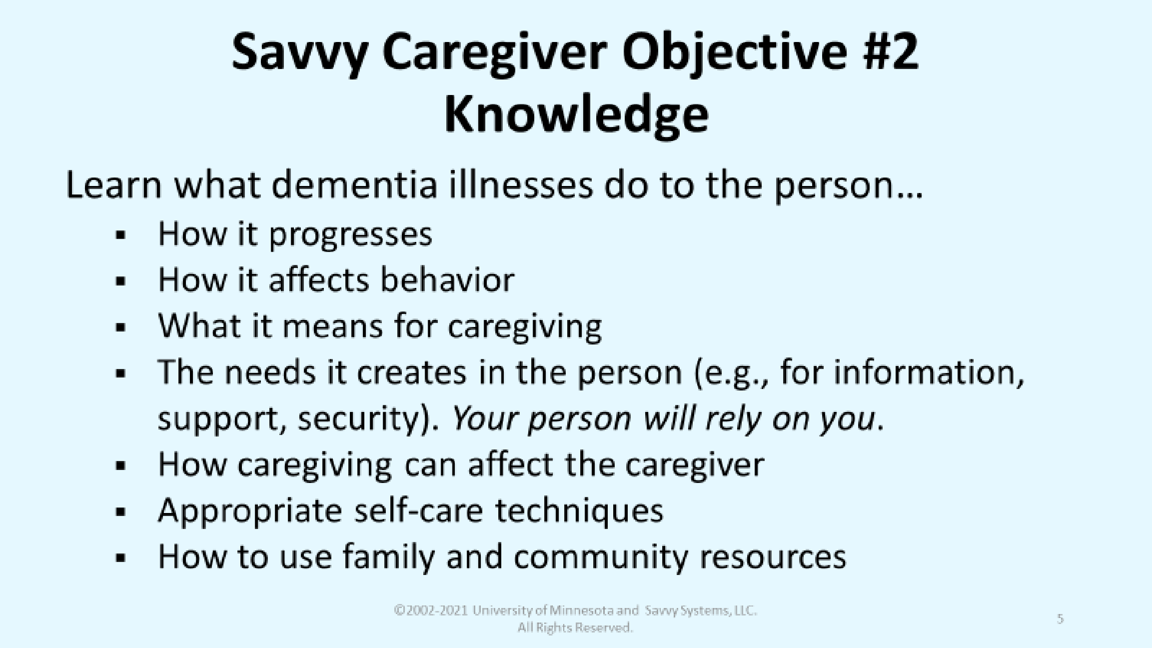
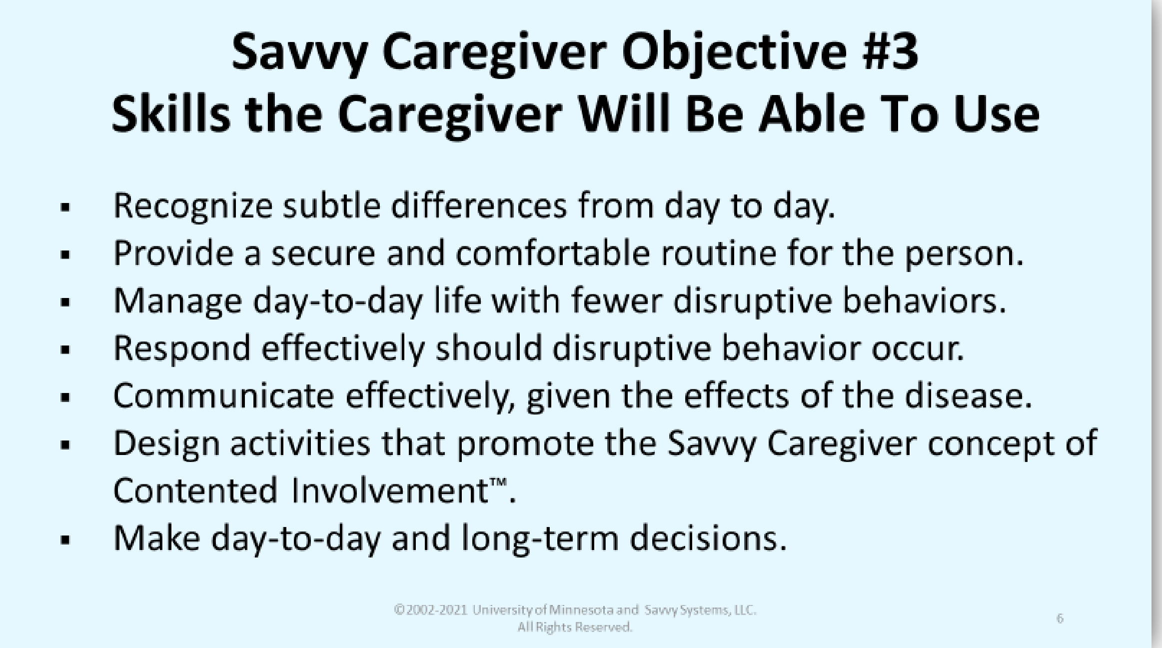


Savvy Caregiver Objective #2
Knowledge

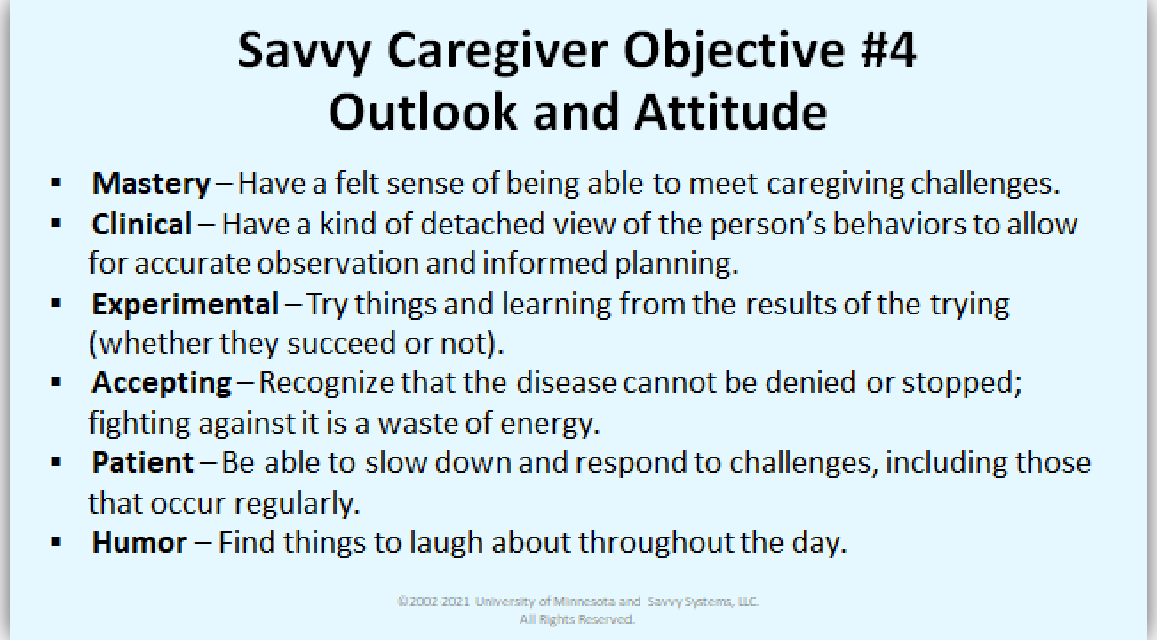
Learn what dementia illnesses do to the person…

- How it progresses
- How it affects behavior
- What it means for caregiving
- The needs it creates in the person (e.g., for information, support, security). *Your person will rely on you*.
- How caregiving can affect the caregiver
- Appropriate self-care techniques
- How to use family and community resources



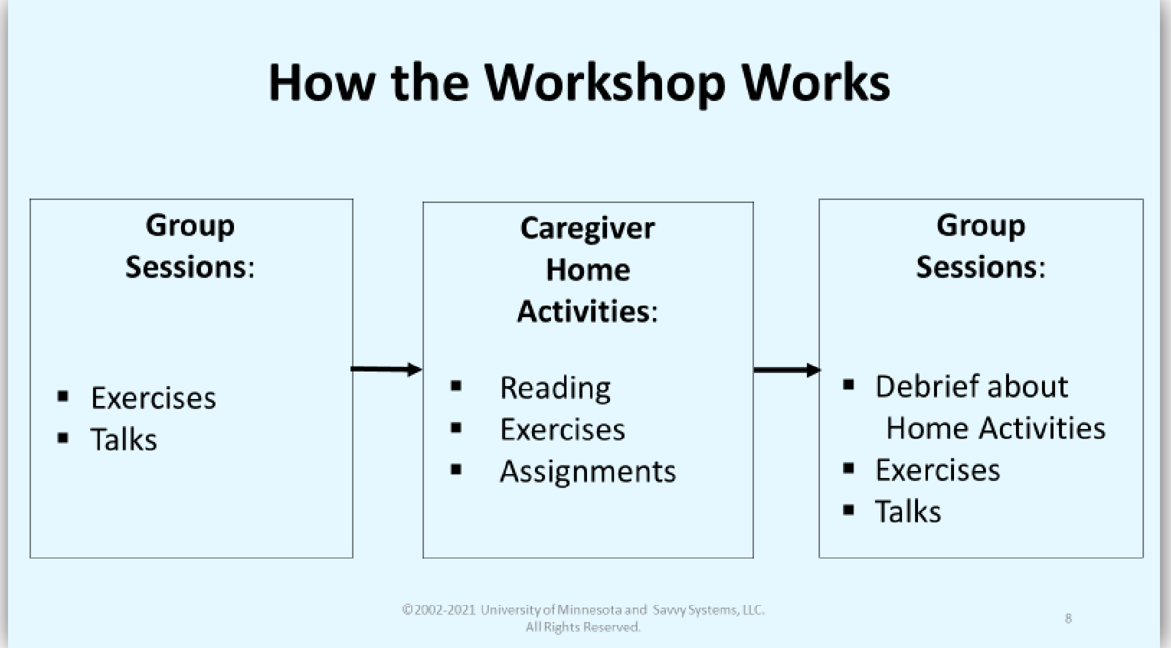
Savvy Caregiver Objective #3
Skills the Caregiver Will Be Able To Use

- Recognize subtle differences from day to day.
- Provide a secure and comfortable routine for the person.
- Manage day-to-day life with fewer disruptive behaviors.
- Respond effectively should disruptive behavior occur.
- Communicate effectively, given the effects of the disease.
- Design activities that promote the Savvy Caregiver concept of Contented Involvement™.
- Make day-to-day and long-term decisions.



Savvy Caregiver Objective #4
Outlook and Attitude

- **Mastery** – Have a felt sense of being able to meet caregiving challenges.
- **Clinical** – Have a kind of detached view of the person's behaviors to allow for accurate observation and informed planning.
- **Experimental** – Try things and learning from the results of the trying (whether they succeed or not).
- **Accepting** – Recognize that the disease cannot be denied or stopped; fighting against it is a waste of energy.
- **Patient** – Be able to slow down and respond to challenges, including those that occur regularly.
- **Humor** – Find things to laugh about throughout the day.



How the Workshop Works

Group Sessions:

- Exercises
- Talks

Caregiver Home Activities:

- Reading
- Exercises
- Assignments

Group Sessions:

- Debrief about Home Activities
- Exercises
- Talks

The slide above is meant to help the leaders convey the basic process of the program. It is meant to make it clear to participants that the program depends a great deal on the work they do outside of class time.

Point out that there is a consistent rhythm and structure to each session. Each of the sessions will have exercises and talks that will be beneficial and informative. If caregivers want to get the most out of the program, they should recognize that they will need to do work on their own at home.[*] After Session 1, the sessions build on the work people do at home, and each session will devote time to reporting back on their home activities and getting feedback and coaching on them.

The next slide provides the specific objectives for the first session. It should help participants to focus on **the work** that will be done in the session.

Read and emphasize the points. It is important to emphasize the educational nature of the Savvy Caregiver training. This is not another version of a support group.

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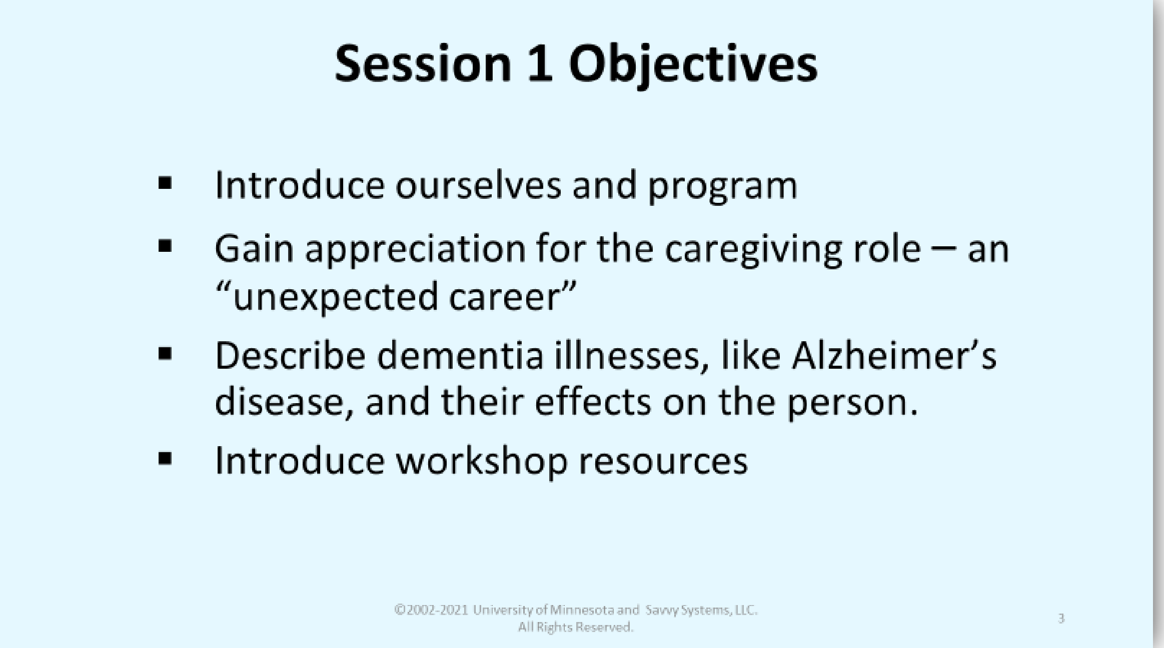
[*] It is important to keep a sense of balance here. Caregivers are busy and may not have the time or energy to do their home assignments (also, this might not be their learning style). They will still benefit from the program even if they don't do these assignments. Even incorporating their new learning by thinking about it as they interact with their person during the week is beneficial and will help them assimilate useful strategies. Practicing at home can also provide an opportunity to draw other family members into the process of caregiving by asking them to help with or participate in the suggested exercises. This is a good spot to make the point – which you can reinforce at each homework review – that caregivers will find the program materials – the manual, the handouts, and the online resources – helpful throughout their caregiving career. They should view these as resources they can use whenever the need or opportunity arises.



Session 1 Objectives

- Introduce ourselves and program
- Gain appreciation for the caregiving role – an "unexpected career"
- Describe dementia illnesses, like Alzheimer's disease, and their effects on the person.
- Introduce workshop resources

The Caregiving Role

Define and Explore the Role of the Caregiver.
This portion of the program involves a brainstorming activity linked to two related exercises. The main exercise is meant to help participants begin to frame the caregiving tasks they perform in terms of a definable role. The role entails work that has content and can be described. It is a role that demands knowledge, skills, and a strategic outlook. It is work with a purpose and that can provide rewards and satisfaction. It is also work that can take a toll. The Savvy Caregiver recognizes s/he has a new role and that this program will help him/her to acquire the knowledge, skills, and outlook that help make him/her successful in it. It is worth pointing out that, even if a participant does have clinical skills and training – for example is a nurse or social worker – taking care of a family member or friend who is living with Alzheimer's or a similar illness will be a different experience. And this will be an experience in which new skills and knowledge will be called for.

There are two exercises:

- The first is the longer of the two; it asks caregivers to identify the scope of their work. In this exercise, you will ask caregivers to brainstorm about all the kinds of work they do to take care of their person.

- The second exercise gets at the idea of the purpose or goals of the work – what are caregivers trying to accomplish in their caregiving – and is also meant to help caregivers identify the rewards that can be associated with caregiving.

Exercise #1: Brainstorm Caregiving Roles. The point of the first exercise is not that there is an exact job description for caregiving. Rather the point is to have participants reflect on the work they're doing and appreciate that it is a big and demanding job. It is also meant to sensitize participants to the fact that many of the roles on this list are skilled roles – roles for which training is required. That is why the Savvy program is a training program.

Ask the group to name all of the roles they play and tasks they perform as they provide care for their person. It would be helpful to have a flip chart or a white board for this exercise. Try to record all responses in the brainstorm and point out that the group already has a grasp of the scope of the job.

As group members identify roles and tasks, the group leaders should interpret those responses in terms of professional roles. Thus, for example, if someone says: "I take care of arranging all the appointments," the leader might say, "Right, just like a Social Worker." Or if someone says, "I'm the one to keep him entertained," the leader could point out, "Yes, you're the household Activity Director." Or, "I make sure she takes her medicine," and the leader could point out, "Just like a Nurse."

In order to keep the exercise going – it should last 5 to 10 minutes – prompts could include:

- "Are there other things you do for your person as a caregiver?"
- "Do you have to do things to inform or get other family members involved?"
- "Do you have a role when s/he goes to see the doctor?"

Once the exercise is over – when people have suggested a broad range of roles – then summarize the results into a list of roles that are encompassed in the care-giving role.

The Role of a Caregiver

- Administrator
- Social Worker
- Chief Financial Officer
- Key Decision Maker
- Home Repair Specialist
- Activity and Tour Director
- Family Counselor
- Family Diplomat
- Professional
- Nurse
- Guardian
- Behavior Manager
- Cook
- Companion
- Comforter
- Maid
- Laundry Attendant
- Safety Officer

- If any roles have been left off the list in the brainstorm, add them – it is very likely this will happen.
- Ask the group to validate the list – do they agree that these are all the things they are called on to do.

- Point out the scope of the role – this is a big task they have undertaken, and they have many responsibilities.
- Point out, especially, that many of the roles are skilled in nature – they typically require training, training that most caregivers (unless they happen to be healthcare professionals) don't usually have before they become caregivers.
- Point out that caregiving takes a toll on caregivers – and that minimizing this toll is what this program is about. Note that you'll be talking more about this in a bit.

Time management is important in the program. You may find that going through the exercises is taking too long. If you feel time slipping away, cut the exercises short. You might go through one role on the slide with the group, so they understand the point, and then invite them to think about their roles as home activities. **Get through the Roles exercise and, if need be, ask participants to complete the purpose and rewards exercise as part of their home activities.**

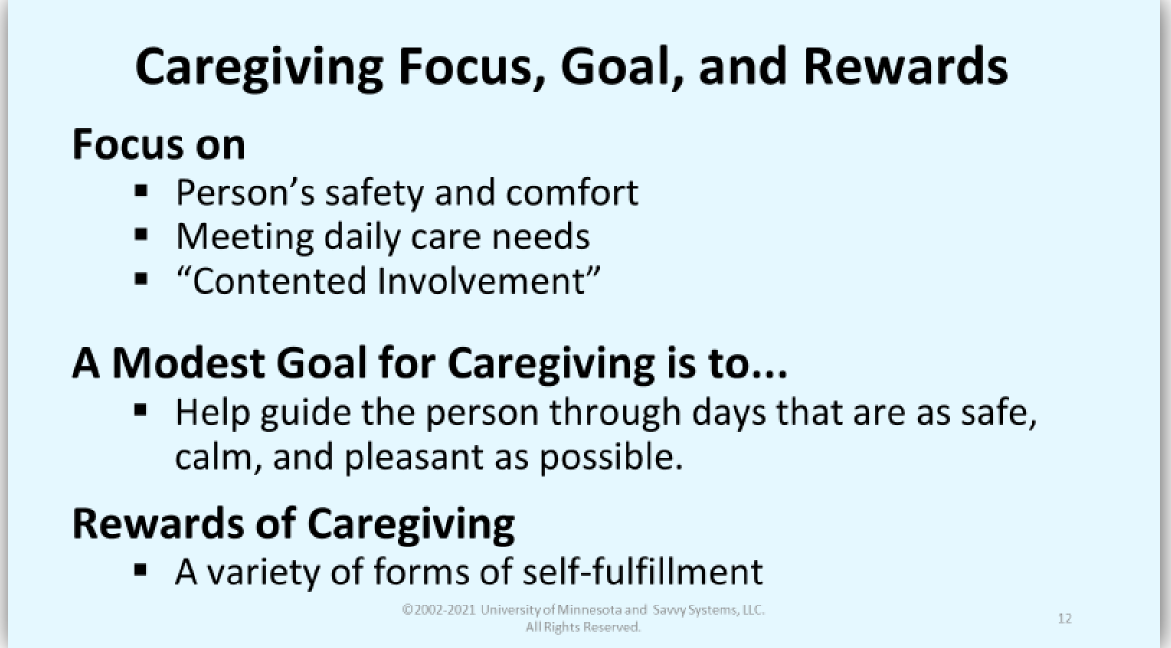
Exercise #2: Purposes/Goals and Rewards Follow Up. The first exercise defined the nature of the work. The purpose of the next exercise is to ask participants to identify the purposes and goals of the work and the possible rewards that can be derived from it.

Ask the group to brainstorm (2 to 3 minutes) on the question: "What do you see as the goals of caregiving? What are you trying to accomplish in the work you do with your person?"

After this part of the brainstorming is over, ask them: "What, if anything, do you get out of providing care for your person?"

You can use the Objectives and Rewards of Caregiving slide on the page below to summarize and discuss this brainstorming exercise and also to introduce the goal Savvy proposes for caregiving.

The brainstorming will come up with a number of suggestions, but most of them will likely fit into the first two points in the slide (safety and care needs). The third point – Contented Involvement – may come up. Often a caregiver will say something like, "I try to see that s/he does something s/he likes to do." If something like that comes up, use it to introduce and emphasize the idea of Contented Involvement – individuals living with dementia can get drawn into a task or activity (like a recreational activity, but also including the everyday activities of life, like dressing and eating) and enjoy being focused in on it.



Caregiving Focus, Goal, and Rewards

Focus on

- Person's safety and comfort
- Meeting daily care needs
- "Contented Involvement"

A Modest Goal for Caregiving is to...

- Help guide the person through days that are as safe, calm, and pleasant as possible.

Rewards of Caregiving

- A variety of forms of self-fulfillment

This is an important concept in the program, one you'll deal with at length in later sessions, and one that it is useful to introduce early on. The idea is that dementia does not strip the person of a basic human drive to do something that has meaning – to be helpful, to be part of something, to do something important or useful, to make a contribution, to be creative. The reason this may not come up is either because most caregivers won't think of it on a conscious level, or because they're shy about bringing it up (early in the program or at all). There is a somewhat spiritual dimension to the notion of fulfillment – at least something having to do with the human spirit. It is important that the leaders suggest this category not only because it is an appropriate goal, but also because caregivers do operate with this as a goal whether they do so consciously or not. It also opens the door for discussions later in the program related to issues of the person's autonomy and personhood and the caregiver's "intrusion" into these usually untouchable areas as they make more choices for the person.

The notions of satisfaction and fulfillment are suggested in the slide as generic rewards of caregiving. The terms may not come up in the brainstorm, but they might encompass a number of participants' responses and they are terms that the leaders should put forth. Connection is included as a possible reward, because many caregivers express a sense of loss of connection with the person, and moments of Contented Involvement may actually provide instances in which the connection with the person is experienced.

In this discussion, be sure to recognize and legitimize the feelings of people who are not happy to be caregivers – and, indeed, not all are. They may not contribute to the conversation, so make a note to the group that some folks are caregivers because of duty, not wanting to have regrets, or maybe wanting to set an example for their children – and that all reasons are valid. Or perhaps they don't feel they have any other choice and are actually angry or resentful at being forced into the role.

At the end of the exercises, caregivers should have a good picture of caregiving as a new role in their lives. For many, if not all, this will be a different way of thinking about what they're doing. In terms of educational objectives, these exercises are meant to help participants:

⇒ Recognize the sheer number of tasks they are performing.

⇒ Appreciate that caregiving is a role – that it has a job description, one that changes as the person's illness progresses (different caregivers at different stages of the disease may list roles that others may not have reached or may no longer play – this will help establish the dynamic nature of the role).

⇒ Recognize that while the impulse to provide care may spring directly from their relationship with his/her person, the wherewithal for the work – knowledge, skills, and attitude/outlook – typically have to be acquired.[*]

⇒ Begin to identify with the assertion that work – like that of the caregiver – should have objectives (that is, the caregiver should be clear about what s/he is doing and why) and that, like all other forms of work, it should have rewards and satisfactions.

⇒ Appreciate that, like all caring professions (nurses, doctors, etc.), caregivers need skills, knowledge, and a clinical outlook to be able to perform their role well.

⇒ Many of these roles are taken on gradually and, depending on previous arrangements (e.g., an already established financial guardianship or the presence of advance care directives and a healthcare power of attorney) or the course of the person's illness, there are some roles that may never be assumed.

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[*] This is the whole point of the program: Unless a caregiver happens to have been trained as a nurse or other healthcare worker, s/he cannot be expected to know what the task demands or how to accomplish it – hence, the need for training.

Caregiver Knowledge, Skills, and Outlook

You can use the table below to outline this set of knowledge, skills, and outlook, pointing out that this is exactly the set that the Savvy program is designed to help them acquire. There are separate teaching slides, as well, that you can use to review these with participants. This table in in their handouts as well.

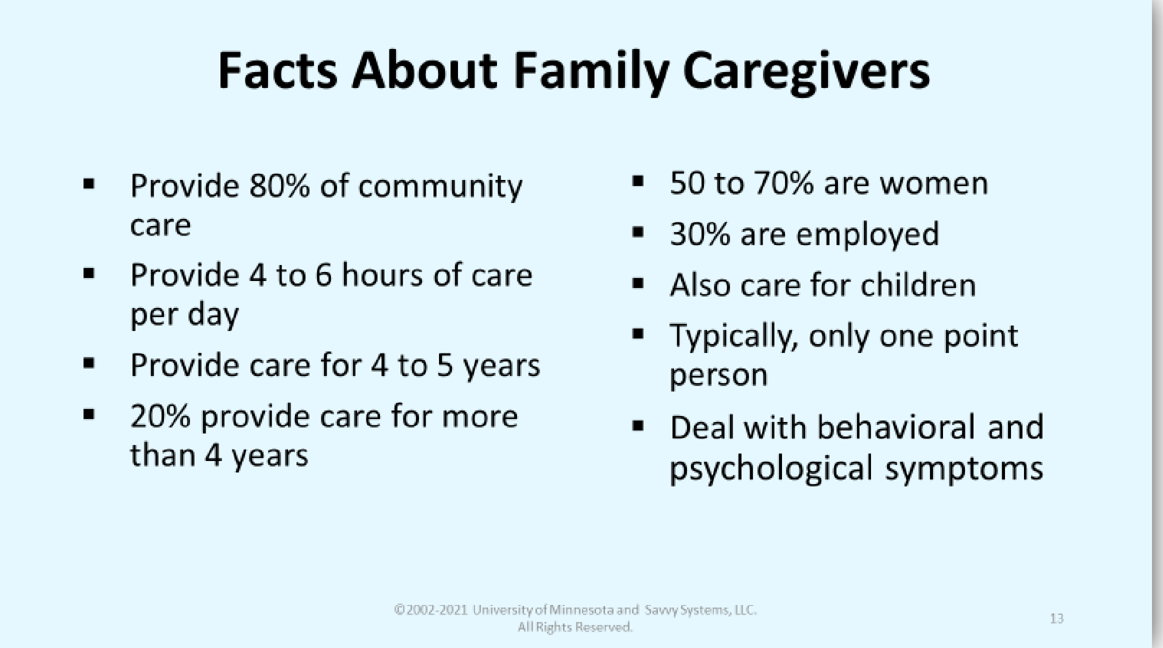
Key Caregiver Knowledge, Skills, and Outlook	
Knowledge	✓ Knowledge about the dementia condition: what it does to the person; how it progresses; what it means for caregiving Recognize the needs dementia creates in the person (e.g., for security) Understanding of how much the person will rely on you Knowledge of strategies and techniques that can be employed to manage day-to-day life with the person Knowledge of what dementia does to a family Knowledge of what caregiving can do to the caregiver and of appropriate self-care techniques ✓ Strategies to engage others to assist in the care of the person
Skills	Skilled observation: recognize subtle differences from day to day Creating and sustaining a secure and comfortable routine for the person Management of day-to-day life with a minimum of disruptive behavior Identify and use effective responses should disruptive behavior occur Effective communication, given the effects of the disease Ability to think up tasks and activities that suit the person and that allow him/her to be enjoyably involved in them Ability to bring family into caregiving, as much as possible Recognition of the need for and use of strategies for self-care Effective interaction with your caregiving network
Outlook	✓ Clinical – have a kind of detached view of the situation and influences to allow for accurate observation and informed planning Experimental – be able to try things and learn from the results of the trying (whether they succeed or not) Accepting – recognize that dementia cannot be denied or stopped and that fighting against it is a waste of energy Humorous – trying to see that there might be things to laugh about in day- to-day life

Once this brief exercise is over, take a moment to summarize the series. Without dwelling too much on it, point out that the caregivers have now completed an important first part of the work of becoming Savvy Caregivers. They have developed an explicit – though not necessarily complete – description of the job they have undertaken as caregivers.

Facts About and the Toll of Caregiving

Talk: Facts About Caregiving and the Toll It Exacts. At the end of the exercise, use the two slides about caregivers (see below) to draw participants' attention to the importance of the work of caregiving. Caregivers do virtually all of the work to ensure that persons living with dementia remain in the community as long as possible. However, caregiving can take its toll. They should be clear that the program is built, in part, on the recognition that the role is a demanding and, potentially, damaging one. Being a Savvy Caregiver is one way to reduce the toll and increase rewards.

Use the slide below to make the main points about what we know about caregiving. Point out that the demands of dementia caregiving (what they are dealing with) do relate to the toll of caregiving. In particular, research does link dealing with difficult behaviors to caregiver burden and stress.



Facts About Family Caregivers

- Provide 80% of community care
- Provide 4 to 6 hours of care per day
- Provide care for 4 to 5 years
- 20% provide care for more than 4 years
- 50 to 70% are women
- 30% are employed
- Also care for children
- Typically, only one point person
- Deal with behavioral and psychological symptoms

Most of the points are self-evident. Explain the overabundance of women as the result, in part, of male mortality (i.e., men die younger than women and also have traditionally married younger women). Other teaching points:

⇒ The caregiving task is typically a 24-hour-a-day job (even if the caregiver doesn't live with the person, s/he is involved in visits, phone care, and coordination – and is worried and concerned). The 4- to 6-hours figure relates to the amount of time spent in **specific and identifiable** caregiving tasks – like getting the person dressed or doing extra laundry. It doesn't include all the time of just being with the person.

⇒ The length of time people spend as caregivers varies enormously. The 4- to 5-year figure is a kind of working average. Some spend much less before their person's condition requires more care than they can provide. And, some spend much more: 20-year caregivers are not unheard of.

⇒ For many, this is not their only "job." Many (perhaps as many as 40%) work, are spouses, raise kids, have community obligations, and more.

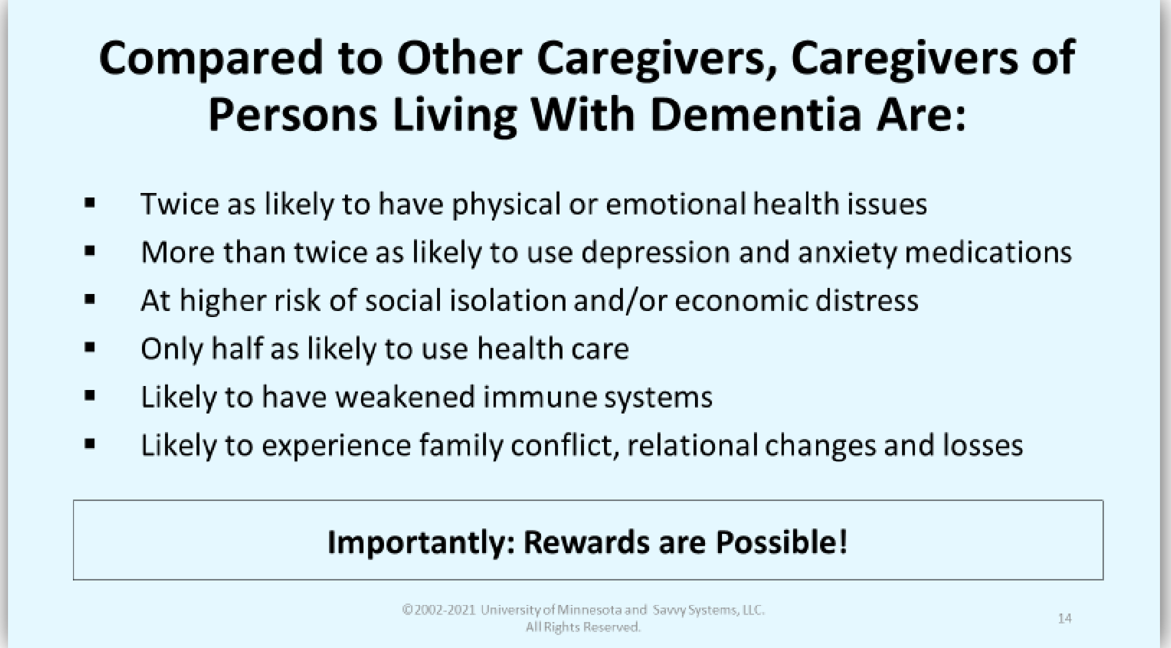
⇒ Even if there are many in a family, it is usually the case that just one person gets to be "It." It makes sense that a team would have a leader, but it's important that the leader feels s/he has a team. This structure – one in the center, with one or more satellites – may contribute to one of the greatest sources of caregiver burden: social isolation.

⇒ The obvious point is that caregiving represents a tremendous commitment, and the sources of that commitment and the willingness to enter into the commitment vary widely across caregivers. Sources might be – likely often – love and fidelity; sometimes it's a sense of obligation or duty; sometimes it's just because there are no other alternatives.

⇒ For most caregivers, taking on the role involves not only providing physical care but having to acquire large sets of new skills and knowledge – which can be taxing in itself.

⇒ Caregiving usually exacts a substantial toll on the caregiver (see slide below).

⇒ BUT: There are elements of caregiving that caregivers report to be rewarding. Savvy caregiving that enables the person to engage in activities can promote a sense of connection between the person living with dementia and caregiver. Carrying out the role can provide a sense of accomplishment and a satisfaction at having fulfilled a commitment or obligation. Beyond that, caregivers can appreciate that they are performing a complicated task in a competent manner.



Compared to Other Caregivers, Caregivers of Persons Living With Dementia Are:

- Twice as likely to have physical or emotional health issues
- More than twice as likely to use depression and anxiety medications
- At higher risk of social isolation and/or economic distress
- Only half as likely to use health care
- Likely to have weakened immune systems
- Likely to experience family conflict, relational changes and losses

Importantly: Rewards are Possible!

Impact of Caregiving. There are volumes of research findings to back the slide shown here, and all the studies basically agree on the adverse effects of caregiving on the caregiver. Make the general point that caregivers are at risk for spending themselves until there is little left. For most, if not all, this will be new information. The takeaway messages include the following:

- If you thought you were feeling under pressure, you likely were – it goes with the job.
- You're not alone, unique, or "a failure" if you're feeling burdened, swamped, etc. This is what caregivers regularly report.
- If you're feeling these things, it's important to recognize and acknowledge them. Burnout is an occupational hazard. Seeing to your own wellbeing is critically important. The stress of caregiving has been shown to negatively affect caregivers' immune systems, as well as contribute to other health issues
- Family conflict is not unusual. There are often disagreements or tensions about what is happening to the person and/or the methods or types of care being provided.
- With the many demands on their time, many caregivers stop doing things they enjoy, and stop attending to their own wellbeing and sense of personal fulfillment.
- Caregivers, particularly spouse caregivers, may have their own health problems. Many indicate that they let their own health needs slip in order to provide care.

The Savvy Caregiver program is designed to help caregivers recognize and deal with the stresses of caregiving and also to function in caregiving in ways that help prevent or minimize stress.[6]

Demographic Trends and Family Caregiving. Dementia caregiving is challenging for every family – however "family" is defined in each case. Family members must cope with the realities of chronic illness and the physical and financial demands of providing care. At the same time, they must manage their own commitments to children, career, and community.

Several significant demographic trends add to the challenge of family caregiving in the United States and elsewhere. These social realities are likely familiar to you, yet are important to take into account as they affect the abilities of family caregivers and other family members to manage the demands of providing high quality, long-term care to persons living with dementia. These trends are highlighted below.

- **We live in an aging society.** Increased longevity means that we are, on average, living longer than ever before. The "oldest old" – adults more than 85 years of age – is the fastest growing group of adults. As cognitive disease is associated with old age, this increases the number of people living with dementia-related conditions.
- **Increased mobility across all generations** means that younger family members often live far away from their older parents or grandparents. Thus, a growing number of older adults are either managing caregiving on their own or with limited family involvement. There is also growing concern about the increasing number of persons living with dementia who live alone, far from family supports.

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[6] It is appropriate to suggest that some caregivers benefit from participation in support groups. It can be helpful if your sponsoring organization can provide a list of nearby support groups. In addition, you can refer participants to the Alzheimer's Association website, which can also help them identify nearby support programs.

- **Most women are employed** in full- or part-time work. As women continue to provide the majority of informal care, their career schedules and demands may curtail their ability to provide sufficient care, or the demands of caregiving exact an even higher toll on their wellbeing.

- **The very notion of "family" is changing.** As the definition of family changes, issues of values and prejudices can complicate family relationships and communication and add to caregiver stress and burden. **Divorced families, stepfamilies, inter-racial families, multi-cultural families, and same-sex and other LGBTQ families** are all becoming more common. Often, families are able to successfully negotiate caregiving responsibilities. However, when this is not the case, family conflict can increase given minimal social norms and support. Research has shown that conflict can add significantly to the stress and burden of caregivers in these situations. It is essential that leaders appreciate that dementia caregiving can exacerbate extended family tensions or conflicts.

As a Savvy trainer, you need to listen carefully to the caregivers in your group for information regarding their own family circumstances. Do they have family nearby – or do other members of their family live in other cities? How are they communicating with members about their person's disease progression? Even when family members live nearby, do you hear that the caregiver describes getting any assistance with caregiving? Caregivers often rely on emotional support from adult children or other relatives, but actual "instrumental" assistance will be invaluable as the disease progresses.

You need to recognize that the stresses always occur within a context, and you need to listen to understand the context of each participant. Each caregiver occupies a place in the world that is affected by cultural and/or religious norms and values. A caregiver may have a family of origin and a different family choice and, because of the caregiving situation, be caught between different – if not conflicting – value sets. Some caregivers may experience stigma or disparities that are unique to their own situations or that are part of a broader social pattern linked to class and/or race/ethnicity/gender identity.

Alzheimer's Disease and Dementia

The Impact of Alzheimer's Disease and Other Neurocognitive Disorders

This section on the toll of caregiving sets the stage for the rest of the program – to give participants a sense of the scope of the task facing the Savvy Caregiver. The brief talk that follows is meant to **firmly establish that caregivers are dealing with a disease-based problem.**

The talk is important because it sets the tone for what follows in the program. The punch line of this talk is that **the caregiver is dealing with a disease, not normal aging or a personality problem.** This point – a disease is at work – is important in itself, but it can be particularly important if multiple family members are involved in the situation and disagree among themselves about just what is going on with the person and what caregiving is about. This section is meant to equip the caregiver with the fact that diseases are real and have to be faced. Diseases and ways of treating and managing them can be described. The first step to being a Savvy Caregiver is to understand just what it is the caregivers are dealing with – in this case a progressive (likely), irreversible, and still incurable – and, therefore, terminal – disease.

The idea is that the more you can get the caregivers to think about dementia in terms of a medical condition, the more they will be able to tap into a behavior pattern they all have of how to deal with illnesses. They all know how to look for signs and symptoms and how to watch to see if various methods of "treating" an illness are working. Similarly, they all know about thinking up ways to interact with family members. They are likely all familiar with hearing a physician say, "Let's try this" in response to symptoms. This process is part of what you want the caregivers to start seeing about their caregiving: they are in the business of trying to find what works best in guiding the daily life of their person. They should be thinking in terms of, "Let's try this, see what happens, and see what we can learn from it."

You might use the example of their caring for a child with a cold or virus – an example pretty much everyone in the group will have some experience with. At some point they come to believe the child is really ill (not just trying to get out of school), because of all the symptoms (coughing, stuffy nose, sore throat, queasiness, etc.). The doctor assures them it's something that's going around, that the child won't die, that antibiotics won't help, that they should just make the child comfortable, and that it will clear up in a couple of days. Basically, what they are left with are home remedies and experiments in making the kid comfortable – and filling time so terminal boredom doesn't set in. They try honey and lemon, chicken soup, hot baths, various over-the-counter medications (pills, sprays, rub-ons). They read to the child, let him/her watch TV, stream videos, etc. All the while, they are watching to see which things work and which don't, and to see whether the child is showing signs of improvement, recovery, worsening, restlessness, etc. Very quickly they develop a repertoire of care strategies and become skilled in applying them with an increasing rate of success. By the time the cold is over, they have pretty much learned how to handle it with as much effectiveness and as little stress as possible. When the next cold sets in, they're more prepared for it and less frightened by it – and they learn more. Over time, they become very skillful and have a big "bag of tricks."

This is the idea with dementia caregiving. Caregivers need to understand just what kind of diagnosis they have been handed and then begin the task of establishing a repertoire of caregiving strategies.

Neurocognitive Disorders.

This is intended to be a very brief talk – perhaps 20 minutes at most. This is really an introduction to material that participants have in their manual, and it should serve to refresh their memory if they've done any previous reading or learning about dementia.

The main focus of the talk is on progressive neurocognitive diseases, like Alzheimer's, that produce dementia symptoms. Point out the sections in their manual as you deal with each one. This will make it very concrete to group members that they have this material – and then you can point out that part of their assignment in the next week will be to read through the material carefully. The Caregiver's Manual points them to online sites where they can learn more about the diseases and where they can track to other sites where even more information is available. Encourage participants to be active learners about the disease(s) they are dealing with.

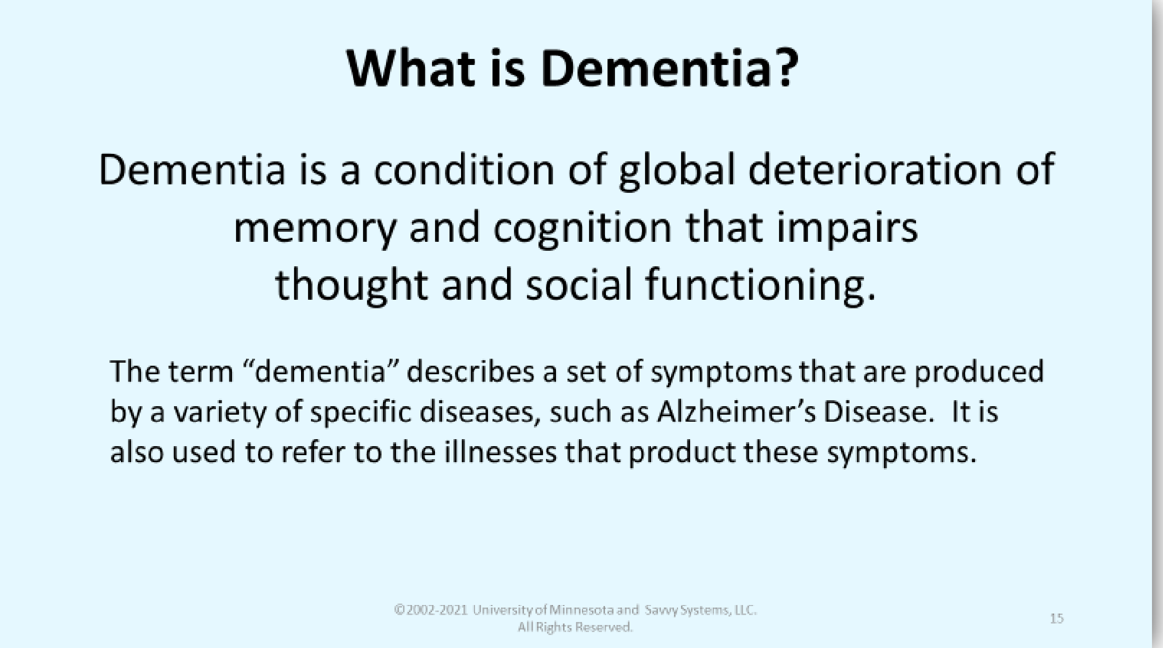
The objective of this brief talk is to enable participants to understand and appreciate that neurocognitive disorders and the symptoms associated with them – symptoms that are typically described by the word dementia – are illness-produced conditions. They should understand that these disorders are not a normal part of aging, that this is a widespread problem, and that many people are dealing with it – the caregivers are not alone in their work. Finally, they should understand that personhood remains, although these illnesses progressively erode persons' own access to their personhood and, likewise, make it progressively difficult for caregivers and others to connect with that personhood. The two slides that follow provide the introduction to the talk.

Basic Facts About Dementia

There are some key teaching points related to these slides:

1. "Dementia" is not a disease. It is **a condition** (sometimes called a syndrome) **that can be caused by many diseases**. The word "dementia" describes a group of symptoms and effects, not a specific disorder.

   Dementia is disease-related – not just a memory problem – and not a personality disorder or a developed character flaw. Clinicians are not always precise in using their terms, so some caregivers report being relieved to have learned that their loved one has dementia but not Alzheimer's. This can be confusing and produce false hope.



What is Dementia?

Dementia is a condition of global deterioration of memory and cognition that impairs thought and social functioning.

The term "dementia" describes a set of symptoms that are produced by a variety of specific diseases, such as Alzheimer's Disease. It is also used to refer to the illnesses that product these symptoms.

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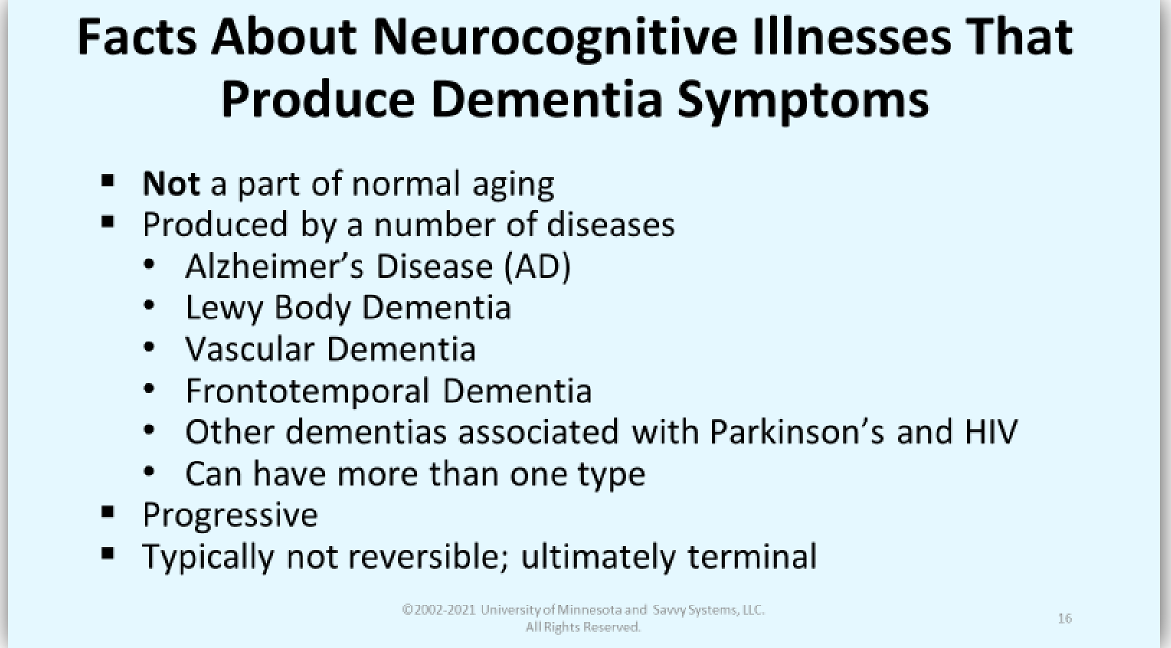
2. Neurocognitive illnesses are **global** in nature – they gradually, but eventually, affect a person's entire range of abilities that are "governed" by the brain. Often, dementia-related diseases are thought of as disorders of memory. Memory is almost always involved, but it is especially important to realize that other or all areas of thought or cognition are also progressively affected.

3. A neurocognitive illness **interferes with social functioning** – a person's ability to act thoughtfully and purposefully in the world. As the disease progresses, those living with it become more cut off – from themselves and from the world. The impact on social functioning has enormous implications for caregivers. This really means that the person gradually loses all the abilities he/she once had that allowed him/her to do things in the world – not just hold a job but hold a conversation; not just perform complex tasks but, eventually, do even the simplest of self-care activities.

   Neurocognitive illnesses interfere with social functioning in another way, too. The neurocognitive disorders that produce dementia symptoms are often misunderstood by the larger community. Persons living with these disorders – and their family caregivers – are sometimes stigmatized or shunned, cut off from their communities by ignorance or fear.

4. These illnesses are not just what happens normally as individuals age. Most persons over the age of 65 are not and will not become affected by these disorders. Just as there is normal decline in all muscle and organ functioning with aging, there is also a normal slowing of brain function. The brain does not work as fast, but all its capabilities are intact. The losses and slowing in neurocognitive disorders are much more extensive and serious. These losses are disease-driven – not normal.

5. Dementia symptoms are associated with a few commonly known illnesses, *and almost all* such disorders are progressive. As you will note in the talk, the most common form of a dementia-related disease is Alzheimer's, either alone or in combination with Vascular Dementia. Alzheimer's and most other dementia-related diseases are progressive. A very small number of conditions are not progressive. When you went through the introductions, early in this session, you will have learned what most of the care recipients in the group have been diagnosed with. From this, you will know whether there are any caregivers dealing with a more or less static illness. In progressive disorders, the person's condition deteriorates over time and the effects of the disease become worse.



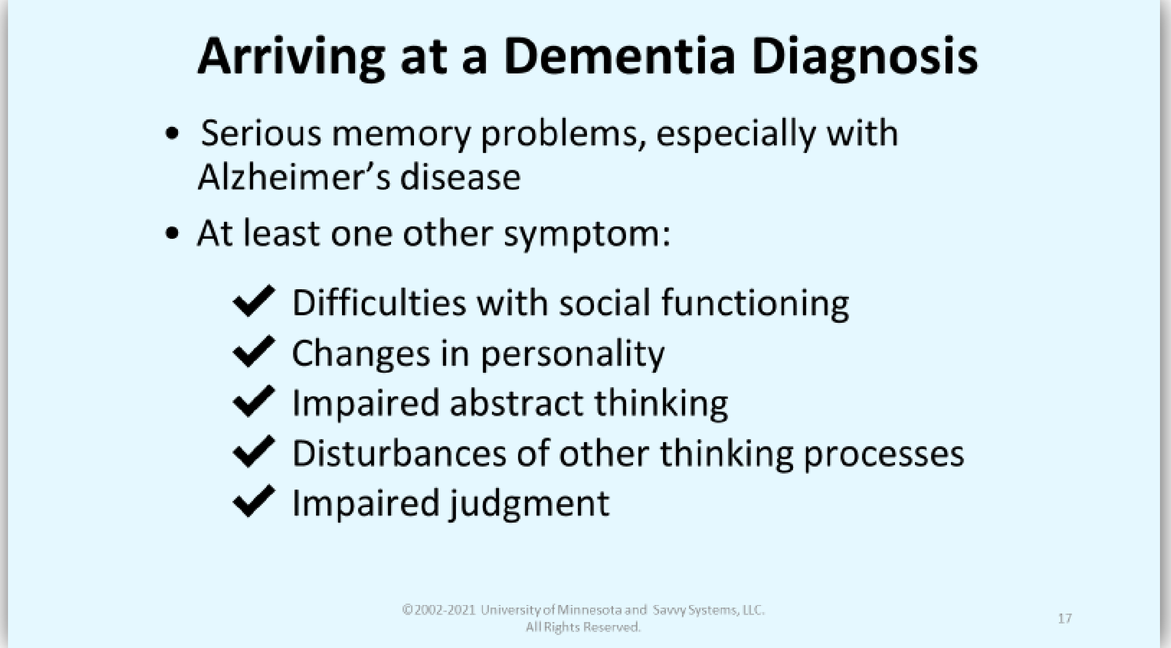
Facts About Neurocognitive Illnesses That Produce Dementia Symptoms

- **Not** a part of normal aging
- Produced by a number of diseases
  - Alzheimer's Disease (AD)
  - Lewy Body Dementia
  - Vascular Dementia
  - Frontotemporal Dementia
  - Other dementias associated with Parkinson's and HIV
  - Can have more than one type
- Progressive
- Typically not reversible; ultimately terminal

6. It is important to note – and this is spelled out in the Caregiver's Manual – that most neurocognitive illnesses are irreversible. However, a few are. This underscores the need for a clear, informed

diagnosis and for a relationship with a medical provider they can trust. It is also the case that these are terminal illnesses; the individual will die with, though not always from, these illnesses.

Over the past decade, methods for diagnosing Alzheimer's and other dementia-related diseases have improved, and the number of physicians able to employ these methods accurately and reliably has increased. The slide below identifies signs that prompt the need for an accurate and comprehensive diagnostic workup. You can simply read them. It is important to note that memory *plus one or more of the others* is what is looked for in diagnosing Alzheimer's disease. Other dementias may or may not have an early loss of memory.



Arriving at a Dementia Diagnosis

- Serious memory problems, especially with Alzheimer's disease
- At least one other symptom:
  - ✓ Difficulties with social functioning
  - ✓ Changes in personality
  - ✓ Impaired abstract thinking
  - ✓ Disturbances of other thinking processes
  - ✓ Impaired judgment

All of the signs will not necessarily appear in every person. You might want to provide some examples of what some of the points mean:

- **Difficulties with social functioning.** The person may be unable to participate in social activities s/he previously enjoyed – for example, taking part in family gatherings, remaining active in church groups or in social clubs, entertaining friends.

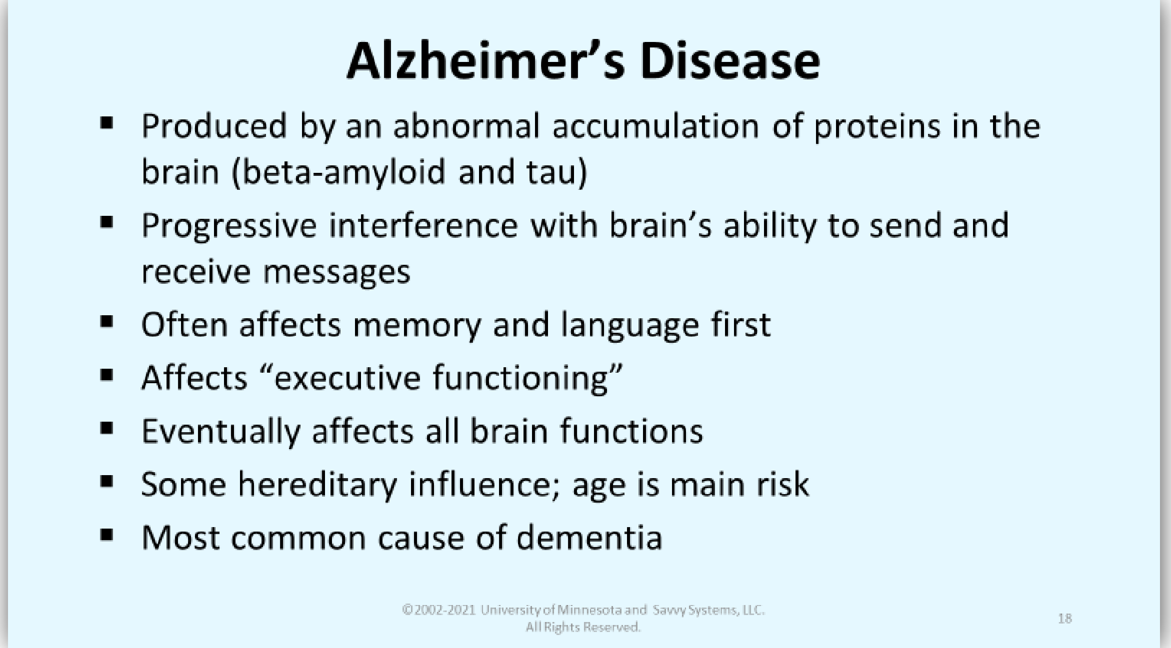
- **Change in personality.** Some people's personalities change. Usually, the change seems to be that the person is somehow less of him/herself – quieter, more indrawn. Sometimes the change is more dramatic, and the person can seem to be quite different from how s/he was before the disease came on. A usually placid person is reported to be aggressive and to use language that would have shocked and offended him/her before. A friendly and outgoing person goes into a shell or actively pushes people away. And then there are reports of people who were mean spirited becoming very gentle. Any change in personality should be noted to the healthcare provider in developing a diagnosis.

- **Problems with thinking "processes."** Impairment of abstract thinking and judgment, as well as disturbances in other areas of cognition all relate to evidence of problems with thinking processes.

> Examples of this include: difficulties with complex tasks (handling finances, following elaborate plans); making significant mistakes (getting lost, or becoming disoriented); making poor choices (ordering lots of useless things seen on TV, overspending on a credit card); and demonstrating a breakdown of usual patterns (house not as orderly). **The important feature to note is what has changed.** Some people never had good judgment or a strong sense of direction to begin with, so having difficulties now would not be diagnostic.

The point, though, is that to arrive at the diagnosis, the doctor has to see that **there is more wrong than memory problems**. This is a condition that affects all thinking processes. It affects the whole person.

The Most Common Neurocognitive Disorders. Now you will provide a talk on the main dementia-related illnesses. Watch the time here. You want to be able to get through as many of the eight cognitive losses portion as possible, so make sure participants understand there is more information in their manual.

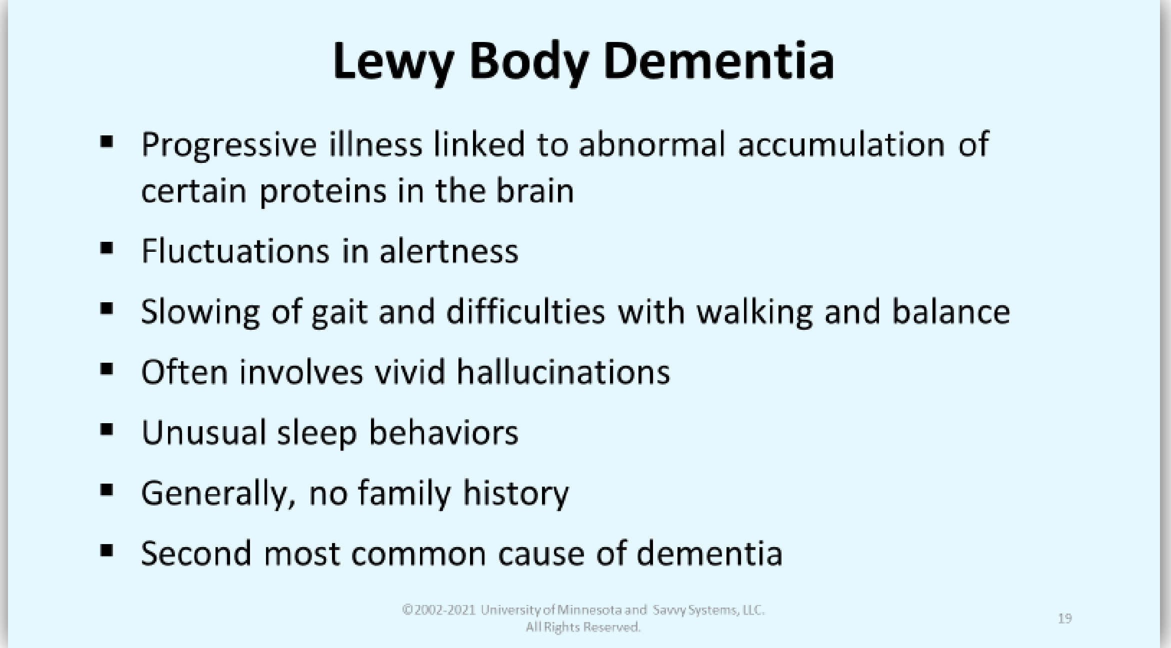


Alzheimer's Disease

- Produced by an abnormal accumulation of proteins in the brain (beta-amyloid and tau)
- Progressive interference with brain's ability to send and receive messages
- Often affects memory and language first
- Affects "executive functioning"
- Eventually affects all brain functions
- Some hereditary influence; age is main risk
- Most common cause of dementia

Alzheimer's Disease is the most common of the dementia-related diseases. People generally say that about 60 to 80% of dementias are due to Alzheimer's, but it may be that it is involved in combination with other diseases in an even greater percentage (up to 90%). Alzheimer's involves a process in which protein structures (called **plaques**) accumulate in various parts of the brain; the plaques then affect the functioning of critical cells – neurons). Another process causes the neurons to atrophy (shrivel and develop internal **tangles**) and become less efficient and effective. The chemical medium through which signals are passed between and among neurons is also altered. The result is that communication between neurons becomes less reliable and eventually breaks down altogether.

This communication is responsible for all of the activities of the brain. So as a result, over time, Alzheimer's erodes all areas of life that the brain controls – which is to say: all areas of life. Alzheimer's is the fifth leading cause of death among older adults – death usually from complications of undetected infections or illnesses (undetected because, as the disease progresses, the person loses the ability to recognize and report on symptoms), or from aspiration pneumonia, due to the loss of swallowing ability. Of the top ten causes of death in the United States, Alzheimer's is the only one for which there are no effective treatments.[7]



Lewy Body Dementia

- Progressive illness linked to abnormal accumulation of certain proteins in the brain
- Fluctuations in alertness
- Slowing of gait and difficulties with walking and balance
- Often involves vivid hallucinations
- Unusual sleep behaviors
- Generally, no family history
- Second most common cause of dementia

Lewy Body Dementia (LBD). LBD is thought to be the second most common of the neurocognitive disorders. In LBD, as in Alzheimer's, there is an abnormal accumulation of a particular protein in the brain (alpha-synuclein) – commonly called Lewy bodies.

In addition to progressive cognitive losses, persons living with LBD may experience changes in mobility (issues with balance and slowing of pace) and alertness. They often experience very vivid hallucinations – which may not appear to be troubling to the individual but reports of which can be worrisome for caregivers (so it's important to emphasize that these are "normal" and may not be harmful). Sleep behaviors may change, including sleepwalking and highly active dreaming and flailing that could result in injury to a bed partner. There appears to be some mechanistic link between LBD and Parkinson's, and it is not uncommon for persons diagnosed with Parkinson's to develop symptoms of LBD as they age.

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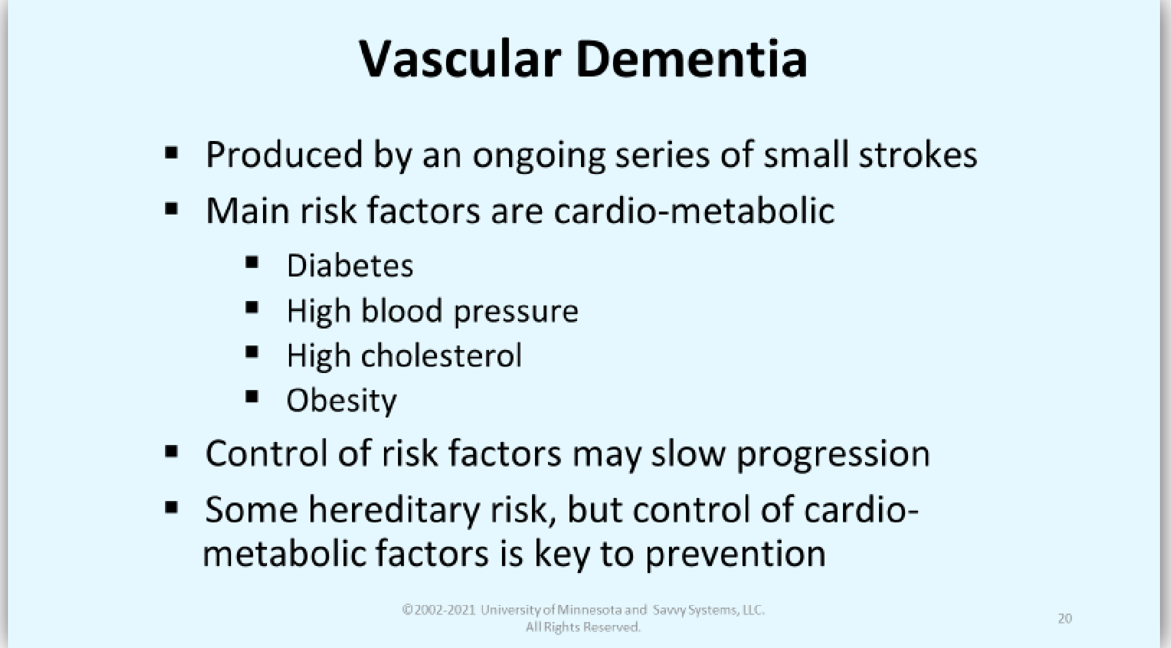
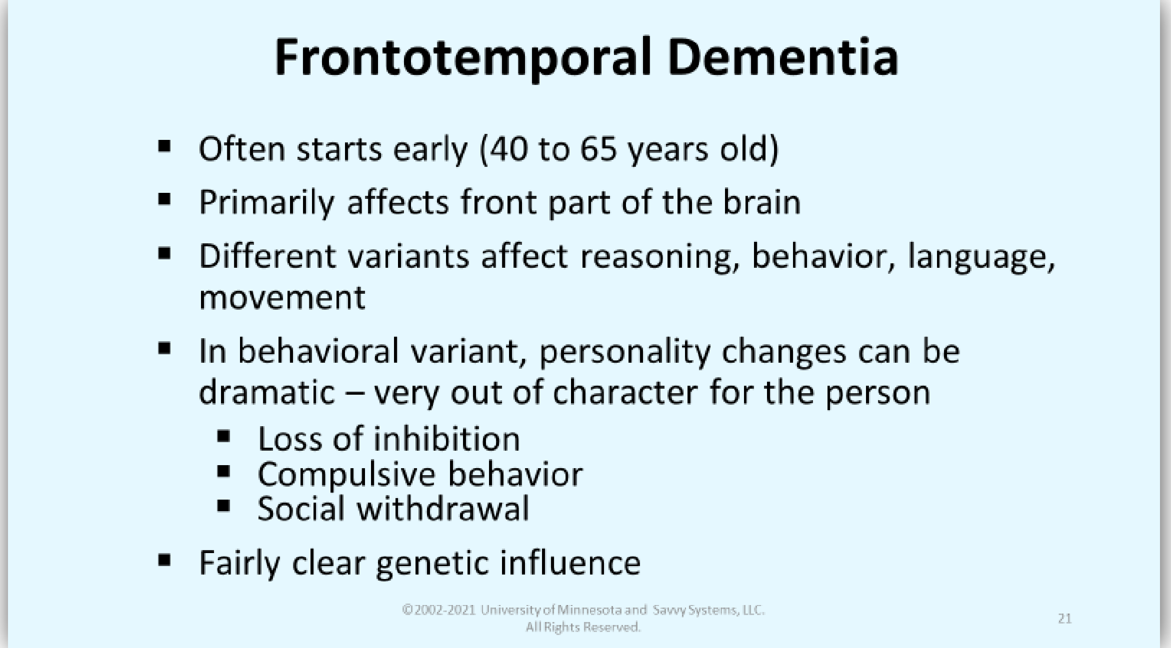
[7] 2020 Alzheimer's Facts & Figures



Vascular Dementia

- Produced by an ongoing series of small strokes
- Main risk factors are cardio-metabolic
  - Diabetes
  - High blood pressure
  - High cholesterol
  - Obesity
- Control of risk factors may slow progression
- Some hereditary risk, but control of cardio-metabolic factors is key to prevention

Vascular Dementia is produced by multiple small or large strokes and sometimes called multi-infarct dementia. It works differently from Alzheimer's disease, but with many of the same effects. The strokes kill off the parts of the brain where they happen. Since brain tissue doesn't regrow, these areas in the brain are no longer effective. The progress of vascular dementia is stepwise (with each stroke), rather than smooth. There is a remarkably high occurrence of Alzheimer's and vascular dementia combined.



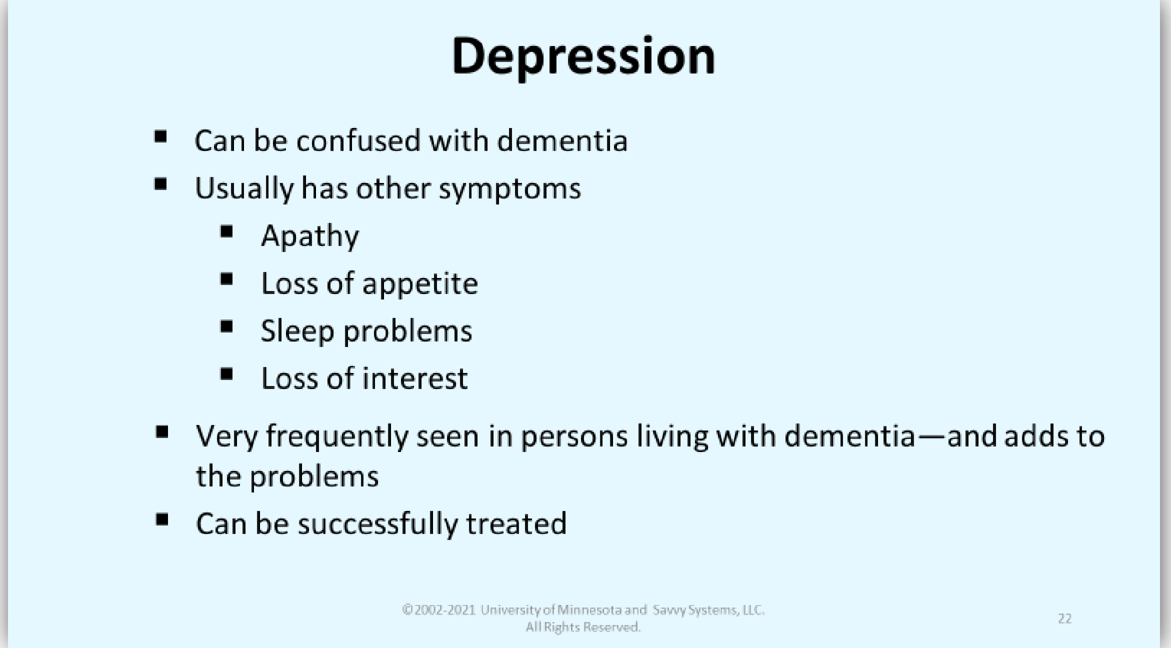
Frontotemporal Dementia

- Often starts early (40 to 65 years old)
- Primarily affects front part of the brain
- Different variants affect reasoning, behavior, language, movement
- In behavioral variant, personality changes can be dramatic – very out of character for the person
  - Loss of inhibition
  - Compulsive behavior
  - Social withdrawal
- Fairly clear genetic influence

Frontotemporal Dementia (FTD). A set of associated neurodegenerative conditions that affect the front part of the brain and that most typically present in younger people (ages 40 to 65). In addition to cognitive losses that FTD has in common with other dementias, the illness is often associated with some movement difficulties as well as unusual behavioral symptoms and personality changes. Persons living with FTD may lose inhibitions and behave in very uncharacteristic ways. They may engage in aggressive verbal behaviors, become sexually aggressive, or act compulsively. Because the illness frequently occurs in younger persons, there is often some difficulty obtaining a timely and accurate diagnosis, and misdiagnoses of psychiatric conditions do occur. FTD appears to have a fairly strong genetic component, so parental history is a major risk factor.

There is also a much less frequent variant of the illness that very early on affects the person's language abilities and interferes with communication, even as cognitive functioning is only slightly affected. This language-affecting variant is usually referred to as Primary Progressive Aphasia.

Reversible Neurocognitive Disorders. Only a very few dementia-producing conditions are reversible, including Normal Pressure Hydrocephalus (a build-up of fluids in the head, putting pressure on the brain), brain infections, and certain nutritional, metabolic, and endocrine (thyroid) disorders. The most common reversible condition that presents with dementia symptoms is depression. When depression produces these symptoms, it is sometimes referred to as pseudodementia.

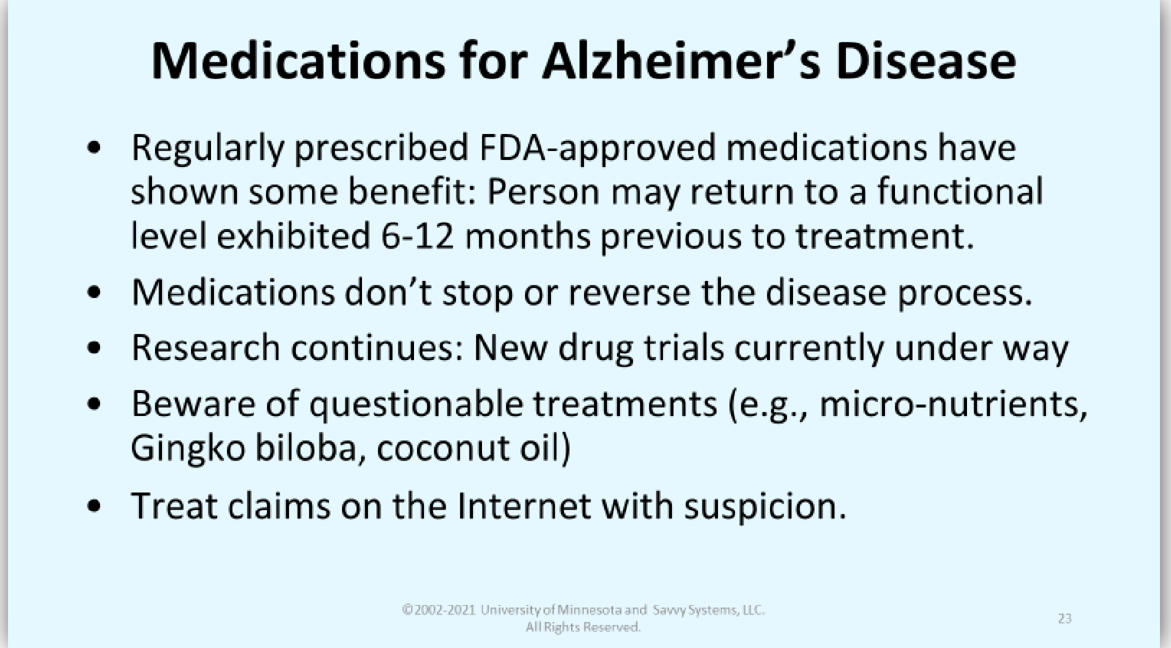


Depression

- Can be confused with dementia
- Usually has other symptoms
  - Apathy
  - Loss of appetite
  - Sleep problems
  - Loss of interest
- Very frequently seen in persons living with dementia—and adds to the problems
- Can be successfully treated

Depression. Up to one third of those living with dementia-related conditions have a depression at some time – usually early in the disease. This may be related to the insight they still have about what the disease means for their future.

It is especially important that caregivers look for indications of depression in the persons for whom they provide care. If there are sudden changes in behavior in a person living with a dementia, they should be looked at by their care provider – and depression should be questioned. It's worth noting that the incidence of depression in caregivers of people living with a dementia-related illness is about twice that of the general public. If participants' care recipients are experiencing depressive symptoms, encourage them to talk with a healthcare provider, since it is generally a highly treatable condition.



Medications for Alzheimer's Disease

- Regularly prescribed FDA-approved medications have shown some benefit: Person may return to a functional level exhibited 6-12 months previous to treatment.
- Medications don't stop or reverse the disease process.
- Research continues: New drug trials currently under way
- Beware of questionable treatments (e.g., micro-nutrients, Gingko biloba, coconut oil)
- Treat claims on the Internet with suspicion.

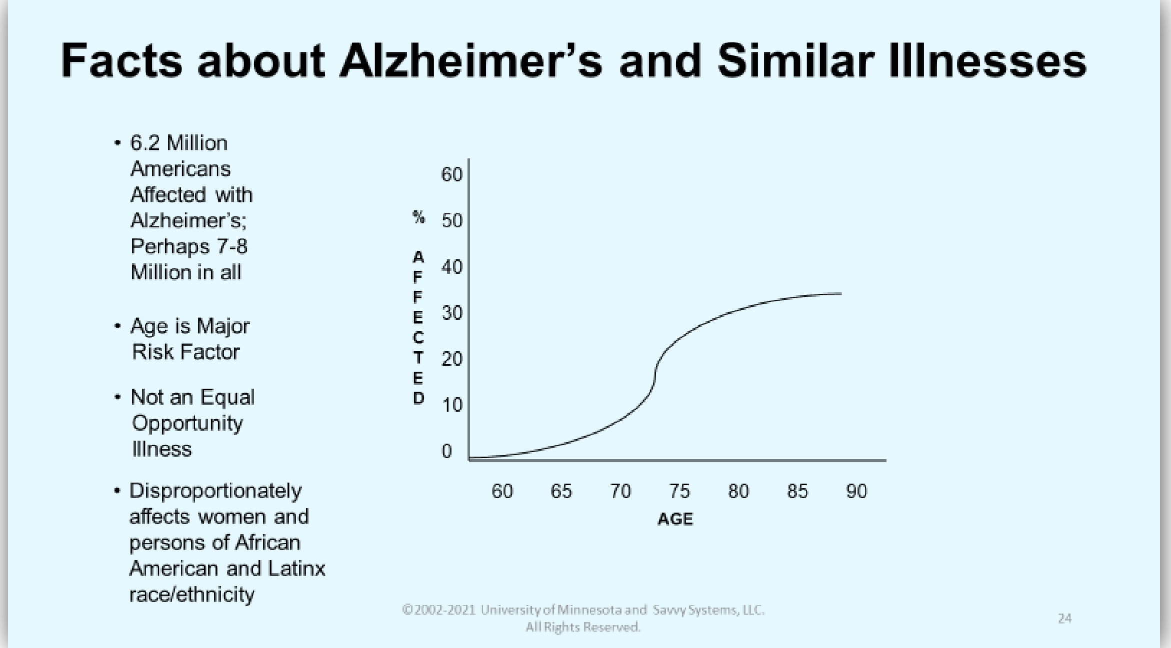
Medications for Treatment of Alzheimer's Symptoms. The currently most prescribed Alzheimer's drugs (cholinesterase inhibitors) act to improve brain communication affected by Alzheimer's disease alone. An excess of cholinesterase in the brain seems to create "noise" that interferes with neuronal communication. These drugs work to reduce the interference to allow the disease-weakened signal to get through better. People who begin these drugs and are able to remain on them (i.e., are not so affected by the side effects that they discontinue them) seem to return to a level of cognitive functioning that they had been at 6 to 12 months previously. Some positive effects on mood and behavior have also been reported with these drugs. They do not stop the disease process, however, and gradually the effect of the noise reduction wears off and there is a return to decline.

Vitamin E, estrogen, and non-steroidal anti-inflammatory drugs (NSAIDs – e.g., Ibuprofen) have all been suggested as having benefit and continue to be studied. It is important to check the appropriate websites to ascertain the current and validated findings on any of these or other substances that are under clinical trial.

This section of the Trainer's Manual is bound to go out of date quickly as new advances in drug research and therapies continue. Be sure to check the Alzheimer's Association (www.alz.org) and the Alzheimer's and related Dementias Education and Referral (ADEAR) Center (www.nia.nih.gov/health/about-adear-center) websites for the most up-to-date information on evidence-based drug therapies.

The proliferation of websites that appear by searching on the keywords "dementia" or "Alzheimer's" is astounding. Internet search lists will have the most popular sites on top, but do not provide guidance about the accuracy of or the evidence for the information that is being presented. Great caution should be advised, and participants should be reminded to seek consultation with a physician, pharmacist, or nurse practitioner as an essential part of undertaking any form of therapy – even therapy that involves "natural cures" or complementary medicines. Even substances that might be harmless in themselves could interact with other medications the person is taking, so professional consultation is essential.

Before showing the next slide, ask learners to estimate how many people in the U.S. are living with dementia-related illnesses.



Facts about Alzheimer's and Similar Illnesses

- 6.2 Million Americans Affected with Alzheimer's; Perhaps 7-8 Million in all
- Age is Major Risk Factor
- Not an Equal Opportunity Illness
- Disproportionately affects women and persons of African American and Latinx race/ethnicity

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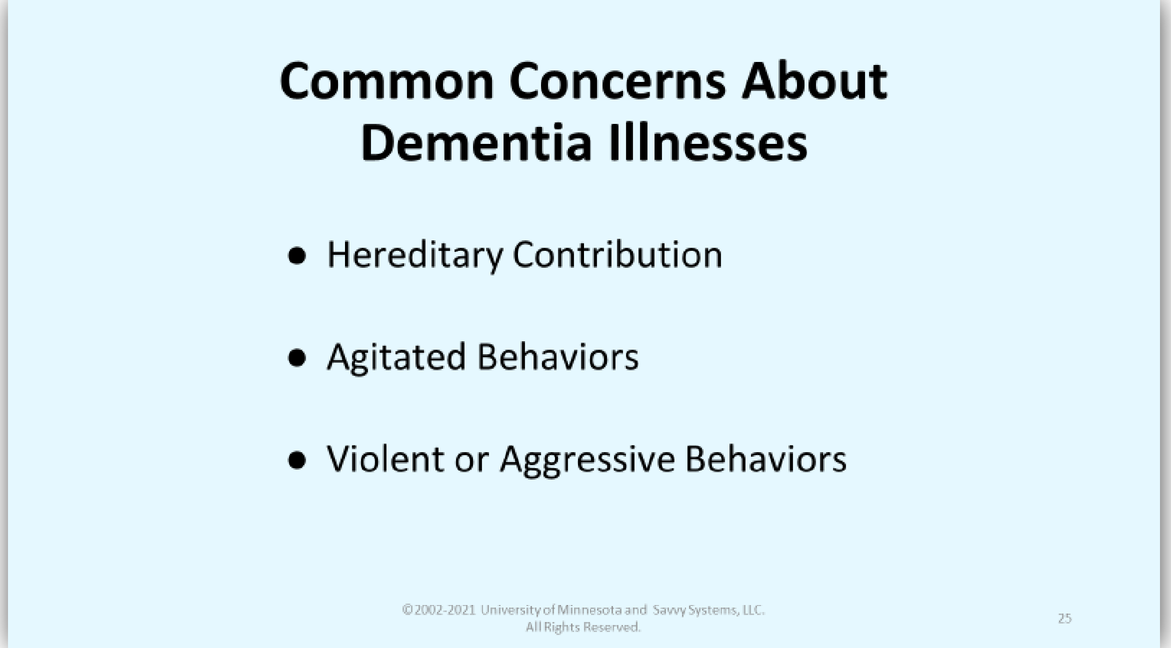
The commonly quoted figure of 6.2 million refers to those with moderate to severe Alzheimer's. While this number is the generally accepted figure, there are other estimates that upwards of 7-8 million persons live with the full range of neurocognitive illnesses. The most important thing about the prevalence (how many people have the disease) is that **it is related to age. As you look at the population, the oldest adults represent the greatest proportion of people who have the disease.** This means that as the number of older persons, especially those over age 85 years, grows dramatically over the next 50 years, the prevalence of dementia-related disease is also predicted to grow. By 2050, there will be at least 14 Million Americans with these disorders. Right now, there are about 16 million family caregivers, but there could be as many as 35 to 40 million caregivers by mid-century. It is worth noting that a small percentage of all dementia cases – perhaps 5% – appear before the age of 65, sometimes even early in the 40s. Such "young-onset dementias" tend to have a more rapid decline, and thus come with unique challenges involving work, finances, and – often – while young children are still in the home.

Alzheimer's appears to affect women more than men – and not just because they outlive men. Alzheimer's and other dementias, particularly vascular dementia, also appear to be twice as prevalent among African Americans and one and one-half times as prevalent among Latinx individuals (and perhaps at an earlier age). Broader issues of social and health disparities are thought to contribute to the striking discrepancy in prevalence. There are more European Americans (Caucasians/ Whites) with the disease than persons from other racial groups, but this has to do with longevity rates and the overall larger proportion of Caucasians in the U. S. population. This group outnumbers and outlives most other groups – and this makes them more susceptible to the disease.

The diagram points out two facts that the learners need to consider. The accumulation of dementia-related illnesses among the very old stems from two causes: first, people who develop the disease usually live a long time, so they live to be old; and second, as people age, there appears to be a somewhat increased risk for developing the disease, so as unaffected people age, they are more likely to develop a neurocognitive illness and to join the ranks of those who acquired the disease earlier in life.

It is important to note that virtually every other health problem – other diseases as well as declines in the ability to function and take care of oneself – also increase with age. Alzheimer's Disease or other neurocognitive illnesses do not grant immunity from other problems. So, care recipients living with these illnesses may be frail and/or beset with other health problems as well, and may also have care needs not related to the dementia. This further adds to the care-providing role that caregivers play.

While on the topic of general issues related to dementia-related illnesses, it is useful to point out that there are a few concerns that are almost always raised. You can use this slide to raise and discuss these concerns.



Common Concerns About Dementia Illnesses

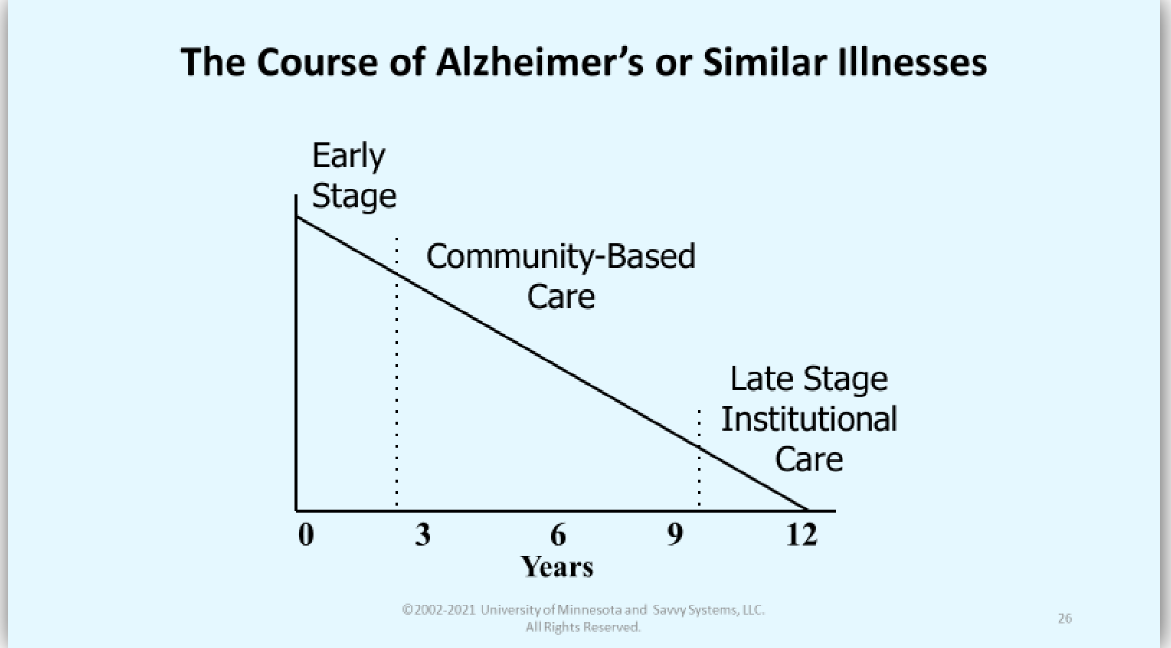
- Hereditary Contribution
- Agitated Behaviors
- Violent or Aggressive Behaviors

Using the slide above, make the following points:

- If a person has a first-degree relative who has the disease (e.g., a parent), that person's chance of contracting the disease is greater than someone without a first-degree relative with the disease. If a person has two first-degree relatives, s/he has an even greater chance than a person with no relatives with the disease. The presence of one or two copies of a particular form of a gene everyone carries (apoἐ) also appears to confer greater risk. There is a familial form of Alzheimer's disease (where more than half the members of each generation in a family have the disease), but it is rare – it only accounts for 1 to 2% of all cases.
- Most of the actual behaviors of persons living with dementia are very routine and not agitated. Still, many people fear situations in which the person becomes visibly upset and begins to act in ways that appear uncomfortable to the person and that may be disturbing to others. Such behaviors – termed behavioral and psychological symptoms of dementia (BPSD) – are a main contributor to caregiver burden. While dramatic behaviors do occur, it is the more mundane

behaviors that caregivers will have to deal with the most. Such everyday behaviors include pacing, asking the same questions over and over, calling out or yelling, following someone around, wandering, and rummaging.

- Many people worry that their person may become aggressive. It is true that striking out – physically and verbally – does occur. These behaviors, however, are almost never spontaneous and are almost always defensive in nature. The best way to think about this is to understand that persons living with dementia-related illness are very vulnerable. The disease produces profound confusion, and this makes it easy to startle someone with such a disease. When a person is startled or feels under pressure, s/he may react defensively, which may involve striking out.



The Course of Alzheimer's or Similar Illnesses

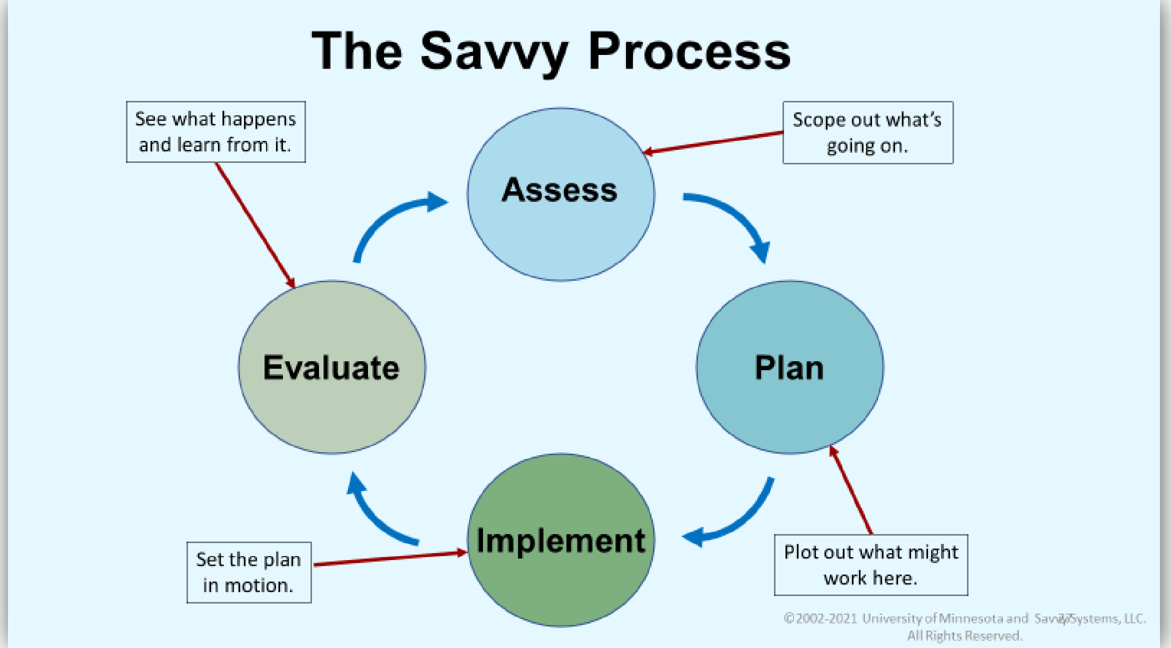
Another concern commonly raised regards the duration and progression of these illnesses. This slide is not meant to be taken literally. It is a somewhat loose representation meant to give participants a sense of the general course of the illnesses. Thus, the 12-year timeframe in the slide is only for illustrative purposes. The course of any individual's disease will vary. A range of 3 to 20 years (or more) is possible. The downward slope of the line indicates, again, that these are terminal illnesses, the sixth leading cause of death among older persons. Death is usually from a complication of the disease – the inability to report a problem, like an infection (so, many persons die of pneumonia). The main point of the slide is that community-based caregiving generally is the major portion of the illness trajectory; this is very likely the stage in which most of the program's caregivers will find themselves.

Cognitive Losses in Dementia

Cognitive Losses in Neurocognitive Disorders

This is a major turning point in the training. It is where we begin to involve caregivers in the development of a strategic perspective on caregiving. The talk and exercise are meant to prepare caregivers to read and understand the material on cognitive losses in their manual and to begin to complete the worksheet on cognitive losses you will distribute as a handout. They are principally meant to focus them on the issue of strategy – how everything they do and say with and around their persons should be guided by an appreciation of what the disease is doing to them and by a planned approach based on this appreciation.

This is also the point in the program where we are trying to broaden participants' understanding of dementia-related illnesses. They are not illnesses that only affect memory; they affect all aspects of thinking and behavior – the person's capacity to function well and effectively in the world. As a part of this talk, you will provide the caregivers with the **Cognitive Losses Worksheets** they will use in the home activities. Ask the learners to interact with you and perhaps jot down notes as the talk proceeds. This may serve to help them with the home activities.



The Savvy Process

Assess

Plan

Implement

Evaluate

Scope out what's going on.

Plot out what might work here.

Set the plan in motion.

See what happens and learn from it.

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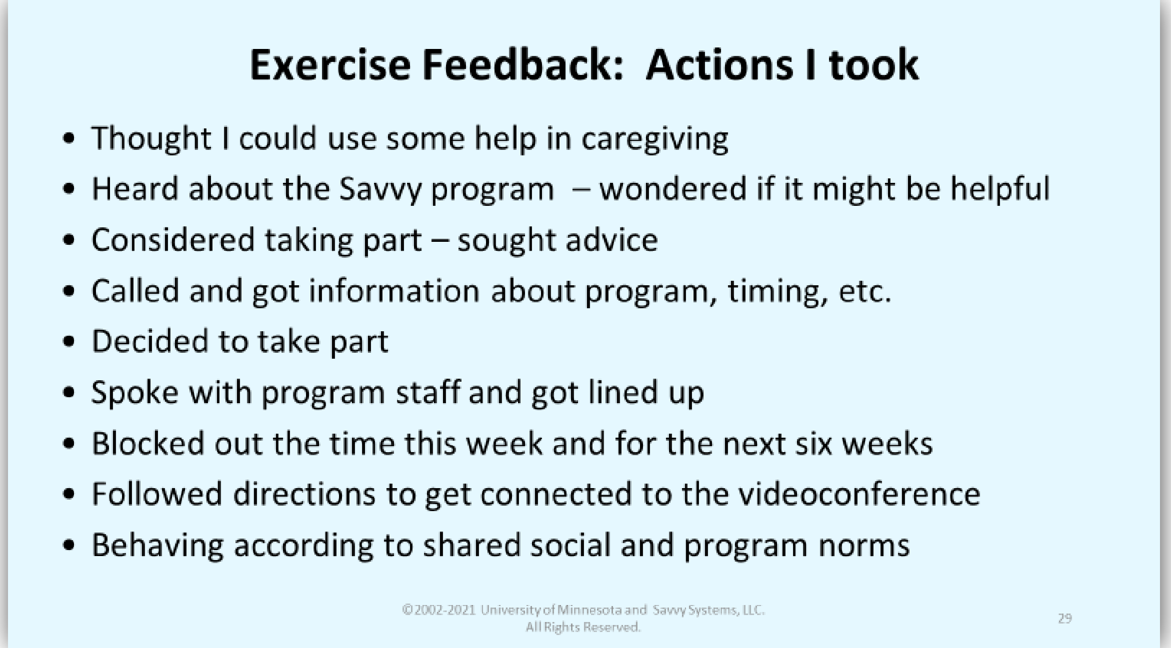
This is a good place to reinforce the idea that caregivers will gradually need to learn how to function like "clinicians," and that the Savvy program is designed to help them acquire the appropriate knowledge, skills, and outlook they need to be effective in their care role. The slide above describes the **"Savvy Process"** to which they are being introduced. It's a process that they can use to live the Savvy "Don't just do something" mantra. This process asserts that a Savvy caregiver first sizes up a situation (Assess), and then uses what they know about their person and the illness to create a Plan for what they would like to have happen. Then, they put the plan into effect (Implement) and observe what happens (Evaluate). They incorporate the knowledge from that evaluation into their existing fund of knowledge, thereby expanding the capacity for ongoing assessment and planning. This is a process that is continuously applied and adapted across the disease course in Savvy caregiving. It is worth noting that this same basic process is used by nurses, physicians, and other professionals in their clinical work.

This is also a good place to introduce a key Savvy mantra – **Don't Just Do Something . . . Stand There**! The mantra is a kind of shorthand for the Savvy process as a whole. It is meant to remind caregivers of the importance of mindful action and of avoiding reflexive reaction.

An Optional Exercise. The mini lecture you'll give next is really a talk on "thinking about thinking," and it is a particularly important part of Session 1. If there is time to do so, you can engage participants in an exercise that may set the stage for them to begin to think about thinking. Many trainers find this a helpful warm-up, but having enough time to get as much as possible of the "thinking about thinking" talk done during the session has to be your main concern. So, use your judgement about whether and how to include this piece.

The exercise begins with the following question to the group: **"How did you all come to be here today? What were all of the things that you had to do and think about that resulted in your being here?"**

Allow a brief brainstorm to occur and then use the slide below to summarize all of the activities that went on to bring the group together in this place, at this time.



Exercise Feedback: Actions I took

- Thought I could use some help in caregiving
- Heard about the Savvy program – wondered if it might be helpful
- Considered taking part – sought advice
- Called and got information about program, timing, etc.
- Decided to take part
- Spoke with program staff and got lined up
- Blocked out the time this week and for the next six weeks
- Followed directions to get connected to the videoconference
- Behaving according to shared social and program norms

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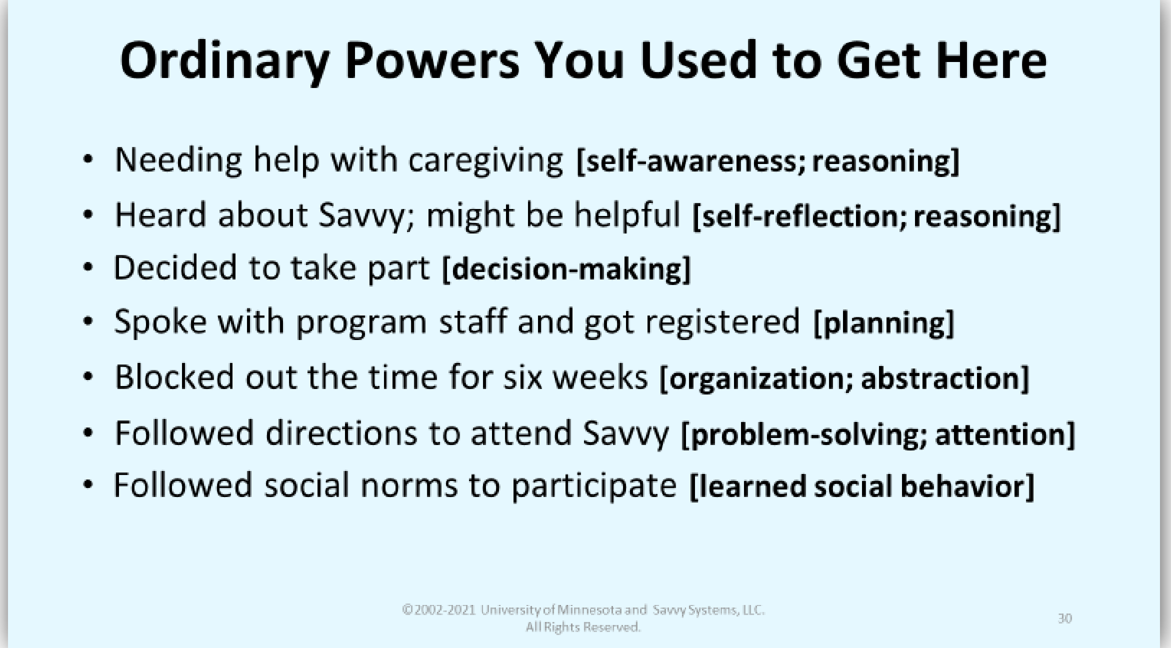
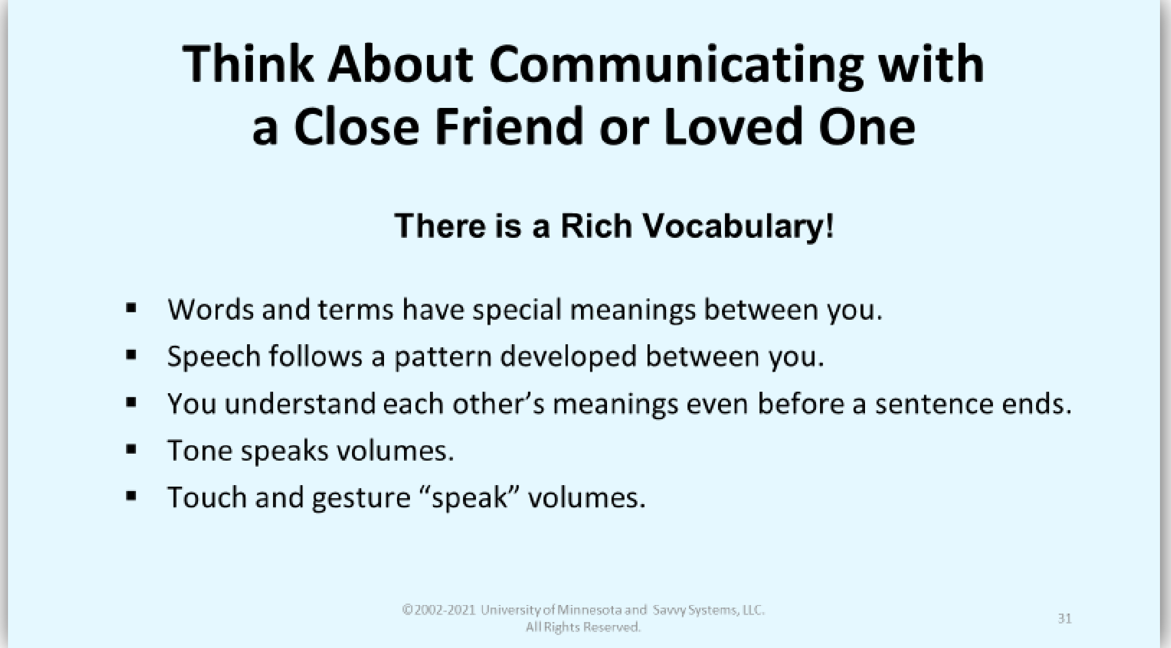
Then use the slide below to give names to the cognitive processes underlying those activities.



Ordinary Powers You Used to Get Here

- Needing help with caregiving **[self-awareness; reasoning]**
- Heard about Savvy; might be helpful **[self-reflection; reasoning]**
- Decided to take part **[decision-making]**
- Spoke with program staff and got registered **[planning]**
- Blocked out the time for six weeks **[organization; abstraction]**
- Followed directions to attend Savvy **[problem-solving; attention]**
- Followed social norms to participate **[learned social behavior]**

Next, ask the participants to think about a close friend or loved one – and a recent conversation they had with that person. Use the slide below to draw attention to the extensive way we take tone, gesture, and personally established meanings for granted in our everyday interactions with individuals in our lives.

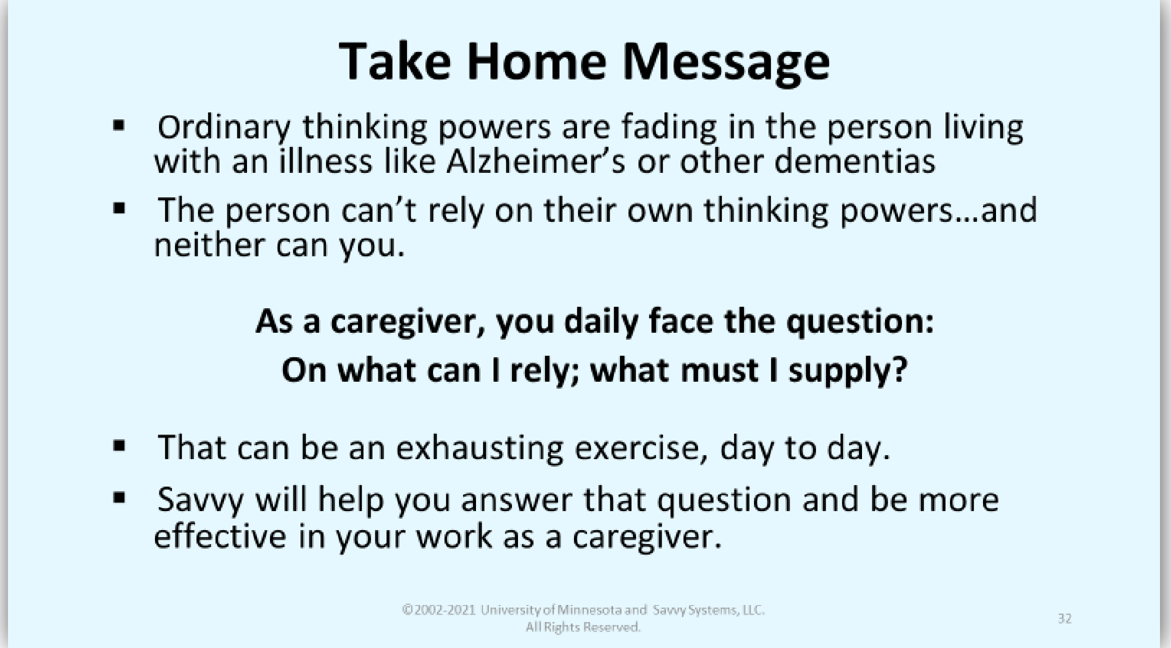


Think About Communicating with a Close Friend or Loved One

There is a Rich Vocabulary!

- Words and terms have special meanings between you.
- Speech follows a pattern developed between you.
- You understand each other’s meanings even before a sentence ends.
- Tone speaks volumes.
- Touch and gesture “speak” volumes.

The slide below makes the point of this segment: When we are in good health, we generally take all of these powers of thought and communication for granted; we rely on them every day to keep ordinary life moving smoothly forward. Caregivers are faced with a situation in which they cannot rely on these abilities in their person because of the effects of dementia-related illnesses at work. They are always having to consider: “To what extent can I rely on these capacities, and what parts of them do I have to fill in or supply?”



Take Home Message

- Ordinary thinking powers are fading in the person living with an illness like Alzheimer’s or other dementias
- The person can’t rely on their own thinking powers…and neither can you.

As a caregiver, you daily face the question:
On what can I rely; what must I supply?

- That can be an exhausting exercise, day to day.
- Savvy will help you answer that question and be more effective in your work as a caregiver.

An Alternative Strategy. If you see that time is running short and you think the full exercise will eat into the time for the next segment, give participants the punch line in the form of a very brief, 1-minute talk:

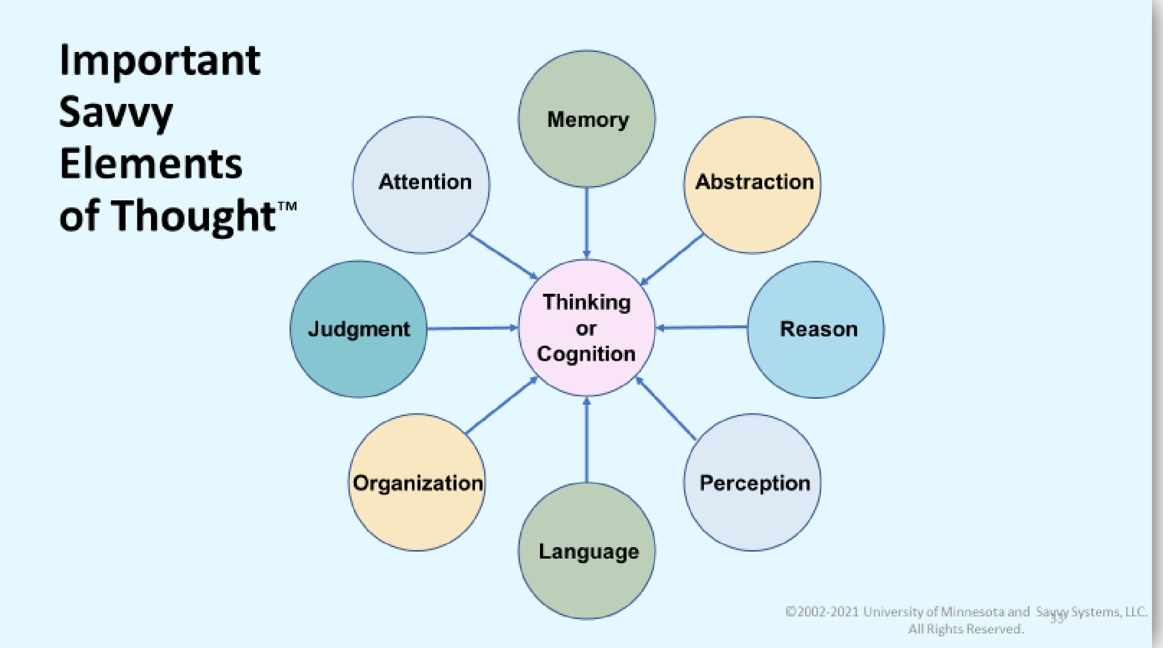
> *If you think about how you got to be here today, you’ll realize it involved planning, information gathering, decision making, organizing, and other high-level thinking powers.*
>
> *And if you think about a recent conversation with a good friend or a close family member, you’ll realize that the communication between you relied on much more than words. There was a rich vocabulary of words with special meanings for the two of you, a pattern of speech you rely on, and comfortable use of tone and gesture.*
>
> *These activities – getting to this place and talking with the other person – are examples of “ordinary life” that depends on sophisticated capacities you rely on and really don’t think about.*
>
> *Living with and caring for a person living with a dementia-related illness places you in an “out of the ordinary situation.” You cannot be certain about which capacities you can rely on in the person, and you are faced with having to figure out which of these you might have to supply.*

If you chose this alternative, the take home message slide on the previous page can be used to give participants the message you’re getting across.

The Start of the Cognitive Losses Talk

The talk that follows examines the effect of dementia-related diseases on eight of the most important elements of thought or cognition. This talk is meant to get caregivers to do even more "think about thinking" – that is, to reflect on what losses they see in their persons – and about the strategies they can use to fill in the gaps created by these losses.

Using the slide shown here, make the point that dementia-related illnesses affect many powers that we associate with cognition – **memory, reason, language, abstraction, judgment, perception, organization, and attention**.



Important Savvy Elements of Thought™

Memory

Attention

Abstraction

Judgment

Thinking or Cognition

Reason

Organization

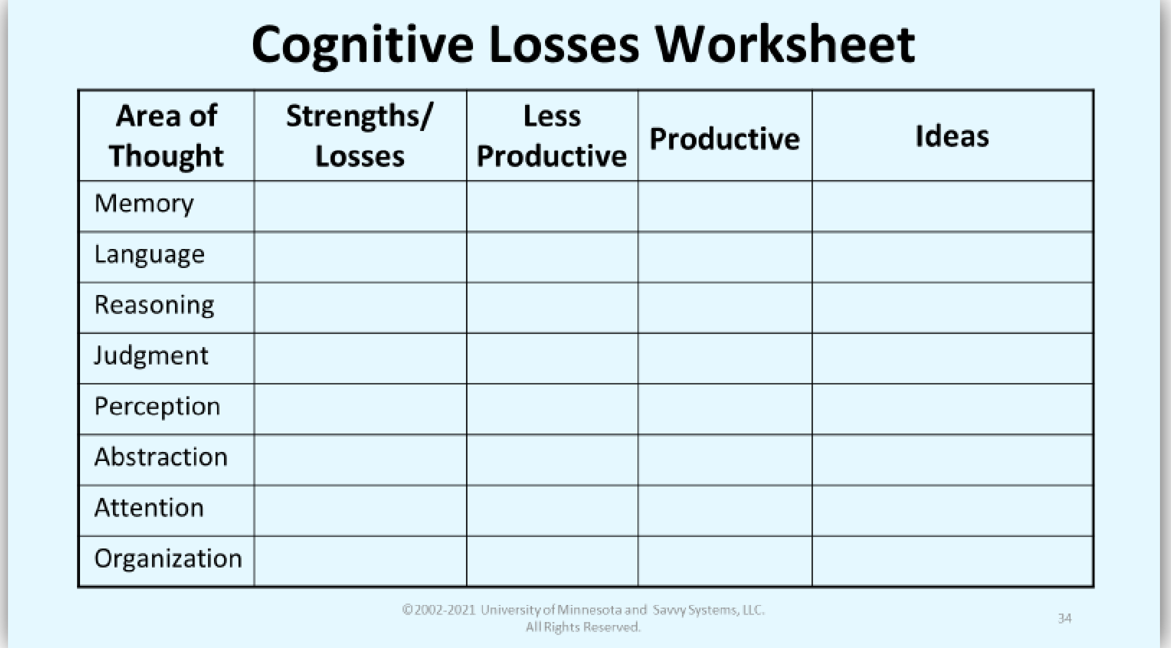
Perception

Language

Then move on to the talk that follows. The talk is meant to draw participants' attention to the way in which our adult interactions assume normal cognitive functioning. The way people interact with each other and the environment assumes their thinking functions are normal. It assumes normal reasoning, memory, and judgment. It assumes people can deal in hypotheticals ("what if…") and that they normally create plans and follow their sequences (attention and organization). Practically everything we do as adults with other adults is based on these assumptions. It structures how we treat other people, the expectations we have about them, and the language we use to talk with them.

It's important for group members to see this because it leads into the first exercise that deals directly with strategic Savvy caregiving. Caregivers need to understand whether, or to what extent, they are interacting with the care-receiver still based on assumptions of normal functioning. They need to form new ways of interacting based on a more accurate understanding of the person's cognitive capacities – and to appreciate that their strategies will need to adapt as the cognitive abilities continue to decline over time.

This portion of the program uses the slide shown below – and more on the following pages – to describe the various cognitive losses and to help participants relate these to practical aspects of caregiving. This material is all in the Caregiver's Manual. Prior to the talk, distribute the Cognitive Losses Worksheet to the participants. Encourage participants to use the worksheet to make notes as they hear and think about things during the talk. Point out to them that it will be part of their home activities assignment to complete this worksheet.



Cognitive Losses Worksheet

Area of Thought	Strengths/ Losses	Less Productive	Productive	Ideas
Memory				
Language				
Reasoning				
Judgment				
Perception				
Abstraction				
Attention				
Organization				

The four columns of the Cognitive Losses Worksheet represent the following:

- **Current Cognitive Strengths.** This relates to the care-receiver's current condition with regard to that specific capacity. They should note not only what the person **can't do**, but also what the person still **can do**. For instance, the person might remember who everyone is in the family, but not remember what day or month it is; s/he might have no problems with perception, except in the evening when s/he mistakes reflections for people in the yard; s/he may be able to organize small and familiar tasks – e.g., getting appropriate clothes out of the closet – but not be able to organize larger tasks.

- **Current Productive Ways.** This column should be used by participants to record ways in which they see themselves dealing effectively with the particular losses. What have participants seen themselves do that they feel is built on a sensitive understanding of the person's current strengths and losses – and really worked or works well?

- **Current Less Productive Ways.** Caregivers should use the second column to note ways they see themselves interacting with the care-receiver that don't work as well as they'd like. This piece has to be carefully done. It is not meant to make the caregivers feel bad or guilty, or like some kind of failures. Instead, it should be seen as part of the overall effort to become better at what they have chosen to do. They need to recognize how they are functioning and to assess it in light of their new knowledge. Once they have done that, they are ready to go to the third column. Next week, when they report these examples to the group, they may stimulate others to see things about how they interact – but they also desensitize them and make them less "shameful."

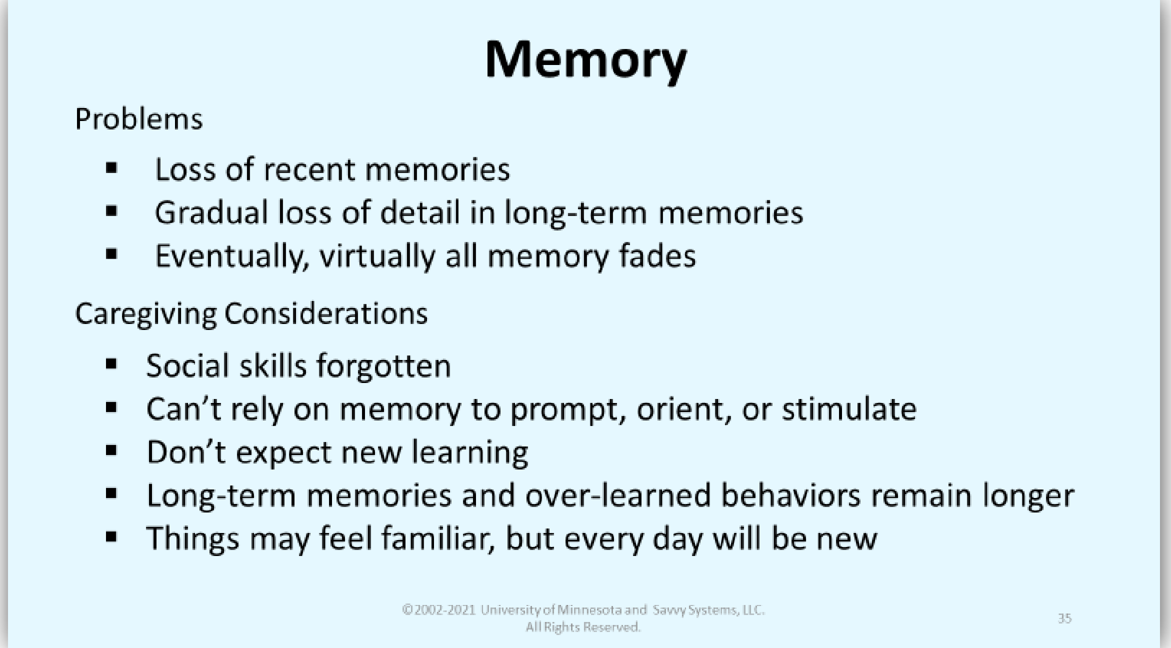
- **Ideas.** In this column, caregivers should jot down – and again be ready to report to the group – ideas they have about how they can change their pattern of response to ways of interacting that take the person's cognitive losses more into account. These should be "notes" – things that they would be willing to try and modify, based on their experience. Group interaction and participation will be helpful here, because ideas will stimulate other ideas and also because, as group members recognize that good ideas are coming out of the group, they will come to appreciate that they are experienced caregivers with real expertise. The idea that caregivers are experts in the care of their person is very important and should be reinforced throughout the program.

Caregiving Issues Linked to Cognitive Losses. Here begins the short talk on the problems and caregiving issues related to eight areas of cognition that can be affected by dementia-related disorders. The way you will present this material sets the pattern for how, in later sessions, you will present information about the effect of Alzheimer's and other such disorders on feelings/emotions, behavior, and the ability to do things in everyday life.

- First, the particular losses are detailed – what the disease is doing (over time) to the particular function that is being described.
- Next, this information is presented in terms of what the caregiver can expect to observe happening – what s/he will see the person doing.
- Finally, the material covers caregiving strategies – techniques the caregiver might use to compensate for the losses the person is experiencing. The section on losses of powers of thinking begins with the signature loss, that of powers of memory.

It is worthwhile to note that this information is formatted differently. There, the eight items are presented in chart form, with columns representing each bulleted item above, so that all of the information is visible at the same time and covered in one or two pages per area. Thus, caregivers are able to simultaneously see "what's being lost," "what the effects are on daily life," and "what strategies might be useful." Point out to participants that this is meant to be a handy reference for strategies to try when they come across a new or increasing cognitive loss in their person.

1. ***Memory*** is a capacity that links the present to the past and provides a sense of connection and continuity to life. The fabric of relationships is held together by memory, not just the "facts" of who's who in one's life, but the emotional bonds that have developed over time and that are at the core of those relationships. Memory anchors a person's place in the world; it enables a person to be at one with his/her life story and to see how that story has evolved. Memory has other functions, as well, enabling people to know how to act in a variety of situations and providing a key ingredient for acquiring new skills and behaviors.



Memory

Problems

- Loss of recent memories
- Gradual loss of detail in long-term memories
- Eventually, virtually all memory fades

Caregiving Considerations

- Social skills forgotten
- Can’t rely on memory to prompt, orient, or stimulate
- Don’t expect new learning
- Long-term memories and over-learned behaviors remain longer
- Things may feel familiar, but every day will be new

All of these functions are progressively lost in a disease like Alzheimer’s. The loss of memory is sometimes said to be “retrograde amnesia”: loss of memory working backward from the most recent to the most distant memories. Losses begin, early on in the disease, with short-term memory, while older memories are retained. Early on, families will notice that conversations that occurred hours before are completely forgotten. Visits to relatives or friends are not remembered. Older memories are retained in the early stages, but then deeper into the disease older memories seem to fade including, for example, the ability to remember the names of loved ones. Eventually, all memories seem to fade; this is hard to be sure about, because language and expression may also diminish by then, so the person may not say much or use language very effectively – so if there are memories, we don’t hear them.

What Caregivers Will Observe. Caregivers can expect to see memory functions getting worse over time. The person’s ability to recall events and to recognize friends and family will fade. Learned behaviors are forgotten. This is important because appropriate social behaviors (manners) are learned behaviors, so caregivers can expect to see coarser behaviors from their care recipient. Over-learned behaviors – behaviors the person acquired early on and practiced a great deal – may be retained very late into the disease. Such over-learned behaviors might include well-used verbal expressions or physical actions (e.g., playing piano or cards, knitting, or – more dangerously – driving). It can be confusing to caregivers when their persons perform so well in such activities; it may cause them to overestimate the person’s global capacities and underestimate the overall impact of the illnesses on the person.

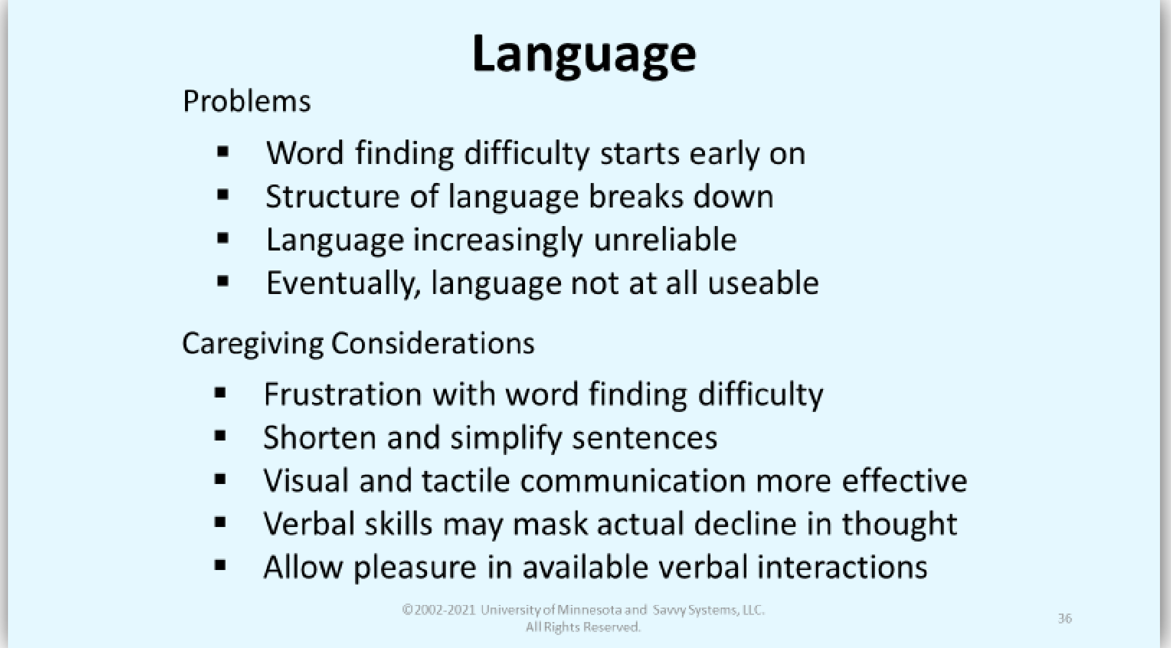
Some Caregiving Strategies:

- Supply what’s missing. Don’t test or make the person try to remember – the losses are disease-produced, not a matter of choice on the part of the person; you can’t jog the person’s memory back into working order.

- Individuals living with Alzheimer's or a similar illness may forget their learned manners and behave in a rude or impolite way (e.g., at the table), and they may use language they would be ashamed of – indecent language, racial slurs, etc. They may behave impulsively and blurt out things – "Boy, your hat is ugly." Be prepared, and help others to understand that the person is affected by a disease.
- If you don't remember that the person won't remember, you can get frustrated – and that will communicate itself to the person.
- Be prepared – daily or more often – to demonstrate and remind the person how to do even familiar tasks.
- Repetition and routine are particularly important and help to develop a sense of the familiar – which is very comforting and security producing. It may be that repetition will make it easier to retrain the person's ability to do something – either because some kind of memory process is still at work or simply because the person is more comfortable and relaxed and therefore finds it easier to attend to what's in front of him/her.
- People living with dementia may retain learning better if it involves procedural or "muscle" memory, and this can be an effective strategy.
- Loss of memory can work in the caregiver's favor. If a situation is going sour, the general rule is to leave it for a while and then come back. If the person was upset, it is unlikely s/he will remember being upset, and when you return, it will be to a new encounter, one without history.
- Be prepared for the emotional blow that can occur when the person doesn't remember who you are, no matter how long the relationship has been in place.

2. ***Language*** – both expressed and received language – is an essential capacity for communication. As a dementia-related illness advances, the use of language as a means of communication – by and with the person – will be increasingly unreliable. The use of language for cueing, prompting, supporting, etc., will likewise become less effective. Anticipating another area presented later, you can point out that language involves very abstract and high-level thought. Things we relate to through language can be completely non-material – like ideas. Things we relate to through the senses – like through sight and touch – are much more concrete and immediate to us. So, there's a way in which the loss of language as a power of thought parallels the gradual slipping away from the world that goes on in dementia-related illnesses. A person loses the subtlety and fine details and is more and more left with a gross vision of things. Eventually, things become undifferentiated entirely – and are unnamed and unnamable.

It is worth noting that in one variant of Frontotemporal Dementia, Primary Progressive Aphasia, severe losses in language and communication ability occur very early in the presentation of signs and symptoms. These losses are more pronounced and earlier than in Alzheimer's, and in this illness, memory losses occur later on. This variant is relatively infrequent, but it is important to be aware of, in case any participant is dealing with it.



Language

Problems

- Word finding difficulty starts early on
- Structure of language breaks down
- Language increasingly unreliable
- Eventually, language not at all useable

Caregiving Considerations

- Frustration with word finding difficulty
- Shorten and simplify sentences
- Visual and tactile communication more effective
- Verbal skills may mask actual decline in thought
- Allow pleasure in available verbal interactions

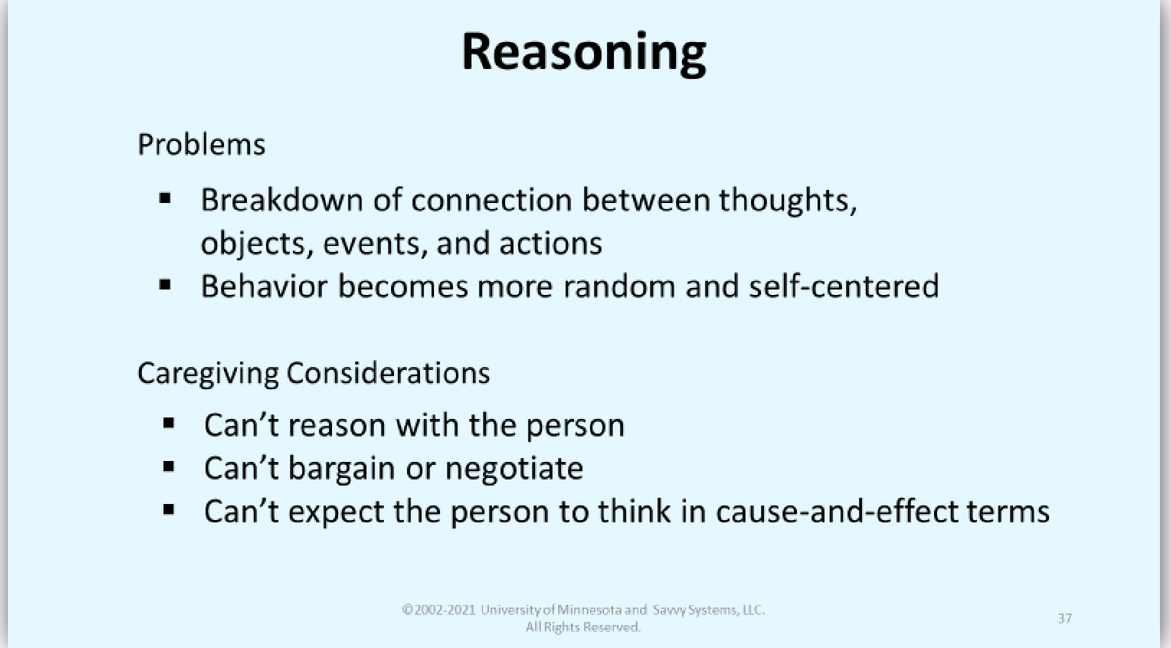
What Caregivers Will Observe. It’s particularly important to note that, in some people, verbal skills remain at a fairly good level, even deep into the disease. They retain many “stock phrases” and can seem to carry on a quite ordinary social conversation. As a result, they can appear to be in pretty good cognitive shape. The content of their conversation is typically not as sophisticated as their speech.

Caregivers should be aware of this for two reasons: 1) They, and other family members or friends, can get fooled into thinking the person can do more than s/he really can. Everyone then expects the person to perform at a higher level than possible. 2) This is a retained skill – something over-learned, like playing the piano. As such, the person may take some pleasure in it – and so caregivers should encourage the person to use the skill. They should have social conversations with the person, encouraging him/her to feel as much a part of the social environment as possible. They should remember, however, that the conversation may have little real meaning, will quickly fade from memory, and shouldn’t necessarily be taken too literally. The person may seem to understand, might give cues of understanding, but the caregiver should proceed on the assumption that understanding might not have been complete.

Some Caregiving Strategies. Like memory, loss of language skills can’t be reversed, so efforts to do so won’t work and may prove frustrating and counterproductive for everyone involved. Help the person; make it as easy as possible to get past those moments when word- or name-finding difficulties occur. At the same time, keep in mind that persons living with dementia can be extremely sensitive to tone, pitch, and voice quality. Using a calm, patient voice will become particularly important. Note that some people try word games and crossword puzzles as a way to restart the mind. This can be frustrating for the person *and* the caregiver. Some caregivers report their persons enjoy hidden word puzzles – those are really visual pattern games rather than linguistic word-finding games. If the person enjoys doing these and can become comfortably occupied in them, that’s great. Just do not expect a rehab effect. The lost powers will not be restored by use.

Over time, using language to communicate should be modified. Simplifying how one speaks is one way to modify communication. Gradually, using other forms of communication – using visual methods (pointing to things) and using touch – should support and, increasingly, replace language.

3. ***Reasoning.*** Point out how fundamental the power to reason is to adult interactions, and how the loss of the power of reasoning may pose as much of a problem for caregivers as it does for the person living with dementia. Review the losses, emphasizing the loss of connections and "cause and effect" thinking. ("You have to get dressed so we can go to lunch.")



Reasoning

Problems

- Breakdown of connection between thoughts, objects, events, and actions
- Behavior becomes more random and self-centered

Caregiving Considerations

- Can't reason with the person
- Can't bargain or negotiate
- Can't expect the person to think in cause-and-effect terms

What Caregivers Will Observe. Perhaps more than any other power of thought, we rely on the presence of reason in other people for the basic way we predict and understand behavior and interactions with one another. This ties closely to issues related to behavior, because we typically use reasoning as a way to persuade or convince someone to do something.

Caregivers will see that, increasingly, the person living with the illness will not be able to think through issues and will not be able to assess situations. They might take a position and stick with it, and no amount of "reasoning" will change the person's mind. They might also misinterpret others' intentions. Loss of reasoning powers may also contribute to self-centeredness. The person is less able to think through the consequences of his/her actions, think about the whole picture, or consider how another may be affected by what s/he does.

Some Caregiving Strategies. Early in the disease, reasoning may continue to work with the person, but as the dementia progresses, this strategy will be less effective and will actually cause more confusion for the person. Caregivers have to become more concise and directive. And, over time, they have to offer less explanation.

4. The next thinking power covered is ***Judgment***. This is a big area of concern for families. They worry about safety and about inappropriate behavior because the loss of judgment affects both.

Judgment

Problems

- Increasingly make poor choices
- Safety issues
- May lead to hesitancy or impulsivity
- Insensitivity to others

Caregiving Considerations

- Assume responsibility for safety
- Don’t overprotect
- Remember: “It’s not personal”

Judgment helps us make good choices and remain safe. In its broadest sense, it is a capacity that allows us to think, abstractly, about a range of possibilities, assess them in terms of our values and the potential outcomes of the possibilities, and make choices that are to our best advantage. Judgment allows us to monitor our own behavior. For example, thinking before we speak – so as not to offend or provoke others – is an act of judgment. Considered more narrowly, judgment enables us to behave in ways that protect our wellbeing. Judgment allows us to drive carefully and respond to driving emergencies. It also supports using tools, hunting and fishing equipment, and even kitchen utensils carefully. It is also critical when making investments and purchases prudently. These are all examples of ways judgment comes into play in everyday life.

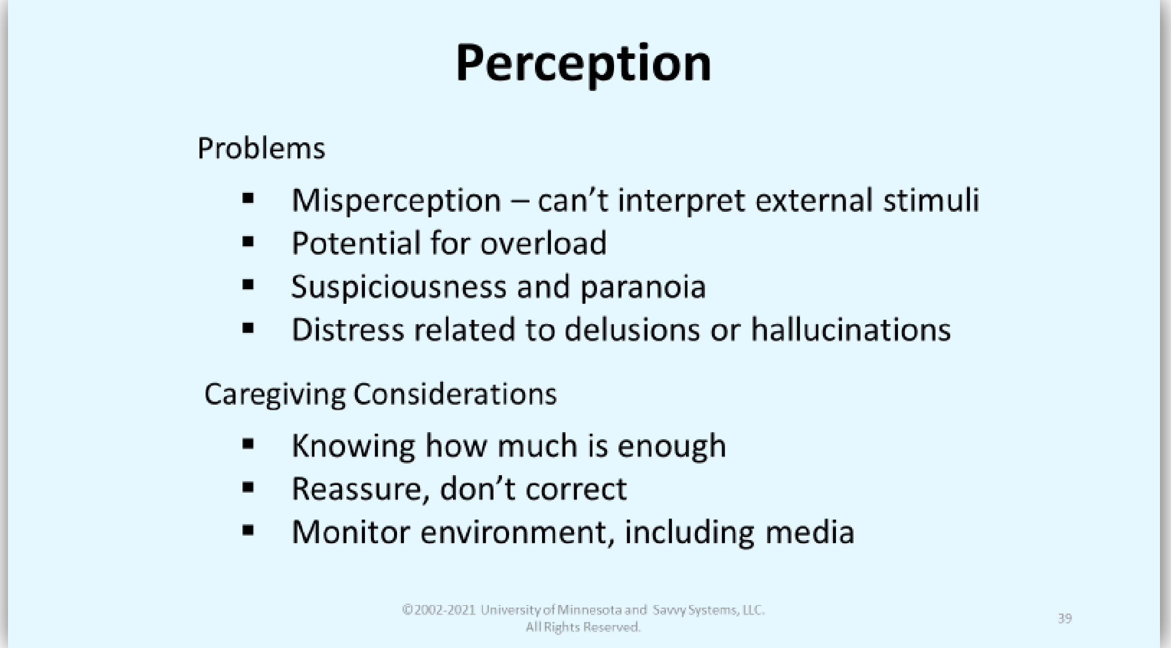
What Caregivers Will Observe. As with all thinking powers, errors of judgment show up early in somewhat harmless or innocent ways and become more frequent and more serious as the disease progresses – until the person cannot be relied on at all to watch out for his/her own wellbeing. Early on, families report that they find errors in finances (checkbooks that don’t balance) and impetuous behaviors (e.g., buying sprees on TV networks or on the Internet, or answering door-to-door or mail solicitations). Impetuous behavior may occur – especially in public or around strangers. Such behavior can be embarrassing to caregivers.

Some Caregiving Strategies. Safety must be a serious concern, and attention to it should start early. Early on, try not to overprotect – and pick your battles wisely. Let care-receivers make errors in judgment, as long as they aren’t threats to safety. For example, if a person makes a horrible choice of clothing or mismatched colors, so what? If the person is comfortable eating with their hands even though it looks messy, so be it. (Consider serving finger-friendly foods.) If it’s working for them and is a choice between that and either a confrontation or feeding them, let them find their own way. Likewise, if the person uses poor judgment in ways the caregiver finds embarrassing or offensive, it may not be possible to “correct” this behavior. So, the caregiver may need to find a way to live with such occurrences. Recognizing that “it’s not personal” is an important strategy. Often caregivers find ways to let others know about what’s happening to the person. One caregiver, for instance, had business cards made that she could give out discretely (e.g., in restaurants and stores). The card read: “My husband has Alzheimer’s. Please address your questions to me.”

Certain activities – driving or using power tools, firearms, and/or sharp utensils – leave little margin for error. These activities require that the person be able to see the consequences of his/her actions and be able to respond appropriately when an unexpected event occurs. A person who makes the wrong turn while driving has to be able to recognize the error and fix it. The loss of this capacity can put the driver and others at serious risk.

Getting a person living with dementia to stop or curtail a potentially unsafe behavior, like driving, is not easy. It helps if there is clear evidence of impaired capacity, evidence that might be provided by a physician or by a trained driving assessor. It also helps if the family can agree that continued driving poses a problem. Sometimes a person can be convinced that s/he should no longer drive. Sometimes, turning to an authority – like the department of motor vehicles – can force an end to driving. As another option, some families hide or disable the person’s car.

5. ***Perception,*** the next power to be examined, involves both reception and interpretation of information from the outside world through the senses. Most of what we’re concerned with is interpretation. If, however, the person has a problem with reception – for instance poor vision or hearing – this may be a cause of perception problems separate from the dementia illness – and it should be corrected, if possible.



Perception

Problems

- Misperception – can’t interpret external stimuli
- Potential for overload
- Suspiciousness and paranoia
- Distress related to delusions or hallucinations

Caregiving Considerations

- Knowing how much is enough
- Reassure, don’t correct
- Monitor environment, including media

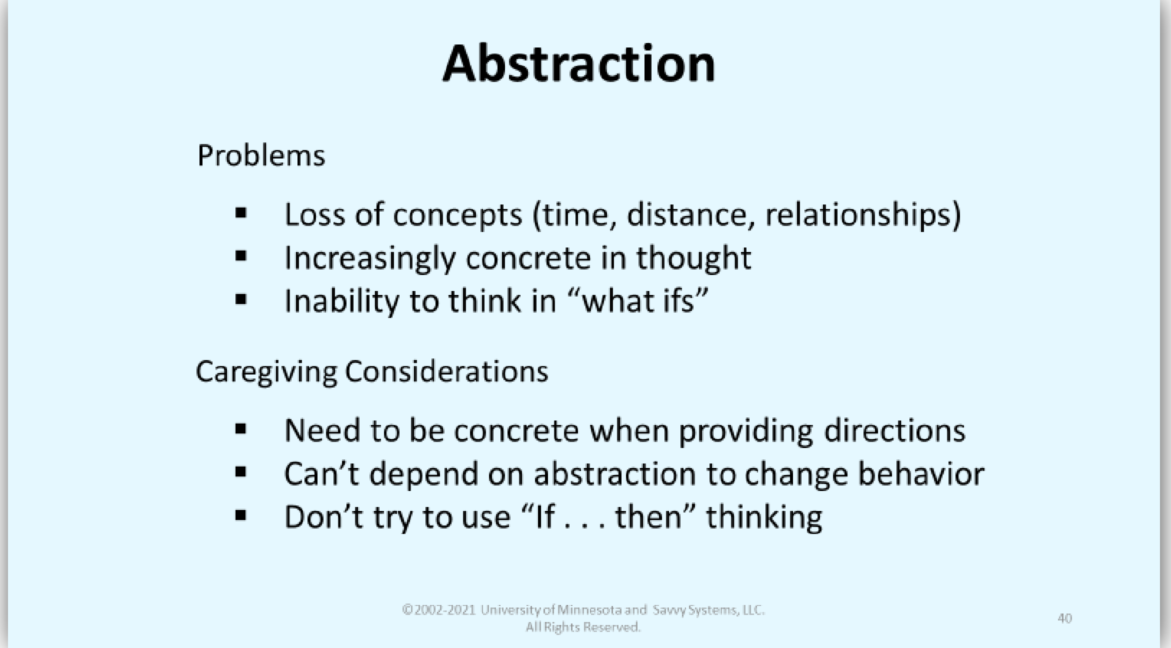
What Caregivers Will Observe. Problems of perception, particularly reception, can cause distress in many forms. Misinterpretation is a big issue. People may see their own reflection in a mirror or a window and mistake it for a stranger. This can lead to fear or suspiciousness. They may report seeing strangers in their room. [Note: This is different from the hallucinations that might accompany Lewy Body Dementia.] When perception loss occurs, they may no longer recognize their own image in a mirror and may mistake what they “see” as someone unknown to them who is in their room. Images on television or a computer can also be misinterpreted as being real. News reports from other times or parts of the world may be perceived as events happening here and now to them. The misinterpretation of events can produce paranoia or accusatory behaviors. For instance, the person may accuse the caregiver of stealing things (things the person can't find because they aren't immediately apparent to them or because they are misplaced) or as being unfaithful. These are challenging occurrences for caregivers.

Some Caregiving Strategies. Problems of perception may relate to a basic issue of overload – too many stimuli or stimuli that are, in themselves, confusing – wall or window treatments or carpets that have complex designs, a noisy room filled with people, abstract (non-representational) art. Outings, even to places the person once enjoyed, can be problematic if these places are too crowded or noisy. As the disease progresses, distractions become more and more of a problem. This is one of the reasons not to drive.

Caregivers will also have to consider whether parts of their home environment might be causing problems for the person. Are some paintings or objects in the home too confusing for the person? This could include furnishings as well as the kinds of shows the person watches on TV. Is the person misinterpreting fictional shows for the real thing? Does s/he personalize what's on – including the news – and does this make the person fearful or upset?

Reassurance is important when responding to perceptual losses. When coupled with other problems of cognition – like problems of reasoning – perception difficulties can be frightening for the person and can pose a challenge to caregivers. For example, it can be frustrating and futile to try to convince a person living with a dementia-related illness that what s/he's seeing is a reflection in a window and not some threatening stranger.

6. ***Abstraction***. Point out how much we rely on abstraction – the next power – for everyday life. Abstraction is the power of thought that allows us to consider the world in non-material, non-concrete terms. Abstraction is the key to the world of ideas and concepts like numbers, time, money, relationships (What's a "dollar bill" or a "nephew"?), directions, and especially the use of hypothetical situations. Note how dependent we are – in our own thinking and in interactions – on the ability to deal in "what if" and "if . . . then" thinking. The ability to see time as a continuum, with a past and a future as well as a present, is a function of abstraction. In Session 2, you will introduce participants to the strategy of validation, operating from the "emotional truth" of the person living with the illness. For example, when suspiciousness and paranoia occur, many times these feelings are produced by problems of abstraction. Therefore, caregivers should seek to allay the person's fears and suspicions by cooperating with the misperception ("Let me help you find the lost wallet.") rather than arguing and trying to convince the person of something.



Abstraction

Problems

- Loss of concepts (time, distance, relationships)
- Increasingly concrete in thought
- Inability to think in "what ifs"

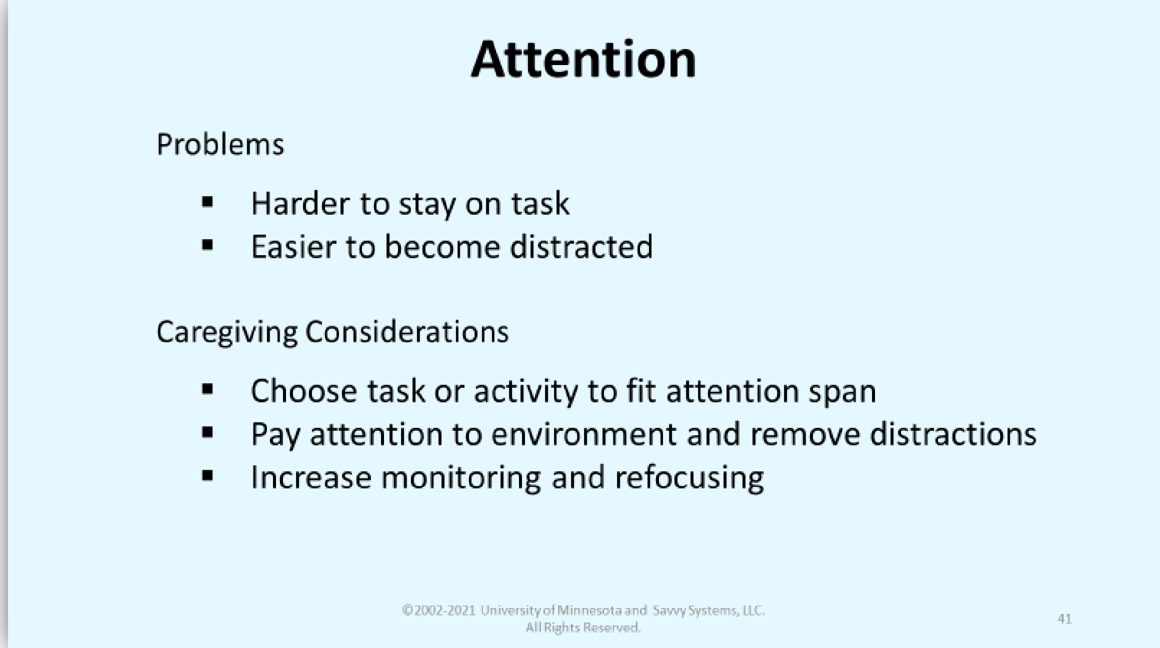
Caregiving Considerations

- Need to be concrete when providing directions
- Can't depend on abstraction to change behavior
- Don't try to use "If . . . then" thinking

What Caregivers Will Observe. As Alzheimer's and similar progressive dementia-related illnesses continue their course, the person lives more and more in the moment. Thinking about things that happened in the past or that will happen in the future become harder and harder, and the person is more likely to be confused by references to past or present. Following special directions and thinking about things numerically will also be increasingly difficult.

Some Caregiving Strategies. There are two basic Savvy caregiver issues related to abstraction. The first is to determine how much (or little) the person is able to use abstract ideas reliably. Does time, for instance, still matter to the person? If you say, "Lunch will be in an hour," will that register and make sense to him? At some point, it will confuse the person to talk about doing something in a few days. S/he may think the event is to take place now, and this could lead to repetitive questioning ("When are we going?"). Eventually, the savvy caregiver learns not to talk about an upcoming event until it is time to get ready for it. The second key idea for the caregiver is to monitor his/her own behavior. As the disease progresses, caregivers will need to watch that they are limiting (and eventually eliminating) the use of abstractions in interaction with the person.

7. ***Attention*** allows us to remain focused and to deal with all that goes on in the environment. We use attention as a filter to make choices among all the competing stimuli (tasks, demands, and responsibilities) in our lives. Some of these are mental stimuli – the agenda for the day or problems we're working through. Other stimuli are more concrete and immediate: the things and people surrounding us in the environment. The power of attention allows us to select from among all of these and to focus on the matter we decide we need to focus on. It allows us to maintain our focus and/or to return to the task at hand when other stimuli distract us. Attention is weakened as the disease progresses. The person becomes more easily distractible, and increasingly loses the ability to "stay on track" or focus on any given task in the face of competing demands in the environment. As the disease progresses, the person requires more structuring, refocusing, and prompting to stay on track with even the simplest tasks.



Attention

Problems

- Harder to stay on task
- Easier to become distracted

Caregiving Considerations

- Choose task or activity to fit attention span
- Pay attention to environment and remove distractions
- Increase monitoring and refocusing

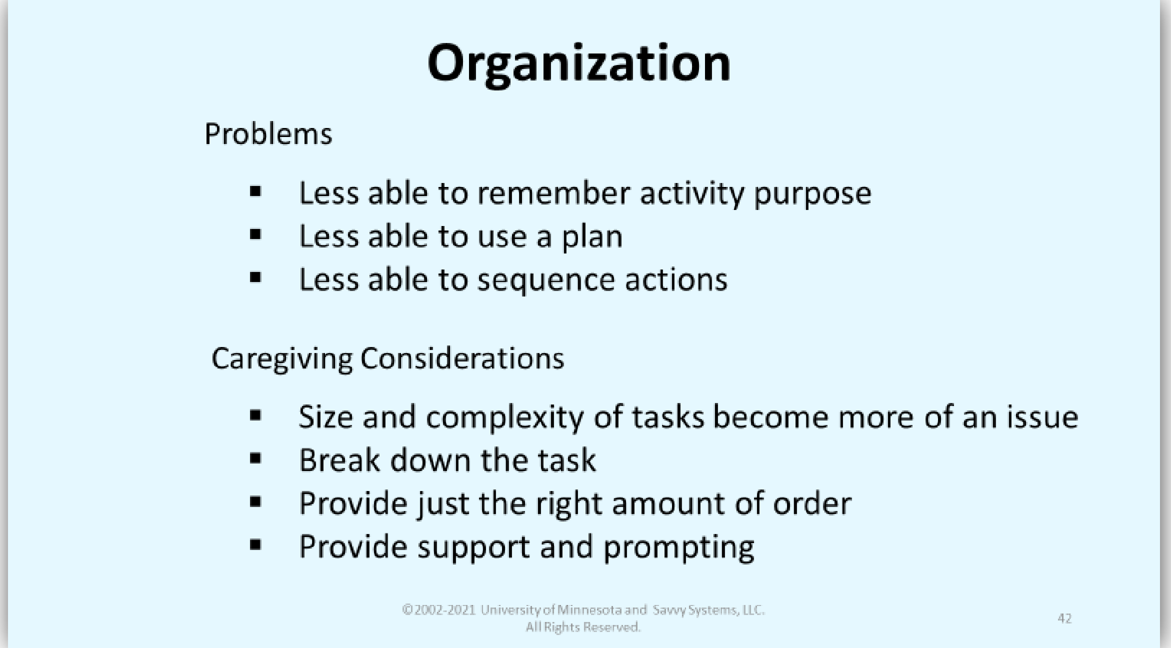
What Caregivers Will Observe. Essentially, caregivers will notice that, increasingly, the person is less able to stay on track and more likely to get distracted.

Some Caregiving Strategies. Attention losses affect a caregiver's choice of tasks and activities and their choice of the environment for tasks. As the disease progresses, tasks have to be simpler, and there should be fewer distractions in the environment. This loss also affects how much caregivers have to monitor their person's focus on a task. Caregiver frustration can come from expecting too much and not being prepared for how much time and energy it will take to keep the person focused and involved.

Attention problems bear on the issue of driving. For example, normal driving requires attention, even though certain parts of it feel very routine. Particularly in rapidly developing situations – like sudden changes or emergencies – the ability to remain both calm and concentrated are essential for safety. Dementia-related illnesses attack the ability to concentrate early on – so driving should be restricted very early in the disease and withdrawn as soon as possible.

8. ***Organization***, the final thinking power to be discussed, is the power that enables us to create and follow the plans that keep our lives in order.

People, typically, assume organization in their normal interactions. We know things are often tied together in some kind of relationship: Step A goes before Step B, and the result of these two go together to result in Steps C, D, and E, which leads to a desired outcome. The progressive dementia-related diseases gradually reduce a person's abilities to see and act on these relationships. As the disease progresses, the person may get stuck, lost, or confused by them. The caregiver has to have a good sense of just what the person "gets" about the organization of complex tasks in order to involve the person as much as possible in them. Even concrete tasks like doing laundry or making a sandwich involve multiple interrelated steps.



Organization

Problems

- Less able to remember activity purpose
- Less able to use a plan
- Less able to sequence actions

Caregiving Considerations

- Size and complexity of tasks become more of an issue
- Break down the task
- Provide just the right amount of order
- Provide support and prompting

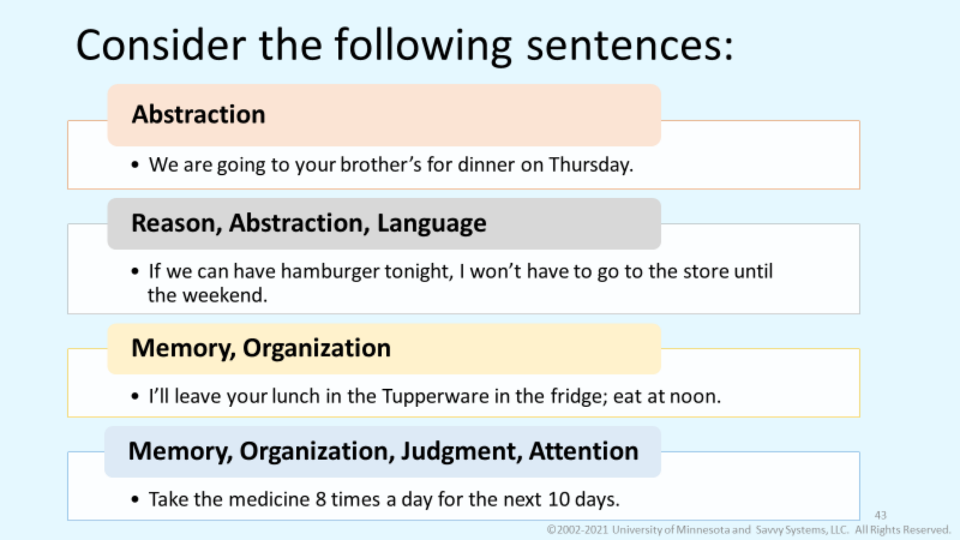
What Caregivers Will Observe. People living with dementia have increasing difficulties establishing and remembering endpoints or the plans to get to them. Later they lose the sense that actions fit into a context of goals or purposes. In the same way, the number of steps they can handle in a task decreases.

Some Caregiving Strategies. Caregivers replace this power in a number of ways:

- fitting the task to the person's abilities
- reminding the person of purpose
- setting up activities with an appropriate number of steps
- keeping the order of steps for the person and prompting at appropriate times

Optional Exercise. If you have enough time, you can make the points about losses and strategies a bit more concrete using a brief exercise.

First, read out the sentences on the slide below (this and the next slide are not part of the caregivers' materials). As you read each out, ask participants to point out what thinking powers are involved in or required to understand each (the main power(s) are identified in the brackets below each sentence).



Consider the following sentences:

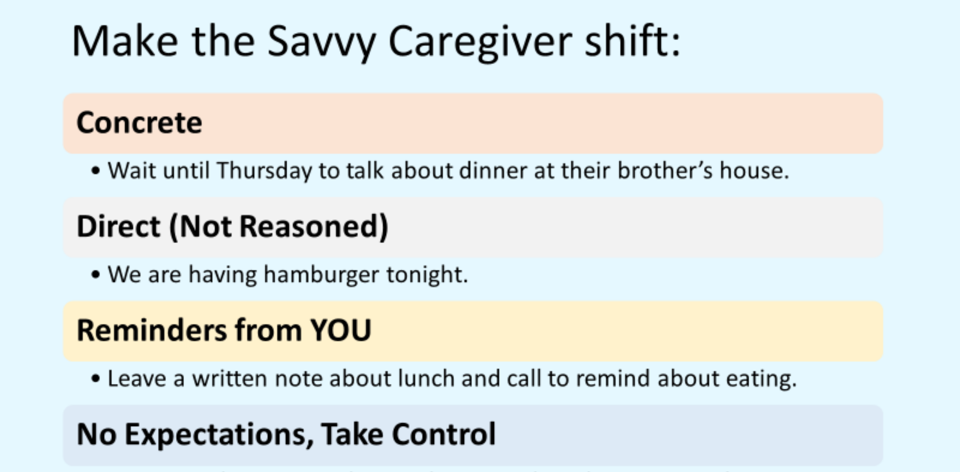
Abstraction
- We are going to your brother's for dinner on Thursday.

Reason, Abstraction, Language
- If we can have hamburger tonight, I won't have to go to the store until the weekend.

Memory, Organization
- I'll leave your lunch in the Tupperware in the fridge; eat at noon.

Memory, Organization, Judgment, Attention
- Take the medicine 8 times a day for the next 10 days.

Next, have the group suggest how they might modify or change the original sentences in ways that reflect better caregiving strategies. The slide below offers some ideas about appropriate modifications.



Make the Savvy Caregiver shift:

Concrete
- Wait until Thursday to talk about dinner at their brother's house.

Direct (Not Reasoned)
- We are having hamburger tonight.

Reminders from YOU
- Leave a written note about lunch and call to remind about eating.

No Expectations, Take Control
- Set up medications and remind or consider administering them yourself.

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Again, if there's time, ask participants to reflect on the suggestions about written notes and use of a pillbox for medications. Do they think these will be effective? If so, under what circumstances and for how long? Ask each whether these strategies would work now for the person for whom they are providing care.

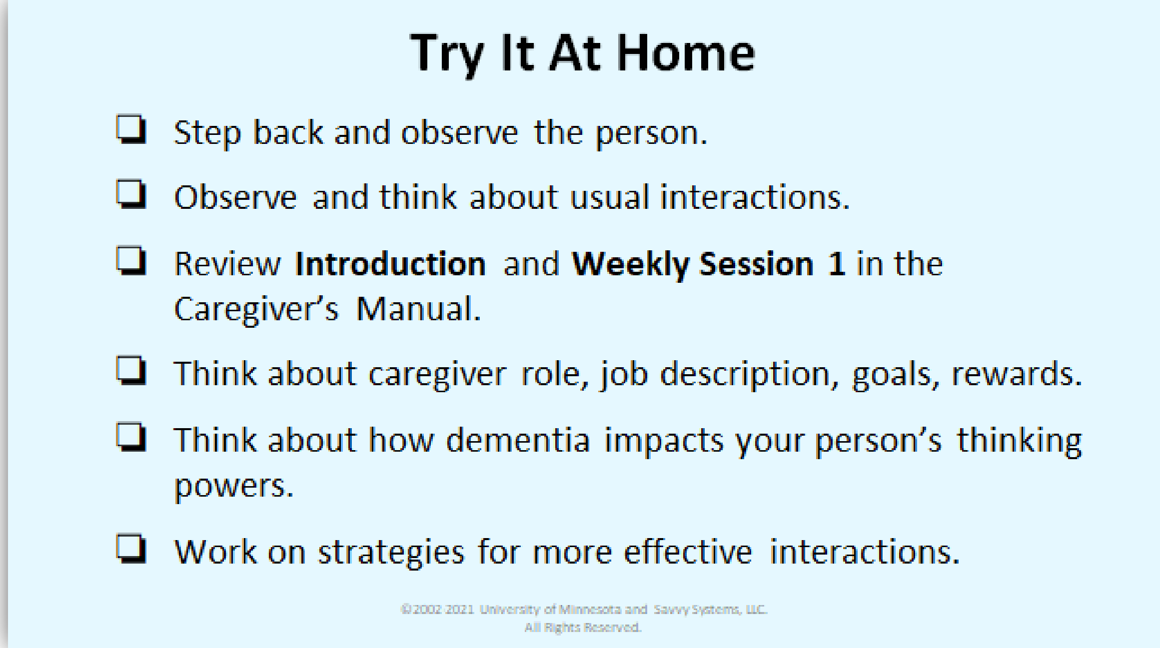
Home Assignments and Program Resources

Introduction to Resource Materials. The most important resource that program participants will have is the Caregiver's Manual. Early in the session, distribute the hard copies of the program slides; encourage participants to bring them to the sessions and use them as a notebook for the program. In the course of the sessions, you will use the various handouts that are provided.

As a Savvy program facilitator, you are not expected to be an Alzheimer's expert. You should read the material on the dementia-related illnesses in this and the Caregiver's Manual and browse the various websites and other information sources that are provided in the Caregiver's Manual.

Finish the session by reviewing the objectives set out for the first session and pointing out that they have been met.

Things to Try at Home. End the session by acknowledging and complimenting the caregivers for coming to the program and for the efforts they are making to expand their caregiving knowledge and skills. Review the assignments for the following week. Emphasize that these home assignments are enriching and valuable, and encourage participants to try 1 or 2, if not all, of the assignments.



Try It At Home

- ☐ Step back and observe the person.
- ☐ Observe and think about usual interactions.
- ☐ Review **Introduction** and **Weekly Session 1** in the Caregiver's Manual.
- ☐ Think about caregiver role, job description, goals, rewards.
- ☐ Think about how dementia impacts your person's thinking powers.
- ☐ Work on strategies for more effective interactions.

- Take time during each day to just step back and observe the person. See what and how they do things. Notice where they are managing well and where they might be struggling with everyday tasks.

- Read assigned materials – the **Introduction** and **Session 1**. These are materials that reinforce and expand on what was covered in Session 1, including the definition of the caregiver role, sections on the caregiver job description, the goals of caregiving, and the rewards of caregiving.

- Using the Cognitive Losses Worksheet handout, work on the Strategies sheet (see handout packet) to begin developing what they consider to be more effective strategies for interaction in the various areas of cognition. Ask participants both to observe or think about how they usually interact with the person, and then ask them to think about and try out other ways of interacting – ways that better take into account the impact of dementia on the person's thinking powers.

- Finish by letting participants know that the next session will cover caregiver self-care and continue the discussion of changes produced by dementia-related illnesses.

Weekly Session 1 Notes

Weekly Session 2

"Life isn't about waiting for the storm to pass.
It's about learning to dance in the rain."

Vivian Greene

Savvy Caregiver Program
Weekly Session 2 Agenda

Session Agenda

Instructional and Topic Areas	Content Included In Topic Area	Approximate Time
Coaching and Review	• Readings in Caregiver’s Manual • Review of Activities to Try Out Caregiving Strategies at Home	30 Minutes
Teaching: Caregiver Self-Care	• Working Towards Positive Powerful Feelings • Developing a “Free-Time Repertoire	40 Minutes
Teaching: More Effects of Dementia Related Illnesses and Dealing with them	• Confusion • Behavior • “Emotional Truth” • Respectful Guidance	45 Minutes
Home Practice	• Assigned Home Readings and Practice Tasks	5 Minutes

Program Leader's Overview of Session 2

Welcome Back. At the start of this and every session, be sure to welcome participants back and acknowledge and thank them for the work they are putting in by taking part in this program. Caregivers often do not get much recognition for all they do. The Savvy program should be one place where their efforts are called out and appreciated.

Review Efforts over the Past Week. This is an important moment in the program. The amount of time and attention you and the group spend reviewing participants' activities at home related to the program – their completing the assignments and trying out things at home – will reinforce the point you made in the first session that the program depends on their participating in their own learning. Plan to spend the first 30 minutes on home activities and questions, including those about the readings. Concentrate on getting participants to share their efforts – successful or otherwise.[*] Later in the program, you will want the participants to understand that they have a great deal of caregiving expertise. They will see this through their own participation. Increasingly, you will want the participants to act as coaches with one another on the efforts they are each making to put the principles of the program into action in their own caregiving. Getting them used to chiming in and reporting back will help develop this kind of coaching culture.

Below are some sample lead-in questions for review of each of the three home-based assignments. You might just start with a very general question such as: what did you observe about your person this week? Did you see any examples of losses in the elements of thought that we discussed last week? Even though you will pose these questions to the group as a whole, be sure that everyone responds. You may have to call on those who don't volunteer answers. Everyone has at least one thing they can contribute to the weekly debrief discussion and reinforcing this method will benefit the entire group. After some of the lead questions, follow up questions or prompts are provided that you might use to prime the pump of discussion.

- ♦ Did you get a chance to read the material on the illnesses that produce the dementia condition? (or do you have any questions left over from last week?)

    - Do you have any questions? (If there are questions, follow the general directions to leaders: answer what you can; don't try to go beyond your own knowledge; tap into the knowledge of the group; make note of questions and try to find answers for next time)

    - Did you notice that anything in the readings applied to your work as a caregiver? The point here is to encourage the caregivers to respond to the readings – and to begin to engage in discourse that shows them to be more astute and analytical than they perhaps give themselves credit for being.

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[*] Don't be discouraged if not too many participants do not report home activities. Some will not have been able to find the time or space to do so (e.g., their person doesn't leave them alone enough to get to the homework). You can use this to reinforce the point made in the first session that caregivers are overwhelmed. You might also use it to foreshadow the self-care portion of this and other sessions – how important it is to attend to and take care of themselves. Additionally, participants may use the homework review time to raise questions about last week's materials. These may be questions they've been mulling over but haven't sat down to think through very systematically. The review may offer an opportunity to review and clarify material.

Thus, the manner in which you process their responses is important. Be sure to point out – when caregivers make contributions that represent a digesting of the written material and either an application or an extension of it to their caregiving – that the caregiver has approached the question with a kind of clinical or analytic eye that has helped him/her to see the situation more clearly.

- Did you continue to complete the worksheet sections on the caregiver job description, the goals and rewards of caregiving, the losses and strengths you observe in the person, and the losses and strategies worksheet)?

- Tell us about some of your caregiving successes over the past week – things you tried; things that worked; things that didn't work. Remember, this is not "win or lose;" it's "win or learn." You're not failing if you're problem-solving strategies and trying new things

  - In particular, did you use the Cognitive Losses Worksheet to think about more effective strategies for interaction in at least one – but preferably more – area of cognition
  - Debrief on this experience – did they understand the sections? Ask them to share portions; this will allow you to give encouragement and feedback and as a stimulus to the rest of the group.
  - Particularly ask if they have seen themselves changing anything they are doing in their caregiving, based on last week's session, their reading, or the work they did on the "Losses" worksheet.

What you're looking for here are examples of Savvy Caregiving. Are they – even this early in the program – beginning to behave in a more tactical or calculating manner? Are they taking the impact of the disease into account as they interact with the person, and are they designing their own behavior to better fit the person's strengths (and to compensate for losses)? Because we want participants to begin to internalize the Savvy Caregiver role description, make an effort – as you hear and reinforce caregivers' reports of changes in their own behavior like this – to point it out and compliment them on being Savvy Caregivers. Similarly, if the discussion leads to problem solving (e.g., a caregiver reports not knowing how to do or think about something), you can label solutions as "Savvy" when they build on the program materials.

Session 2 Objectives. Use this slide to focus participants on the learning tasks you want them to accomplish during this session. You can point out that the session moves between the program's important focus on caregiver wellbeing and its ongoing focus on shaping caregiving strategies around an appreciation for the ways in which the neurocognitive illnesses affect the person living with them.

Session 2 Objectives

- Develop strategies for self-care.
- Develop caregiving strategies based on appreciation of disease impact.
  - The Threat of Confusion
  - The Impact on Behavior
- Develop a communication strategy that deals with losses.

Caregiver Self-Care

This session introduces a major theme of the program – **caregiver self-care**. Note to caregivers that this topic is given prominent placement – it comes before discussion of behavior guidance – to reinforce how important caregivers are in this situation. Caregivers are the key reason the person is able to remain in the community and are the ones at highest risk for distress and burnout. Taking care of themselves is appropriate and important.

The exercise that follows is meant to provide caregivers with a practical tool they can use to identify and categorize the feelings they have that are associated with their caregiving. It also illustrates how they can take steps to do something about feelings that are painful or hurtful. Alert the caregivers to the beginning of this theme and that they will be getting home assignments to focus on their own self-care and to talk about it in the program. You can tease them that – "whether they like it or not – they are going to have to do something that most caregivers don't do – pay attention to and do something about their own needs".

Another point to make is that this focus reinforces the concept that they have undertaken a "clinical" role in caregiving and that this is a kind of clinical training. A crucial part of any clinical education and training is the development of self-care skills. Most caregivers in your group will have heard of the term "burnout," a state of emotional exhaustion that may show up as a feeling of great discouragement or frustration, a sense of hopelessness or uselessness, or even anger and an urge to turn away from the situation. This is something that clinicians understand and work to avoid. The impact of their work takes a toll on themselves, and so they develop strategies for taking care of themselves to prevent burnout and to avoid letting their work affect them in negative ways. Just like nurses and physicians, caregivers are the instrument of their care recipient's wellbeing Just like nurses and physicians they have to avoid burnout – take care of themselves to keep "in tune" and well-functioning.

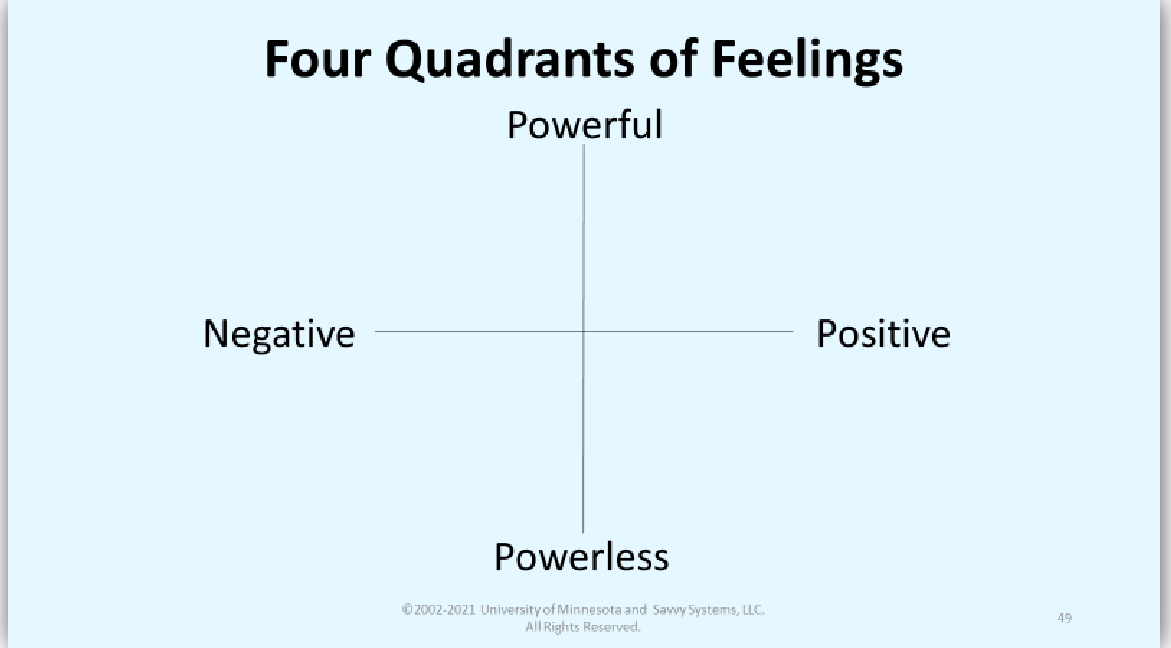
Exercise: Emotions Associated with Caregiving. This two-part exercise helps caregivers to identify and classify the feelings they have that are associated with caregiving. This segment is meant to help caregivers see the kinds of feelings they have in their caregiving and to help them deal with these feelings so that they are not so hurtful. First ask participants to spend the next few minutes reflecting on their experience as caregivers and to list the feelings that have been and are a part of that experience. Tell them that first you will make the list, then you will introduce them to a way of sorting these feelings into categories, then you will assign each feeling on the list to one of the categories. In order to get the caregivers to brainstorm about their feelings, you can use some (just a few) of the prompts below to trigger reflection:

- What did you feel when you first admitted to yourself that something was wrong with your person?
- What did you feel when you first heard the diagnosis?
- How do you feel at the end of a particularly hard day?
- What do you feel when you think about the future?
- How do you feel when old friends don’t call or come by? (covered in Session 6)
- How do you feel when your person smiles and says thank you?

You can ask participants to call out the feelings as they come to mind (at which point you can make a list on a flip chart), or you can give them pads of small sticky notes and tell them to write feelings down on the sticky notes (one feeling per sheet) and hold on to them. This method can allow caregivers to “admit” feelings that they might otherwise be reluctant to express in a group setting.

Feelings Quadrants

Brief Talk: ***The Feeling Quadrants***. Now you will give a brief talk about the four quadrants of feelings. This provides a simple tool for caregivers to use to identify and categorize the feelings they are having regarding caregiving. It also serves to help them organize a way to change how they are feeling. In particular, it offers a way to move from negative, powerless feelings to more positive or pleasant feeling states. The talk is built on the figure below.



Four Quadrants of Feelings

Powerful

Negative

Positive

Powerless

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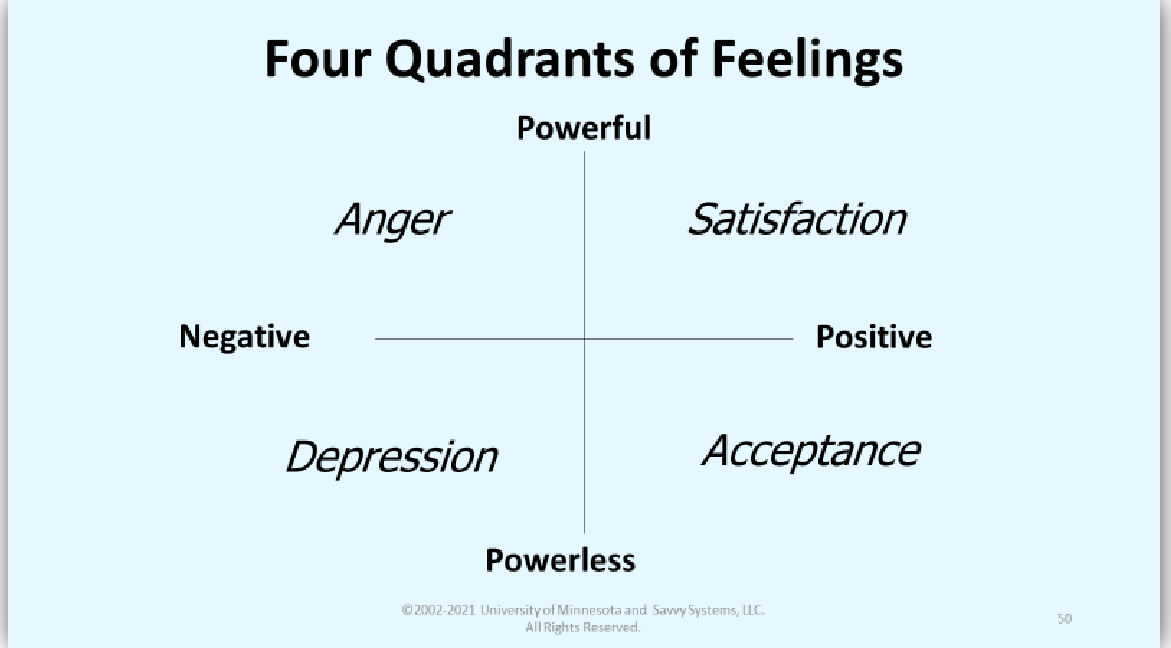
The figure was broadly adapted from the work of a researcher who had thousands of college students record their feelings at random times of the day and night and then analyzed these feelings. What he discovered was that he could categorize the feelings using two simple dimensions. For purposes of the Savvy Caregiver program, we have labeled one dimension according to whether the feeling was a good feeling (positive) or a bad feeling (negative). We have labeled the second dimension in terms of the degree of control the person felt with the situation and feeling. Did s/he feel their feeling(s) stemmed from being in charge of things (Powerful) or is it a feeling related to being controlled by something larger or someone other than him/herself (Powerless). The breakthrough part of the researcher's discovery was to see that, by arranging these two dimensions perpendicular to each other, any emotion could be fit into one of the resulting four quadrants.

Using the quadrants we employ in the Savvy Caregiver program, suppose, for example, that four caregivers reported four different feelings:

- Depression – sorrow at losing the relationship with the person
- Anger – plans for the future are shattered
- Satisfaction – a day of successful caregiving has ended
- Acceptance – the acceptance that this is a disease process beyond my control and that it is really, undeniably happening

The example below uses these four fictional cases as talking points that you can use to give participants examples of how feelings fit into the different quadrants. The idea is that any emotion that participants name can be assigned to one of the four quadrants based on whether the emotion makes the person feel that s/he is in control of the situation or not and whether the emotion makes the person feel positive or negative (happy or unhappy).

The way the feelings quadrant can be used to analyze these four feelings is shown in the figure below. Each one can be assigned to one of the four quadrants. And each can be described in terms of the name that can be given to the quadrant. Thus, Depression is a negative powerless feeling, while Satisfaction is a positive powerful feeling.



Four Quadrants of Feelings

Powerful

Anger

Satisfaction

Negative

Positive

Depression

Acceptance

Powerless

Exercise. Up to this point, the object of the talk is to get the caregivers to understand and accept this simple way of categorizing feelings. The next step is to have them look at the list of feelings about caregiving that they generated and to assign those feelings to the quadrants.

Using a flip chart or a whiteboard, draw the four quadrants figure and have participants assign the feelings they have noted to the quadrants. If you are able to use the sticky notes technique, have the participants paste their notes in the quadrants they feel to be appropriate.

Typically, caregivers will indicate that among their feelings are those of: sadness, devastation, loss, grief, acceptance, fear, being pleased (that s/he can give something to the person “in return”), frustration, exhaustion, rage (at the disease, the person, the system, etc.) – just to name a few.

As caregivers report feelings, have them say where they belong in the quadrants. Have the other group members validate or challenge the placement.

This is a way of getting them to see that this is pretty easy and that they can do it. Thus Sadness, Devastation, Loss, Grief, Frustration, and Exhaustion are all lower left quadrant (negative, powerless) feelings. Rage is upper left (negative but powerful). Satisfaction – being pleased – is upper right (positive powerful), and Acceptance is lower right (positive because the caregiver has stopped fighting the inevitable – s/he has decided to accept the situation even though not in control of the illness).

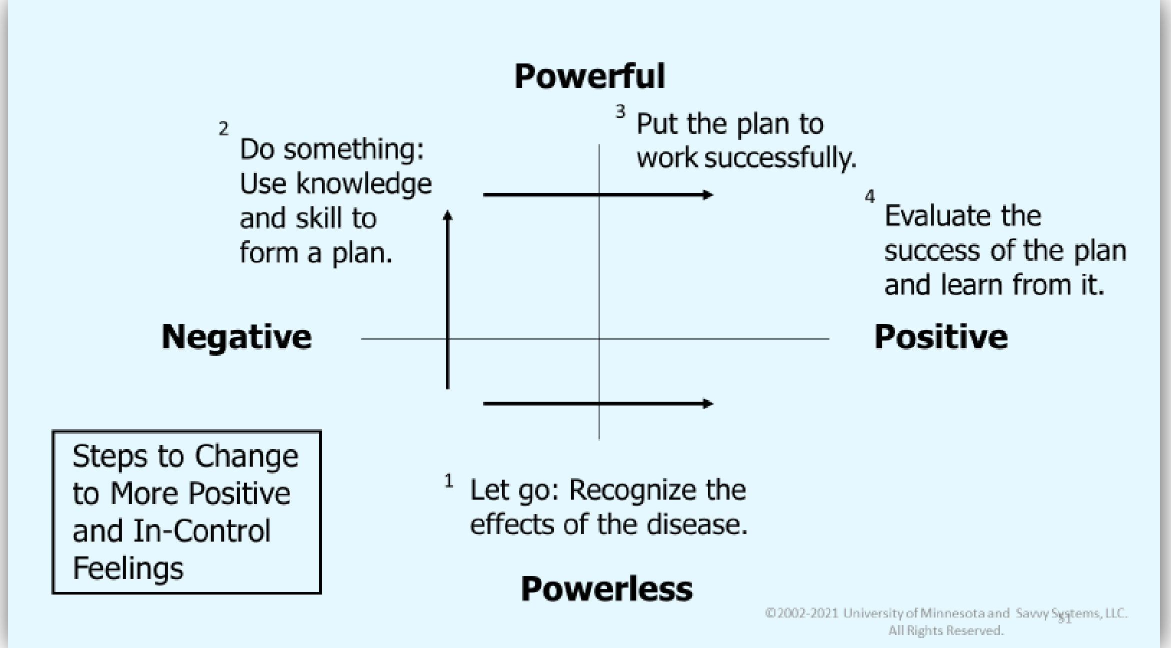
You may begin to sense that some feelings are closer to the line than others. So, for example, Depression seems to be pretty firmly in the lower left quadrant. It's a bad feeling through and through and the person doesn't seem to be in control of it. Anger seems pretty firmly in the upper left quadrant – even though anger can feel bad (negative) something in the person seems to have taken hold and is getting churned up. Feelings like Frustration or Irritation are harder to place. Both are clearly negative, but both are tending to be more active than passive – more expressions of the person taking control than of the situation being in control. The conclusion is that when placing the feelings in the quadrants, some will be closer to one line or another than will other feelings. If a participant brings this up, acknowledge it but note that we won't deal with this because it's more complex than we need – or are able – to be. They can be as precise as they like when using the tool for themselves.

Once this part of the exercise is done and all of the feelings have been assigned to a quadrant, offer the observation that:

Negative powerless feelings are the norm in caregiving. The most dramatic conclusion of the exercise will be how many of the caregivers' feelings are placed in the lower left (negative powerless) quadrant – and how few there will be on the righthand (positive) side of the figure (either powerful or powerless). There are three reasons to point this out:

- ✓ It should serve to validate that the feelings individual participants are having are common and expected among caregivers. Emphasize that they need not feel guilty for having these perfectly normal feelings.
- ✓ You can use this exercise to remind caregivers about the content in the first session and in their readings regarding the toll that caregiving can take. Consistently experiencing predominantly negative powerless feelings can have negative effects on physical and emotional health.
- ✓ They need ways to get out of the negative powerless state and to move to more positive feeling states.

Brief Talk: Strategies for Changing Quadrants. In the last part of this exercise, the leader gives a brief talk about changing emotional states. Briefly, what we want caregivers to see – when thinking of the quadrants – is that the way to move among the quadrants is caregivers will begin to make the determination that they'd much rather be in another quadrant. For example, the caregiver who comes to see that s/he is situated in the lower left quadrant by reason of her/his sense of being overwhelmed may want, instead, to feel a sense of satisfaction or reward. The point of this brief talk is that they cannot simply jump diagonally in a single move. Instead, they may have to make a series of moves to get to where they want to be.



Powerful

2 Do something:
Use knowledge
and skill to
form a plan.

3 Put the plan to
work successfully.

4 Evaluate the
success of the plan
and learn from it.

Negative

Positive

Steps to Change
to More Positive
and In-Control
Feelings

1 Let go: Recognize the
effects of the disease.

Powerless

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What we want caregivers to understand is that to get from lower left to upper right – at least with respect to dementia caregiving – they will have to take several steps. What this means (represented by the figure above) is that if a person is in the lower left quadrant – the typical caregiver quadrant – s/he cannot go directly to the upper right (positive powerful) quadrant. To get out of the negative powerless state that so often characterizes the feeling state of caregivers, the caregiver has to do two things:

1. **The first step the caregiver has to take is to let go.** Another way to think of this is acceptance. Caregivers have to accept that their care situation is produced by the illness over which they truly have no control, that the disease and its effects are real. Then, caregivers can build a response based on that acceptance. The material in the first three sessions of the Savvy Caregiver program will help the caregiver to better understand the disease and its effects on the person. Particularly as the program focuses on behavior and the way the disease affects behavior, the caregiver should come to appreciate how powerfully that person is affected by the disease and how the illness is causing the person to gradually lose control over his/her behavior. This material is meant to provide a way to see caregiving challenges in terms of a disease process that cannot be denied. In the framework of the Savvy Process taught in Session 1, this is a process of Assessment. What this first action of acceptance means is that the caregiver can focus his/her mind more clearly on the situation. That focus, in turn, enables him/her to **Assess** how fruitless it can be to fight against the progress of the disease (or to expect the person living with the illness to be able to combat it). This action is essentially one of deciding to save energy. It is meant to assist the caregiver to undertake the second key action.

   Hope is an important factor in the lives of caregivers. It is important that hope be of an appropriate kind. It is reasonable and likely very therapeutic for caregivers to hope that some medication or treatment might become available that will slow or stop what's happening to the person. It is good for caregivers to hope that their caregiving is providing the person with as good a quality of life as possible, under the circumstances. It is useful for caregivers to hope that they will be able to find good help and resources for caregiving as the task becomes heavier. By the same token, it is destructive for caregivers to hope that their caregiving will somehow "cure" the person or that some treatment or drug will restore him/her to a former state of wellbeing. This kind of denial can serve to keep the person from being or becoming an effective – savvy – caregiver.

2. **The second step is, in fact, to take action – not just any action, but action based on the Savvy Process and caregiver's new knowledge, skills, and experience.** Much of the point of the Savvy Caregiver Program is to equip the caregiver in specific ways to take this action. This action involves two steps

    - The first step is **forming a Plan**. This really is a gathering together phase – it is the point at which the caregiver says to him/herself: "enough. I'm going to do something about this." Sometimes this phase may be characterized by the caregiver feeling angry – and then using the energy of that anger to focus his/her attention on the problem and to set out to do something about it. This step gets the caregiver from lower left to upper left. Things are still not good, but the control has shifted from the situation to the caregiver. This is one of the points in the program when the phrase "Don't just do something. Stand there" can be invoked: this step really calls on the caregiver to stop and look at what's happening (Assess) and to think a Plan through before acting.

    - The second step involves **implementing** the plan – actually doing something that could have an impact on the situation. If this step isn't taken, the energy will be dissipated and the feelings will slip back into the lower left, possibly even more profoundly so. If it is taken, there are at least three possible outcomes to be **Evaluated**:

        ⇒ The strategy (plan) works perfectly, the situation gets better, and the caregiver feels good because this represents a real accomplishment.

        ⇒ The strategy doesn't work or works imperfectly, so the situation doesn't really change. Nevertheless, the caregiver recognizes that s/he has done something powerful just by trying the strategy – and that makes him/her feel good. Furthermore, this outcome (as well as the outcome above) reinforces one of the central points of the program – that caregivers have to be "experimental" and "clinical" in their approach, and this creates or reinforces a predisposition to try to develop and implement other strategies in the future. Furthermore, the effort will likely generate more information that the caregiver can use to revise the plan which can then be re-tried. Again, a principle of savvy caregiving comes into play: the caregiver needs to maintain enough distance from the situation so that s/he can analyze and learn from whatever s/he tries with the person.

        ⇒ The strategy doesn't work, and the caregiver doesn't appreciate that even trying it was a good thing, so s/he slips back to the lower left quadrant.

In the case of the third outcome, caregivers should be encouraged to recognize what happened and to begin the cycle anew.

Free-Time Repertoire

Self-Care: Time and Activities for Yourself. The concluding part of this section of session two is meant to focus caregivers on the development of a repertoire of activities they can do, should they make some free time available. Many caregivers become so immersed in caregiving that they lose the sense of what it is that delights and refreshes themselves. As a result, they don't actively seek time for themselves or, if they find themselves with time, they are unsure what to do with it.

The purpose of this exercise is to enable caregivers to brainstorm about what they need and would like in their own lives. Instruct the caregivers: Imagine you have a fairy godmother and she has granted you 5 wishes. Unlike other fairy godmothers though, she gives five wishes of different amounts of free time.

Building a "Time-for-Yourself" Repertoire

What would you do if you found yourself with:

- 15 minutes of free time?
- An hour of free time?
- Three hours of free time?
- A whole day?
- A whole weekend free of caregiving responsibilities?

You can choose to do whatever you want to during your free time – except you can't use your time for "doing chores or errands" as an activity. The exercise purposefully excludes chores and errands because, even though the caregivers may feel behind in their household tasks, they likely will always feel behind in their chores. Doing chores may make them feel more caught up, but not rejuvenated.

1. You have 15 minutes of free time.
2. You have 1 hour of free time.
3. You have 3 hours of free time.
4. You have 1 entire day of free time.
5. You have a weekend free of any caregiving responsibilities.

The point of this exercise is to illustrate, in a playful way, that it is actually crucial for caregivers to take time to rejuvenate themselves. If they wait until everything is done and they feel caught up, they will never take the time for themselves.

Allow about 2-3 minutes for the caregivers to write down their answers then ask them to report back and to say why they chose those activities.

Ask participants why doing things for themselves is important. You can use the slide below page to summarize their comments and provide addition reasons that may not have been mentioned.

Reasons To Do Activities

Feel more:

- Energized
- Calm
- Centered
- In touch with self
- Connected with
    - Person with dementia
    - Community
    - Family
    - Friends
- Enjoy the activity
- Helps with sleep
- Learn something
- Add something to life
- New experience
- Something different
- Enjoy time with others

Many caregivers feel there are many things they would like to do, but they just don't have time. Ask what some of those reasons are, and brainstorm how they might get some free time. This can be tied in with Types of Caregiving Families (in Session 6) to help caregivers figure out how they might carve out some time for themselves.

More Effects of Dementia

Confusion and Behavior: **More on the Effects of Dementia-Related Illnesses.** You will be switching the focus of the session from the feelings that caregivers have in their caregiving and returning to a basic informational segment on the effect of the illnesses on the person living with a dementia illness. It is helpful to make it clear to participants that you are "switching gears."

The instructional strategy of the program is to present more practical material on ways to understand how a dementia illness affects the person living with it and methods to manage day-to-day life with the person. For example, the focus of Session 1 was to represent how dementia illnesses affect a number of common cognitive processes. From your perspective as an instructor, it's important to see that caregivers' understanding of the elements provides an essential foundation for the knowledge base a caregiver needs to be well qualified and prepared for the caregiver role. It is important, too, to recognize that people don't typically engage in a "Thinking about Thinking" analysis, so participants may need further discussion and explanation about cognitive losses in the coaching segment of the session.

The instructional strategy helps caregivers to begin to break the effects of the dementia illnesses into more discrete and understandable parts. It also reinforces the notion that there is a disease process at work. Still, by itself, basic information on cognitive losses isn't very helpful in improving a caregiver's management skills.

This session's focus shifts to looking at the overall effect of a dementia illness on the whole person. This section introduces the idea of ***Confusion*** as a central reality of the disease for the person. It also introduces the concept of ***Behavior*** – doing things – as a central focus of the caregiver's work. For both topics, the section provides linkages between the impact of the disease and the work of caregiving. It does this in several ways:

- It emphasizes that caregivers need to be able to assess (figure out) what the behavior of a person living with a dementia illness might mean – both in terms of the expression or result of Confusion or contentment, and the guidance of Behavior.

- It reinforces the idea that assessment is the beginning point for developing a successful caregiving strategy (plan). Caregivers' assessment might involve taking time and care to try to understand the behavior s/he is seeing or to envision a behavior s/he would like to promote.

- It provides a fairly simple but powerful way of thinking about what elicits and/or contributes to behavior.

- It offers the caregivers a very clear way of seeing just how what they do can have an impact on what their person does.

In the last part of this segment, the program offers a strategy for communication with the person that acknowledges confusion and cognitive losses and provides a way to engage with the emotional truth that the person is experiencing.

You should make it clear to the participants that this section on Confusion and Behavior touches on **the three important elements of caregiver training objectives**:

- **Knowledge** – Know the global effect of confusion on behavior and emotion.
- **Skills** – Gain the ability to assess behavior and think about ways to affect or respond to it.
- **Outlook** – Develop the capacity and willingness to step back from the moment to assess things as calmly and dispassionately as possible.

You might want to remind participants that this pattern of instruction – looking at a disease-produced effect on the person and linking that understanding to caregiving strategies – will continue in each remaining session. Over the program, they will gain understanding of the effects of a dementia illness as the disease progresses (this will add to their knowledge), and that this information will be linked to ways of improving day-to-day management (thus expanding their skill set).

Confusion – Erosion of Emotional Control

Confusion – A Central Problem in Dementia Illnesses

This section deals with the issue of Confusion. Confusion is a central idea. It provides the easiest and most accurate image or metaphor for how dementia illnesses work their harm on those living with them. It also provides an organizing image for the work of the savvy caregiver: managing the environment and keeping the person focused so as to keep confusion at bay. The next session (3) will deal with the goal of "Contented Involvement," a notion that represents the flip side of confusion, as well as a method to try to avoid confusion. Although promoting Contented Involvement does, in and of itself, entail savvy caregiving work, Contented Involvement offers some protection against confusion, and the "work" of promoting Contented Involvement is likely more satisfying and less difficult than that involved in quelling the disturbing or uncomfortable behaviors that often flow from confusion.

Exercise: Confusion. The first part of Session 2 focused on the caregiver. Now the session swings back to looking at the effect of the disease on the person living with it. This portion of the training introduces a central idea of the program. The idea is a straightforward one:

- Confusion is the central problem of a dementia illness for the person living with the illness
- Confusion is the source or stimulus for the emotional and behavioral problems that caregivers find so troubling
- Finding ways to keep persons living with a dementia illness contentedly involved in tasks and activities is the best way to keep confusion at bay – and avoid the behavioral and emotional problems (this is dealt with in a later session). Although promoting Contented Involvement does, in and of itself, entail savvy caregiving work, Contented Involvement offers some protection against confusion, and the "work" of promoting Contented Involvement is likely more satisfying and less difficult than that involved in quelling the disturbing or uncomfortable behaviors that often flow from confusion.

The first part of the exercise involves taking the participants through a guided imagery exercise. This exercise aims to help the participants experience the feelings associated with confusion – to let them feel what it feels like to be overloaded by stimuli over which they feel no control. The image, as presented, works well in northern parts of the country where participants are very familiar with the conditions imagined. You can substitute other images, such as intense rainstorms or other circumstances that fit better for your part of the world.

Ham it up! You're trying to get participants to experience a sense of the world crashing down on them, making them feel as though they are losing control of the situation. So don't proceed with this as a talk, but as a drama in which you are the narrator and the participants are the players. Use slow pacing and an appropriate tone of voice to reflect the tense, serious nature of the situation.

This exercise is often a turning point for caregivers. They gain a sense of empathy for their person. If they feel tense after just this guided imagery exercise, they can imagine how it must feel their person now living with the disease to be in a world where layers of stimuli can be overwhelming. Trainers should emphasize that gaining this sense of what it feels like to be overwhelmed, out of control, anxious, and/or confused about how to cope helps create or enhance caregivers' patience and compassion for their person, and what they are experiencing.

Exercise Tips:

- Allow participants to really settle in for this and all guided imagery exercises.
- Encourage them to close eyes or look down at their lap, place their feet on the floor.
- After you conclude, be sure to allow the full emotional experience soak in a bit.
- Give this exercise adequate time (15-20 minutes). Rushing this exercise will reduce its impact.

Exercise Directions

1) **Tell the participants that you are going to lead them through a "let's pretend" exercise.**
2) **Ask them to close their eyes (or look down).**
3) **Using a low-pitched and slow-paced voice, tell them:**

Exercise Script:

I want you to imagine that it's winter – bad weather – and that you're driving your car. (pause)

Imagine that it is your least favorite time of day for driving – the light is very poor. (pause)

Imagine that you are driving on your least favorite section of the freeway – lots of merging traffic and lane-shifting going on. (pause)

Now imagine that the road conditions are terrible – it's icy and slippery. (pause)

Imagine that it's snowing – fat, wet snow that quickly covers your windshield. (pause)

And your windshield wipers aren't working too well. (pause)

Imagine that it's very heavy traffic – very little space between cars. (pause)

And imagine that, because of the traffic, you have to be driving much faster than you like. (pause)

Imagine that there's a passenger with you and that that person is very nervous. (pause)

And that s/he is talking excitedly. (pause)

And imagine that the car radio is turned on and is playing loud music that you don't really like. (pause)

And in your side-view mirror you see an 18-wheeler about to pass you very closely.

At this point, stop leading the exercise and give the group a moment to continue to experience the image, then ask:

- **"How do you feel?"**
- **"What do you want to do?"**
- **"What would you like to have happen?"**

Make note of the responses. It is most likely that you will hear caregivers' discomfort, expressed in many versions.[*] Validate that discomfort and the other expression that you're likely to hear –that they would like to slow things down, make them more calm and less complex and generally get in greater control of the situation. Individuals living with Alzheimer's and similar illnesses can no longer take any of these actions to calm their environment. You may also hear people say that they might say or do things in the moment of highest tension that they might later regret having said or done. You can use such self-reports to point out how confusion can over-ride the checks we normally place on our own behavior. This is a point that has obvious salience for how confusion relates to the behavior of a person living with a dementia illness. Use this as the introduction to a brief talk on confusion.

Confusion. The concept introduced in the exercise and talk – confusion – is one of the small handful of central ideas we are trying to instill in the learners. Confusion is a clear, relatable way of describing the global impact of a dementia illness on the person. The exercise and talk are meant to convey to the caregivers an overall sense of the moment-to-moment reality of life for a person living with a dementia illness. It also gives them an appreciation for the integral relationship between confusion and behavior. This section is meant to engage the learners at a very empathetic level. Confusion is something everyone has experienced and can understand. Caregivers should leave this session with a firm grasp of the constant threat of confusion in dementia illnesses – how it is always present around the edges, and that it has the capacity to become the central, controlling and terrifying experience of the person.

The main points that you are trying to get across in the talk are:

- The guided imagery exercise simulates the confusion of a dementia illness.
- Participants also need to understand that as a dementia illness progresses:
  - Declining cognitive powers will provide less protection from external stimuli and offer less of a sense of security and control
  - External stimuli will seem more intense, increasing the need for security and control.
- Confusion is the central problem in dementia illnesses
  - It is upsetting in itself
  - It produces uncomfortable or distressed reactions in the person (withdrawal, striking out, resistance).
- There are very strong emotions connected to confusion - like fear or terror. These emotions produce a strong need for control, security, and comfort.
- A lot of savvy caregiving is about keeping confusion at bay and/or helping the person to come back from being confused, by calming and reassuring the person, or quieting the environment.

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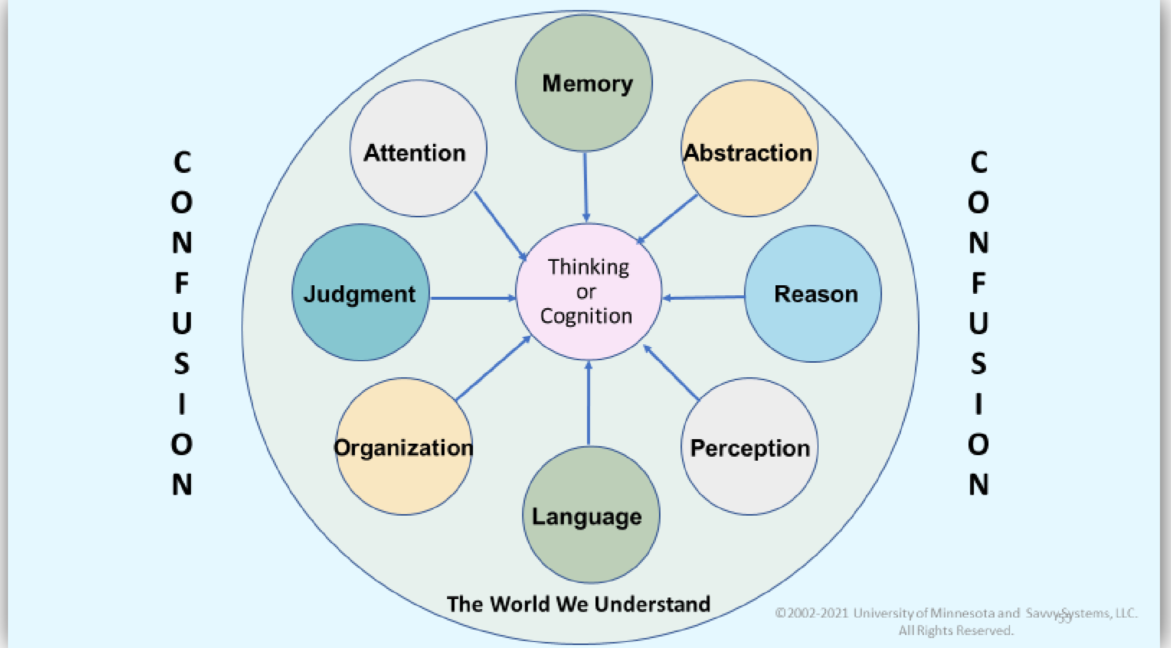
[*] For instance, participants often indicate that they would: ask the person in the car to stop talking and turn off the radio – both ways to reduce the inputs. Many say that they would slow down or move into the slow lane. Many also say that they would get off the freeway altogether. If participants don't come up with responses like these, provide them and see if they don't nod their heads or provide other forms of agreement.

- Confusion – and the fear it produces – is related to a lot of the comfort- and security-seeking behaviors (repeated questions, shadowing), as well as more aggressive behaviors, such as verbal or physical outbursts.

- Foreshadow future sessions: keeping the person involved helps keep confusion at bay.

This section of the program is a platform for other training content that follows, particularly in the sections on behavior and using knowledge about the person's disease stage and performance level to frame structure and support strategies for encouraging Contented Involvement. The leader should foreshadow these in this brief talk simply by mentioning them. An understanding of confusion also prepares caregivers that the idea of Contented Involvement, which is introduced later in this session, is another of the central idea of Savvy, and that Contented Involvement is the alternative that caregivers can offer to their person to prevent and/or respond to confusion.



This slide is meant to illustrate our normal situation. Our powers of mind help us to interpret, understand, and manage the world around us. Typically, we manage and comprehend a large part of the world. Confusion is always a possibility because there is always the chance we'll get in over our heads – like the freeway image. Beyond some certain point, all of us can be beset or even overwhelmed by confusion. It is important to point out that this picture is oversimplified. We also have mechanisms for recognizing that we're nearing that threshold and for backing away from it to protect ourselves. The onset of being overwhelmed is usually well recognized. We are seldom surprised by it. Usually, there is ample warning that we are reaching a limit. Likewise, we can draw on experience to help us draw up a plan or strategy – on the spot – to reduce the chances of being overrun by confusion. Thus, in the guided image exercise, it is very likely a person would have turned the radio off long before things got really dicey – and s/he would probably have asked the friend to be quiet for a while. We have a way of adjusting to see how close we are to our limit, and removing some of the stimuli to keep the experience within our capacities.

We also realize that sometimes we are overwhelmed. In those occasions, we sometimes act (behave) in ways that we wish we hadn't. We might lose our temper, yell at someone, use language we don't ordinarily use, make grave errors in judgment, have accidents, etc. There are three important points to make about this kind of behavior:

- It is an understandable consequence of being overly confused and it can happen to anyone, even to people not affected by a dementia disorder.
- We can look back and regret such responses. Hopefully, we learn from the experience so that it might be avoided in the future.
- We can apologize for it, if necessary.

Persons living with Alzheimer's or a dementia illness may lack the capacity to reflect back on their own behavior stemming from confusion, to regret it, or to make amends for it.

The take-home message here is that everybody knows that beyond their range of control there is a universe that can be overwhelming, but, normally, we control things well enough so that we never feel the terror of being out of control or overwhelmed. The fact that we spend some or a lot of our cognitive resources keeping confusion away should tell us how powerfully scary confusion is. It is important that participants get in touch with this in themselves to more fully understand how vulnerable persons with a dementia illness are, and how confusion can drive many of their reactions and behaviors.

Emphasize for caregivers that as the disease progresses, the chances that the person will experience confusion will continue to increase. Likewise, the chances that the person will not be able to protect him/herself from confusion will continue to increase. This will likely result in some behaviors that are intended to be self-protective or to create distance from the confusion.

Another important part to emphasize: Considering the many areas /elements of cognitive loss, the person becomes less able to draw on experience, use cause and effect thinking, or problem solve to reduce confusion. As the powers of thought decline, so to do these abilities. Thus, confusion often "strikes" with less notice, and the person has fewer protective maneuvers against it. From a caregiver's perspective, this means that the caregiver will have less notice that the person is about to become upset – and therefore, less time to take steps to help the person avoid the discomfort associated with confusion.

At this point, refer back to the guided imagery exercise. Ask caregivers to review their feelings and emotional needs during the exercise. Remind them these are feelings and needs produced by confusion and that confusion is the central reality for the person living with a dementia illness.

Confusion ties in with emotion. In a dementia illness, confusion produces or is the basis for a number of key emotional needs. Use the slide below to summarize the set of needs.

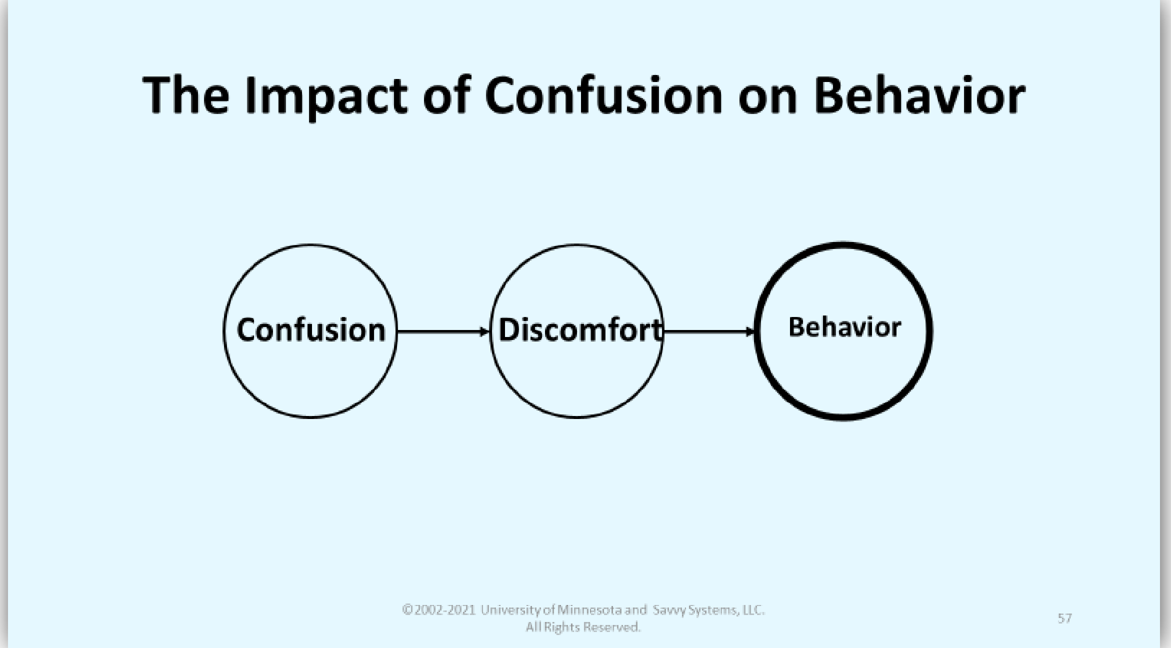
Emotional Needs of the Person

- Calm
- Safety
- Security
- Control
- Reassurance

The key here is that this set of emotional needs can explain two of the often annoying day-to-day behaviors seen in a dementia illness: shadowing (not letting the caregiver out of his/her sight) and repetitive questioning. When seen in the context of confusion and the fear of confusion, these behaviors are more understandable. The person sees the caregiver as "an anchor", or fixed point of stability, in an otherwise uncertain and confusing universe. The caregiver is the touchstone – so keeping in contact with the caregiver, either visually or through repeated verbal interactions, helps make the world feel more stable, at least for a while. Beyond this, the idea of confusion and related emotional needs also offer insight to other troubling behaviors, particularly those that involve agitation. In many ways, agitation is a signal that the person living with dementia is seeking calm, control, security, etc., so the caregiver needs to find ways to offer these.

[Once you have made this point, you might ask participants to identify other behaviors that they have seen in their person that might stem from confusion.]

The slide below illustrates the point that confusion, when unchecked, can promote discomfort for a person living with Alzheimer's or a similar illness. When the person experiences discomfort, s/he does something (behaves). We all do this; when we're uncomfortable in our chairs, we shift our bodies. In the case of a person living with a dementia illness, the behavior may take many shapes.



The Impact of Confusion on Behavior

Confusion → Discomfort → Behavior

This point also offers a basic caregiving strategy: Find a way to help the person become involved in some task or activity that allows him/her to be anchored in the same way s/he is anchored by the caregiver. This will be a main point of most of the rest of the program, but it is very helpful if caregivers can understand a very basic equation. Much of the person's behavior is linked to seeking reassurance and security by staying close to the caregiver. If the caregiver can find ways for the person to derive reassurance and security from someone or something else, this will take some of the pressure of caregiving off the caregiver.

These two key Savvy concepts – Confusion and Contented Involvement – intersect and interact over time as the underlying illness gets worse. The result of confusion is to cause the person (or the person's mind) to spin out of focus or control. This is frightening and can feel like they are coming apart at the seams and fragmenting. The counterforce to confusion is becoming focused on something – becoming zeroed in on some person (the caregiver), task, or activity. The ability to focus shrinks over the course of a dementia illness, so caregivers will need to continually develop solutions to the challenge of how and what to use to capture the person's attention, as the person's attention will likely have a shorter and shorter span.

The message here is that the caregiver's task has to be directed at helping the person to remain as zeroed in on things as possible because this protects against or counteracts confusion and because it's enjoyable or is a kind of comfort zone. In addition, because it might give the caregiver some breathing room. That is really the nature of caregiving work and the way to fend off confusion. [It is useful here to point out that thinking about Contented Involvement is coming up next in the session and that much of the rest of training will focus on how to do this.]

Erosion of Behavioral Control

Behavior. In this section of the program, the focus will be on the behavior of the person living with the dementia disease. Behavior – understanding it and being able, within limits, to guide and/or tolerate it – is a central focus of the Savvy Caregiver program. Research about caregivers shows that difficulties caregivers have with managing or coping with the behaviors of the person living with the illness are the greatest source of caregiver distress and burden. The caregiving literature calls these "the behavioral and psychological symptoms of dementia."

Up to now, your work has been to get the caregivers to understand what the disease does to the person's cognitive or thinking abilities, and to the person's capacity to remain calm and in control in stressful situations (situations that produce confusion). Likewise, you've been working to get the caregivers to begin to relate these effects to the intentional development of caregiving strategies that take these effects into account. The next section of the program begins to introduce caregivers to the more complicated topic of behavior and managing or guiding behavior. The concentration on behavior will be the main focus of instruction for the next three weeks, and participants' home activities for the rest of the program. This section will introduce some background material on behavior – a model of how behavior works and how a dementia illness affects it.

The remainder of this section of the session will cover the following material:

- Provide participants with a fairly simple way of thinking and being able to analyze and assess behavior.

- Link the material about cognitive losses, particularly confusion which was already covered, to the behavioral difficulties persons with a dementia illness experience as the disease progresses.

- Emphasize the importance of the role of the caregiver in terms of the behavior of a person living with a dementia illness.

- Begin to focus caregivers' attention on the important of taking control or providing respectful guidance for their person. This is often a dilemma for caregivers who may continue to believe that their person can still manage safe, self-control of his/her own behavior.

Dealing with Emotional Truth

This segment concludes with a brief discussion on dealing with the emotional truth of situations by using a validation approach.

These materials on behavior will be background for the sessions in the following two weeks. In those sessions, participants will be introduced to another key idea of the program – that persons living with a dementia illness can be content through being involved in things (activities, tasks, events, etc.) and that there are Anchors that caregivers can use to facilitate this kind of involvement. <u>In this segment, you are trying to get the caregivers to arrive at just three basic insights</u>:

- Dementia illnesses affect behavior; and, as these are typically progressive conditions, they affect behavior more seriously as they worsen.

- As a dementia illness worsens, the caregiver will be increasingly responsible for guiding and directing the behavior of their person.

As the caregiver becomes increasingly responsible for guiding the behavior of the person living with a dementia illness, s/he needs skills – techniques – to help him/her manage and guide the person's behavior. The caregiver will also have to become comfortable with the idea that s/he is in control and has to provide respectful guidance. They will also have to accept that the person cannot reasonably be expected to act as a free and autonomous agent. In fact, being asked to make choices that are too complex can be a source of distress and confusion, and taking over and taking charge can provide great relief to them.

A key goal of the Savvy program is that caregivers leave the program feeling both competent (they can manage this situation) and comfortable with what they are doing. We are trying to make them more effective in their approach to caregiving and to enhance their own appreciation for the mastery they are developing. We want them to develop or strengthen the ability to step back from the immediate situation, scope it out, figure out what might work best to keep the situation calm and under control, and then put that plan into effect.

To be able to do this, the caregiver has to feel, at some level, that s/he is more in control of things than the person living with the illness and that s/he is better able to make choices about the situation than the person. A simple example of this that many caregivers have found pivotal in their development as Savvy Caregivers is to clearly tell the person what to do instead of giving their person a reason for doing something. For example, the caregiver might say, "I need you to shower now" instead of saying "you need to shower now because we're going to our daughter's house this evening." This may seem like a small shift, but it is an important one. Instead of offering too much information and choice, the caregiver is guiding the person without providing more than what s/he can handle.

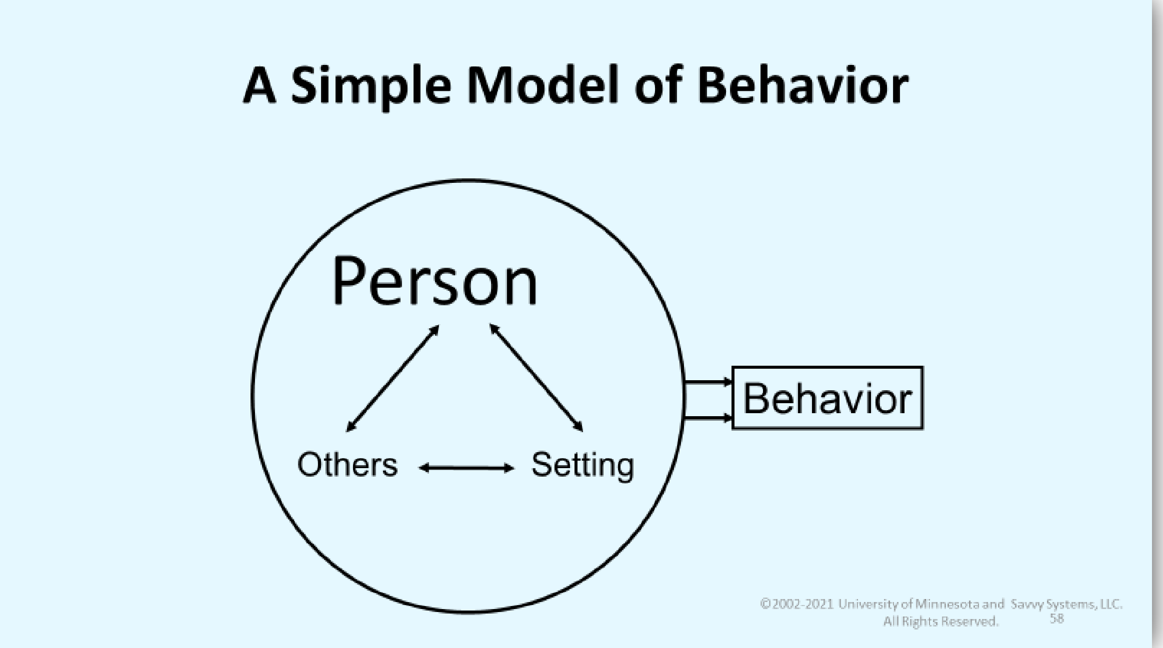
Beneath this simple example is a whole cultural value system related to independence, freedom, autonomy, and the sacredness of the individual. In the US, independence, personal freedom, and the right to make choices on one's own are highly valued. In other cultures and countries, these values are perhaps even more strongly held, and they are often linked to a person's place in the family. It may, for example, be seen in some cultures to be completely unacceptable to contradict or attempt to direct an elder. Thus, under many circumstances, acting in a way that appears to question or abridge independence is deeply disturbing. For caregivers, however, it is imperative that they understand that with diseases like Alzheimer's, they can work to support persons with a dementia illness while still showing respect, even when the guidance they provide may seem to represent an incursion on the person's independence.

What the Savvy Caregiver program is teaching is that a dementia illness is progressively depriving the individual of his/her ability to exercise informed choice. As the disease progresses, choice making can contribute to Confusion. The program further teaches that it is therefore appropriate for the caregiver to substitute his/her judgment for that of the person. The caregiver must assume responsibility, control, and provide respectful guidance within any situation on behalf of the person. This will help maintain a sense of calm and security – both of which are key needs for persons with a dementia illness. As the leader, you will be in a position to detect participants' comfort or discomfort with this idea. Try to keep this in mind throughout the program, and raise the issue as you feel it is appropriate to do so.

The section highlights a **Simple Model of Behavior**. It will begin with a brief exercise through which participants will derive the key components of behavior. After that you will provide a brief talk on the model of behavior.

A Simple Model of Behavior

Exercise. Use brainstorming to demonstrate to the learners that they have an intuitive grasp of how behavior works and to show them that they have frequently engaged in "behavior management." (a talking point here is that the idea of managing behavior is not inherently bad – something some people may feel or fear). Have the participants tell each other how they get things done.



A Simple Model of Behavior

Person

Others ⟷ Setting

Behavior

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You might ask them, for example:

- How would you get a child to do his/her home activities?
- How would you get your spouse to do a chore needed around the house?
- How would you get yourself to do something that is good for you (exercise, relax, diet, stop smoking)?

Record and categorize the responses using three headings – **Person** (self-directed action), **Others** (i.e., the effect that others have on shaping behavior, and **the Setting** (the way the environment works to shape behavior). Note how each response corresponds to the elements of behavior shown in the next slide. Have participants look at the slide to get an intuitive sense of it and then make a few points (below). After that, use the slides that follow to further explain the elements in the model.

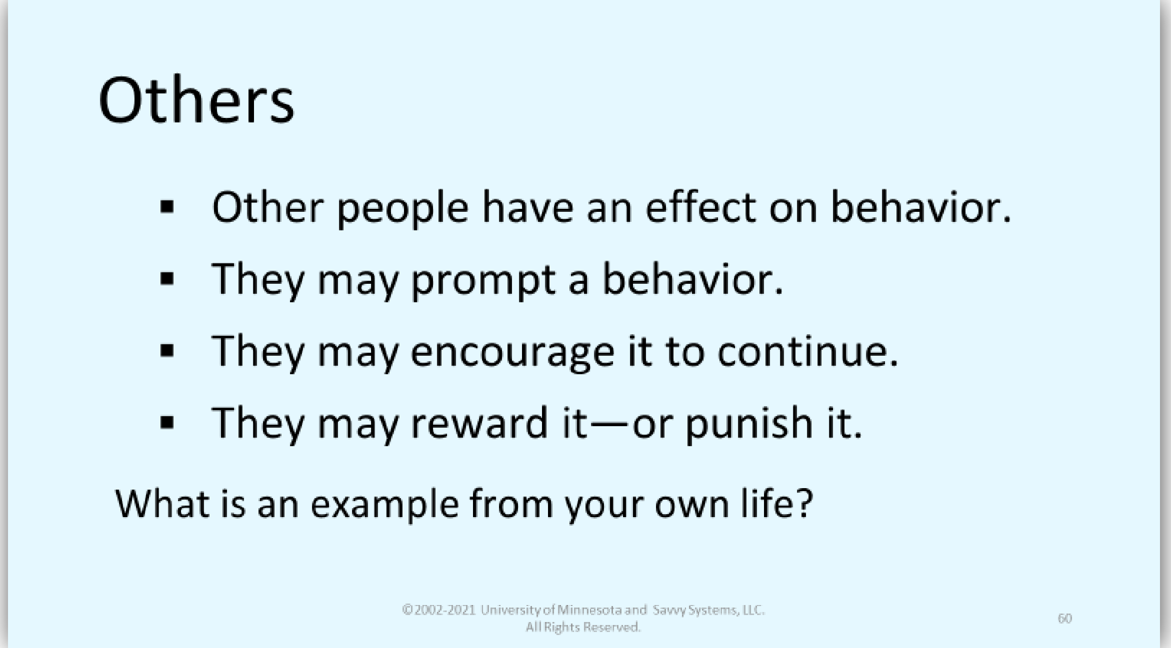
The first point to be made here is that, under normal circumstances, we expect people to be primarily in charge of their own behavior (that's why Person is larger and bolder than Others and Setting). Other people and the setting or environment contribute, but the individual choice factor typically is the main one. Use the next slides to provide more background and detail on the three elements of behavior.

Person. This is really just a point to be made: The nature of the motive is irrelevant. The key point is that the person makes the choice for a behavior and is responsible for it.

Person

- People normally exert control over their actions.
- They choose, based on some calculation of benefit.

Others. Ask the participants to draw on their own experience to recount ways in which others have contributed to their behavior (use the examples of how parents, teachers, important friends, clergy, civic leaders, etc., have "led" them to do things).

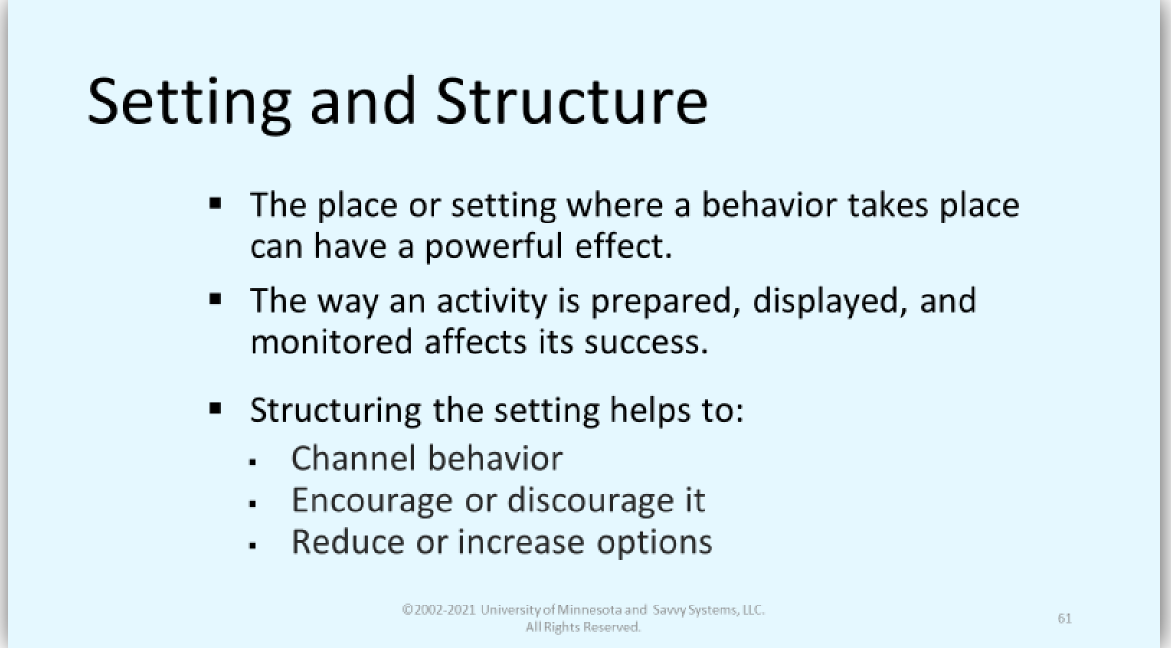


Others

- Other people have an effect on behavior.
- They may prompt a behavior.
- They may encourage it to continue.
- They may reward it—or punish it.

What is an example from your own life?

Setting. Setting, or structure, will be an important concept in the next sessions. The Anchors of Contented Involvement introduced in Session 4 uses Structure (along with Person and Support) as essential parts of the concept. So, you might want to emphasize to participants that Structure is a term they can expect to hear more about as the program continues.



Setting and Structure

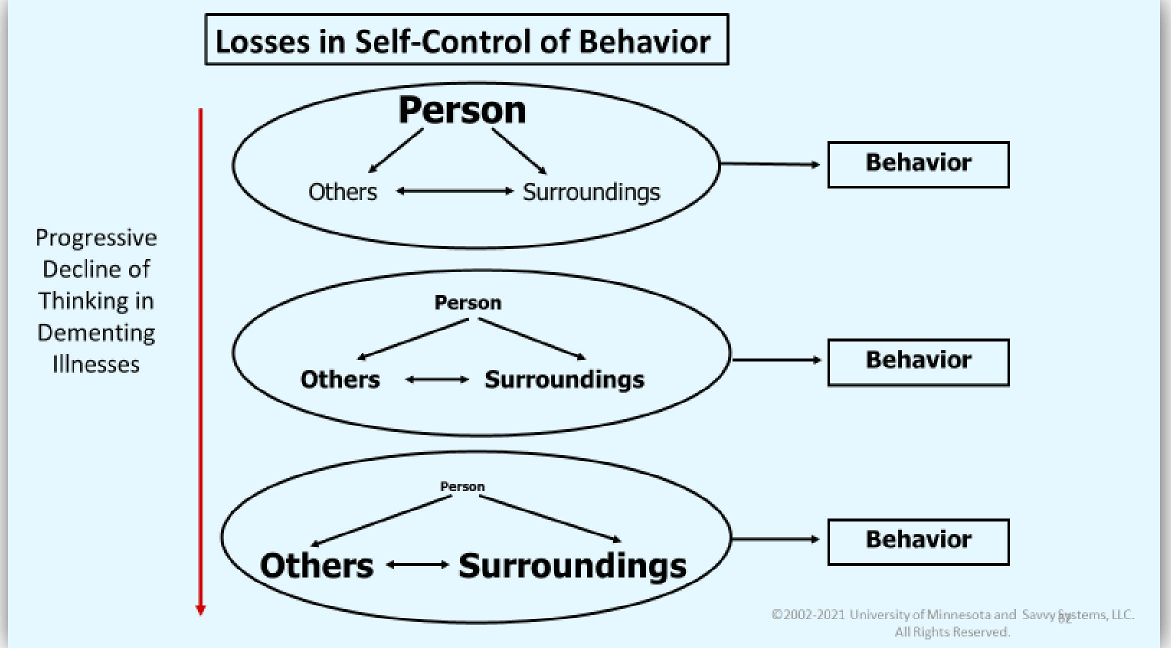
- The place or setting where a behavior takes place can have a powerful effect.
- The way an activity is prepared, displayed, and monitored affects its success.
- Structuring the setting helps to:
  - Channel behavior
  - Encourage or discourage it
  - Reduce or increase options

The idea of how Structure affects behavior is more abstract. A cluttered room might prove distracting to a person living with dementia. To help the person focus on a task or activity, the caregiver might simplify the room (remove a lot of the objects from it). Because persons living with a dementia-related illness may have objects that provide comfort or security, it is important that such objects not be removed when de-cluttering.

- A noisy, crowded area (e.g., a restaurant or a shopping mall – or a big family gathering) might be overwhelming for a person whose confusion is already high.
- A table with just one model car kit on it might prompt a child to play with that whereas a table that has a dozen toys and model kits on it might cause the child to skip from one to the other without much focus.

The idea of structure is one to which the program will return repeatedly in the next few sessions.

Now refer the participants back to the first slide on the behavior model and check with them to be sure that they see how the model works. You can use the exercise example here to pull the model together. "I've decided to get more exercise. What are some 'person' reasons I might make that choice? How might others and the setting contribute to my success or failure?" Ask them what they think happens to this model when dementia is introduced into it, and then use the slide below.



Losses in Self-Control of Behavior

Progressive Decline of Thinking in Dementing Illnesses

Person

Others ⟷ Surroundings

Behavior

Person

Others ⟷ **Surroundings**

Behavior

Person

Others ⟷ **Surroundings**

Behavior

Learners should grasp the notion that, as the disease progresses, the balance of influence shifts in the model. The influence of Others and of the Setting of a task, event, or activity become larger factors, and the Person shrinks in terms of how much s/he affects or controls behavior – at least how much s/he does so on an intentional basis.

The initial talk on the impact on cognition should prepare learners to understand this. When powers like reason, organization, judgment, and perception are compromised, intentional behavior becomes more difficult and unlikely. Emphasize that the proportions in the slide are just illustrative. That is, we are not introducing the learners to a very precise calculation about the relative influence of the three factors as a dementia-related illness progresses.

This is a good spot to foreshadow those parts of training that will further explain the losses that occur. Tell the participants that they will be learning a way of understanding all of this that will allow them to estimate how much the person can do and just what kinds of Support and Structure they can best provide.

Communicating at the Level of "Emotional Truth." Caregivers frequently report that the person they care for says things – and clearly believes them – that are untrue. The person may, for example, say that s/he plans or wants to visit his/her parent (who is long dead) or that s/he's looking forward to visiting a country home that was long ago sold. Such statements emerge from the confusion and cognitive losses the person is experiencing. They may be triggered by something the person sees or hears, or they may just come from a random recollection.

Whatever the source, in this moment these ideas are true and present to the person living with Alzheimer's or some other dementia-related illness. So, the caregiver is faced with having to do something in response to such statements. Caregivers often feel that when faced with such statements they have few good choices: they can either confront the factual truth of the statement or they can deal in what they feel would be a deception – pretend that the statement is true and make something up to placate the person in the moment. This latter choice feels to many like lying to the person, and that makes caregivers understandably uncomfortable; in fact, some people call this a "therapeutic lie."

Session 4 in the Caregiver's Manual on Validation and Reality Orientation covers this topic in some depth, but this is an opportune moment to bring it up in the program. The material in the Caregiver's Manual essentially suggests:

- *Don't Confront*. Given the losses the person is suffering, it is likely the effort to "convince" the person (i.e., reason with him/her) will be unsuccessful and may lead to greater confusion and upset.
- *Don't Lie*. It is disrespectful of the person, at some level, it compromises one's relationship to the person, *and* it could backfire in ways that might produce greater upset.
- *Deal with the Emotional Truth of the Situation*. Search for what the person may be feeling in the topic s/he is bringing up, and do something that validates that feeling. What is the emotional nugget behind the words? So, whether it is a long-lost parent or place or a distant child or friend or a favorite spot or pastime, engage the person in something that taps into those feelings. Try to get the person to talk about the topic; ask for memories; look at pictures that relate to the topic; tell your own stories about the topic. These moments can actually offer a special opportunity for the caregiver or other family member to connect and reminisce with their person. Let the person have time in the emotional moment, and then work to move him/her on to some other task or activity.

Control and Respectful Guidance

Taking Control/Respectfully Guiding. At this point, introduce participants to the notion of the importance of influencing the behavior of a person living with dementia by accepting they are now in a position of Taking Control or Respectfully Guiding. They have already learned a lot about the ways in which Alzheimer's and similar diseases take away a person's ability to function in the world. They have seen –

and experienced – the distress that accompanies confusion. And in this most recent segment of the session, they have considered that the disease gradually deprives the person of the ability to take self-directed action.

It is now a moment to introduce the idea that the workshop participants, as caregivers, have to guide, shape, take control of, and assume responsibility for the person's behavior. They have to design the person's day, structure the person's tasks and activities, and see to it that the person is supported to respond in ways that work for the person and for the caregiver.

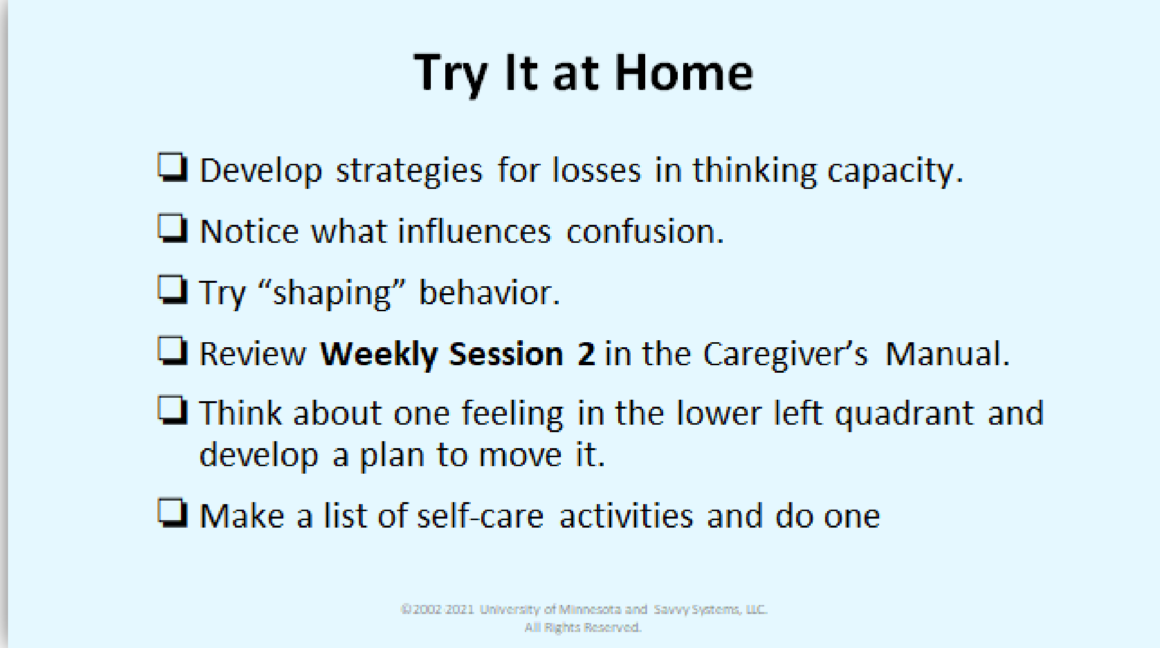
For most participants, this will be a logical idea – but an uncomfortable one as well. The notion of taking control of the actions of another adult goes against the grain for most of us. We want to accord others the freedom of their choices. Autonomy is an important value in our society.

Moreover, for most participants, the historical relationship between them and the person for whom they provide care (child-parent; spouse-spouse; sibling-sibling) is one that is built on mutual respect and on not being in control.

Caregivers should make a conscious effort to understand that they have to be in control more and more as the disease progresses. They can do this in a respectful way, but it is both unkind and unproductive not to exercise the kind of beneficial control the person needs as the disease progresses.

Home Assignments

Things to Try at Home. In general, encourage participants to continue to put things into practice that they are learning. They should continue to work on developing ways to deal with the losses in thinking capacities that their persons are experiencing. They should also begin to watch for signs of confusion in their person and to notice the way things influence their person's behavior. They should try some experiments with "shaping" behavior. These will be hit and miss, but it would be good for participants to begin efforts to assume more control over their persons' behaviors. Remind caregivers that we have some "wisdom in the room" (i.e., try things at home so we can share ideas & problem-solve other options with people who are going through the same things).



Try It at Home

- ☐ Develop strategies for losses in thinking capacity.
- ☐ Notice what influences confusion.
- ☐ Try “shaping” behavior.
- ☐ Review **Weekly Session 2** in the Caregiver’s Manual.
- ☐ Think about one feeling in the lower left quadrant and develop a plan to move it.
- ☐ Make a list of self-care activities and do one

In addition, ask participants to:

- Develop a list of self-care activities – and engage in at least one of them.
- Review Weekly Session 2 in the caregiver’s manual.
- Consider reading ahead on the Staging System for Dementia-related Illnesses in Weekly Session 3. This is difficult material and reading about it in advance might help you absorb the information more easily.
- Consider one feeling this week that is in the lower left-hand quadrant. Develop a plan to move from that to another quadrant, either by taking some informed action or by attempting to accept or let go.

Weekly Session 2 Notes

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Weekly Session 3

"Health is the greatest gift.
Contentment is the greatest wealth."

Buddha

Savvy Caregiver Program
Weekly Session 3 Agenda

Session Agenda

Instructional and Topic Areas	Content Included In Topic Area	Approximate Time
Coaching and Review	• Readings in Caregiver's Manual • Review of Self-Care Activities (Feeling Quadrants; Self Time) • Review of Efforts to Guide Behavior	**30 Minutes**
Teaching: **Goals for Caregiving**	• Contented Involvement • Fit	**25 Minutes**
Teaching: **Performance and Illness Stages**	• The Key Elements of Doing Things	**20 Minutes**
	• Staging System for Dementia-Related Disorders That Relates to Everyday Lif	**40 Minutes**
Home Practice	• Assigned Home Readings and Practice Tasks	**5 Minutes**

Program Leader's Overview of Session 3

In this session, caregivers get introduced to the last of the backbone content information on dementia-related illnesses – the impact of Alzheimer's and similar progressive neurocognitive diseases on a person's ability to do everyday tasks and activities. They begin to learn how they will be able to apply these new insights to their day-to-day caregiving. This session and Session 4 enable caregivers to develop strategies to ensure that their person can become and remain contentedly involved in everyday tasks and activities. This is a marker of Savvy caregiving. Doing things and being zeroed in and pleased while doing them is presented as a target for enhancing the quality of life of a person living with dementia.

To be effective at this, caregivers have to have a basic grasp of what we mean by "doing things" and what elements are involved. Caregivers also have to apply their increasing understanding of what a dementia-related illness does to their person's ability to do things. This session introduces them to the idea of **Contented Involvement** and to a **system for staging** progressive dementia-related diseases. This system derives, in part, from the discipline of Occupational Therapy, a clinical field that aims to provide "just right" challenges for persons who have experienced developmental or illness- or accident-produced losses.

After this session, caregivers should be able to arrive at a ballpark estimate of what Stage their person is in the course of the disease. This estimate will support caregivers' understanding of their person's ability to do things. More practically, it will help the caregiver begin a process of choosing and setting up the kinds of tasks that best fit their person's abilities. It will also enable them to be as effective as possible in the ways they communicate with the person and support him/her in doing things. The context for this is the introduction of the idea that persons living with dementia can and should be described in terms of their remaining strengths, a concept that will be worked on through an exercise.

A Word on Timing. Be keenly alert to going into the last part of this session with ample time. The session ends with a long element designed to teach participants about a staging system we employ in Savvy – and the main teaching method involves showing videos of four women who are living at various stages of their illnesses. The content is important, but the impact of seeing how the women manage the concrete task of making a ham-and-cheese sandwich can be considerable. So, you want to be sure that you have enough time both to cover the material and to help participants process it.

Home Activities Review. The session begins with a review of the home activities. Again, this is not meant to put pressure on the group to "get its work done." Rather, it's a coaching method to provide an opportunity to report back, be proud about trying things (whether successful or not), get feedback and clarification, ask questions, etc. It is also a time when the group should begin to see that the members are knowledgeable – that they are a resource to each other and have, through their experience, a lot of authority for speaking about the care of persons living with dementia. You can use this time at the beginning of each session to make an explicit link between learning new skills and knowledge and feeling good about one's self and one's caregiving.

As a way to stimulate participation, ask about each piece of the home activities:

- Participants were asked to read their manual on self-care, confusion, behavior, taking control, and validating communication. See if they have any comments or questions. They were also told they could read ahead on strengths and the staging system; if they begin to raise questions, point out they'll be covering this later in the session and have them hold off on them.

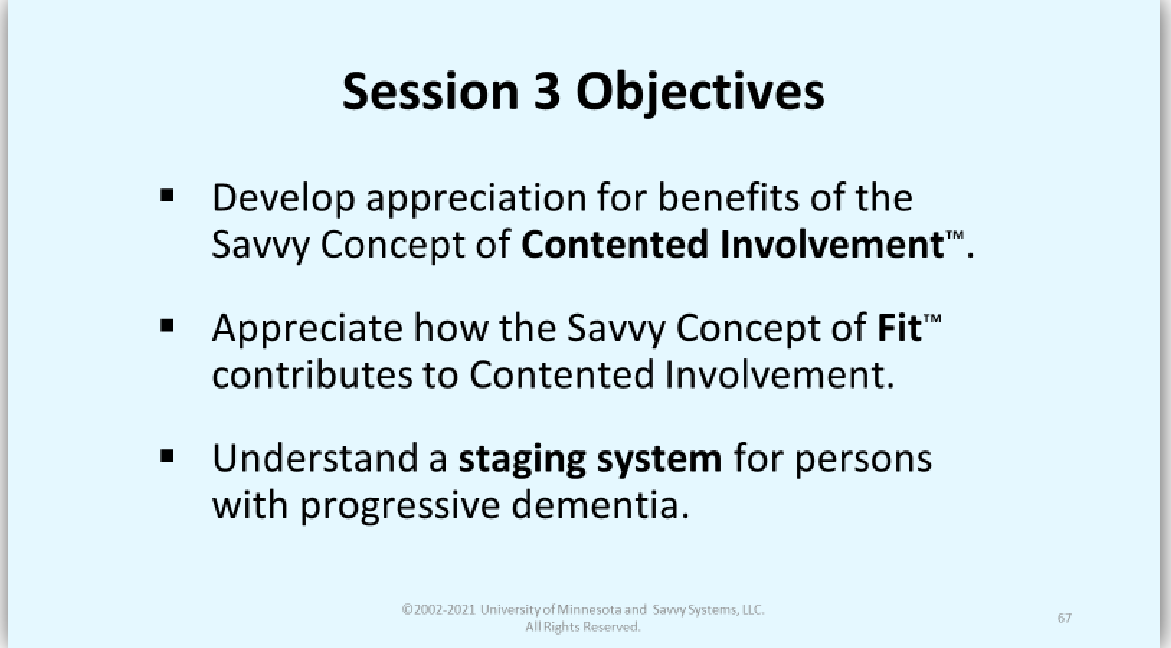
- Check on participants' experiences in caregiving. They were asked to observe for problems in thinking and to develop strategies for accommodating those problems.
- Ask them if they had a chance to examine a lower left-hand quadrant feeling. Did anyone work on a plan to move from that to another quadrant, either by taking some informed action or by consciously attempting to accept or let go?

Remember that the emphasis here is more on their developing skill with the tool than it is on talking about their feelings. Recall the point made in the introduction that this is a program about learning new skills and knowledge – and it is not a support group. Clearly, you don't want to squelch feelings or a discussion, but you do want to be aware whether the emphasis and meaning of the group has shifted and you want to be able to bring the group back to its basic work.

Contented Involvement

At this point, introduce the learning objectives for the session. This offers a transition from the debriefing and coaching portion of the session to that focused on new content.

Contented Involvement. Attention now turns to a basic concept for caregiving, one linked to the core principle that personhood persists throughout the illness. The concept provides caregivers with a goal that can be applied in virtually all caregiving situations. Contented Involvement asserts that the basic human capacity for engagement remains for a person living with dementia, but the caregiving challenge is to find an engaging activity that is a good fit with the person's remaining strengths. A person living with a dementia-related illness can be content and involved in a car ride, looking through a photo album, or peeling carrots. S/he can also be enjoyably involved getting dressed in the morning, having lunch, or taking a bath. You might ask the participants to think back to how they were feeling during the confusion exercise in the last session; that's a good example of *not* being contentedly involved. The concept is also useful because caregivers can use it to monitor almost any caregiving situation. They can use the concept as a yardstick to judge how well an activity is going, or to look back and assess how the day went. This is a useful analytic technique, but it requires that the caregiver be able to stand back from the situation to see what's happening and how it's going – and this is exactly the outlook the program is trying to strengthen.



Session 3 Objectives

- Develop appreciation for benefits of the Savvy Concept of **Contented Involvement**™.
- Appreciate how the Savvy Concept of **Fit**™ contributes to Contented Involvement.
- Understand a **staging system** for persons with progressive dementia.

The exercise that begins this section and the brief talk that follows have a couple of straightforward objectives. As a result of taking part in this exercise and hearing the talk, the caregivers should:

- Be sensitive to and have an intuitive grasp of the idea of "Contented Involvement."
- Appreciate that persons living with dementia can be engaged at times throughout the day in activities that result in "Contented Involvement." Helping them to be in this state is a reasonable goal of caregiving.

Exercise. The first part of the exercise involves another guided image. The two slides that follow the exercise lead you through the debriefing and summarize the key points of the lesson. This is another time when it's important to get the participants "in the mood" for the exercise. You can reassure your group that this exercise is comforting and pleasant (as opposed to the Confusion exercise).

Have them take a deep breath, place feet flat on the floor, and close their eyes (or look downward)[8] for this guided image. Follow the same procedure as with the guided image in the earlier section on confusion. Have participants relax – and give them a moment to get calm. Take your time as you read each step of the guided imagery. This type of visualization about one's "happy place" should be soothing and meaningful.

Walk through the steps of the image slowly and let people get into it:

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[8] This technique of focusing, deep breathing, and just letting oneself go with the flow of something is one that participants might be able to use at home to relieve stress. You can ask participants how they feel in their bodies at the end of the exercise. Are their shoulders relaxed, their breathing deeper? Do they feel less tight? This kind of breathing can be a form of self-care.

- Imagine you’re in a favorite outdoor setting; you could be by yourself – or with one or more people who are special to you.
- Imagine it’s your favorite time of the year and that the weather is what you consider ideal (perhaps sunny with a light breeze).
- You hear only the sounds of the setting you’re in – there’s no other outside noise.
- It seems as though you have the place all to yourself.
- You have all the time in the world.
- There are no pressing demands.
- You are doing something you really enjoy.

Let the participants bask in this image. Give them a few moments to really savor their images. Then, conduct a two-part debriefing.

1. Have people talk about what it felt like to be in the image – take notes on a flipchart or whiteboard – and summarize using the slide below. Be sure to get from them whether they liked/enjoyed the scene.

   You can use the slide below to summarize the first part of the debriefing. Participants may come up with additional concepts and other ways to describe the overall feeling. If they come up with a particularly compelling phrase for renaming “enjoyable doing,” feel free to use it – but link it with “Contented Involvement” as much as possible, because that’s the term we’ll use throughout the program.

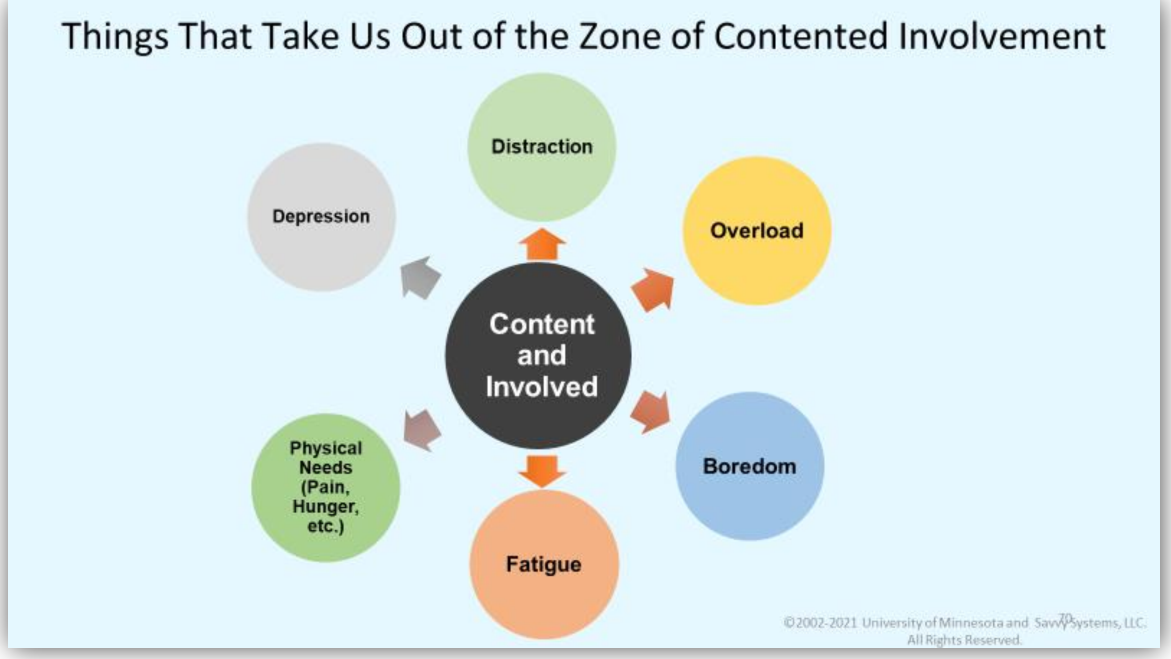
Content and Involved

- Without distress
- Sense of ease
- Pleasant
- Within one’s limits and abilities – not a stretch or effort
- Familiar
- Makes sense
- Fits with who you are
- Engaged
- Zeroed in
- Attentive
- Focused
- Using one’s available skills
- Busy
- Concentrated

Some examples of Contented Involvement might include leisure activities or sports (a runner’s high), fixing a special meal, special times with friends, being involved in a hobby or favorite pastime (doing a jigsaw puzzle, playing cards), or even those parts of work that are particularly challenging or enjoyable. Record all the things participants identify with Contented Involvement, such as the ways participants described their experience of Contented Involvement. Some phrases that might come up include "being in the zone" or "being zeroed in" or just "being tuned into something."

2. Ask them, while dwelling on these pleasant activities, to **identify things that take them *out of the zone* of Contented Involvement**.

Some examples of things that take us out of the zone are included in the slide below.



Things That Take Us Out of the Zone of Contented Involvement

Content and Involved

Distraction

Overload

Boredom

Fatigue

Physical Needs (Pain, Hunger, etc.)

Depression

The exercise takes participants to the point of your summarizing the experience in terms of the concept of Contented Involvement.

A Brief Talk about Contented Involvement. You now want to link the parts of this exercise to caregiving. The slide below provides a conceptual map or diagram for what the participants have been describing. The notion of Contented Involvement provides a target for caregiving.

The point that is relevant for the care of persons living with Alzheimer's Disease or related dementias is that the farther they get from the central zone, the more likely that an uncomfortable or undesirable behavior will occur. Such behavior will involve either some form of eruption or catastrophic reaction[*]– or some form of pulling away and into the self. Caregivers are often as disturbed or frustrated by their person's apparent apathy as they are by outbursts. Both are troubling to the caregiver and to the person.

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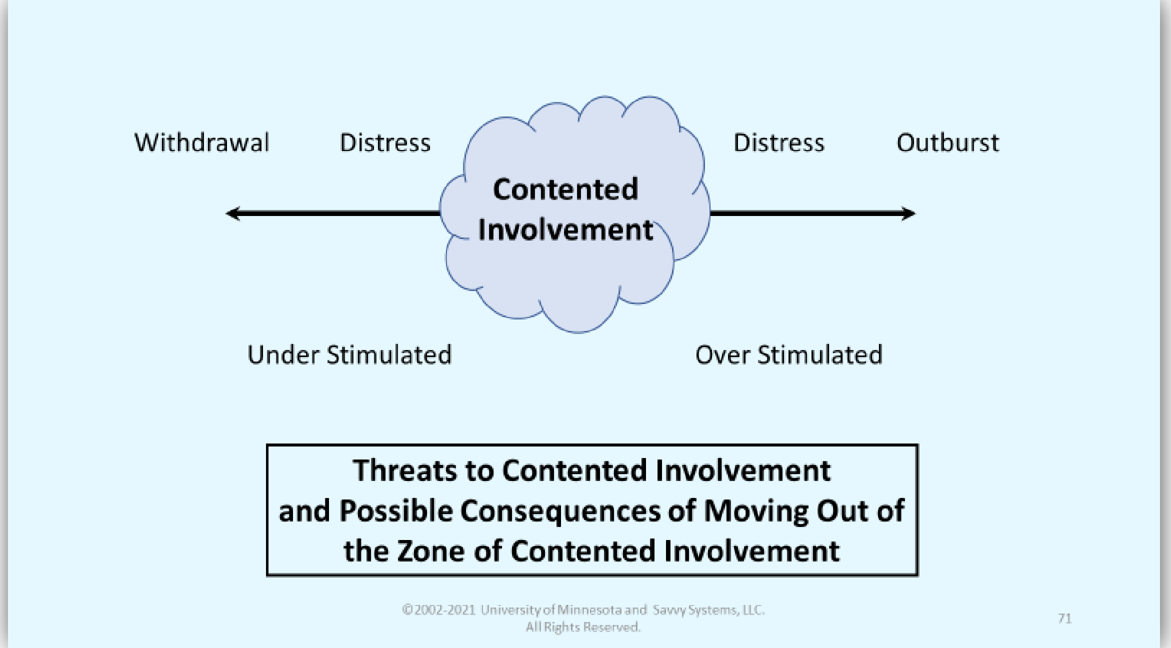
[*] The term "Catastrophic Reaction" is used importantly in the work of Drs. Geri Hall and Kathleen Buckwalter from the University of Iowa's School of Nursing in their work on thinking about and intervening with Alzheimer's disease behaviors in terms of a Progressively Lowered Stress Threshold. Material about this is presented in a later session and in the Caregiver's Manual.



Withdrawal Distress

Contented Involvement

Distress Outburst

Under Stimulated

Over Stimulated

Threats to Contented Involvement and Possible Consequences of Moving Out of the Zone of Contented Involvement

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It is important that caregivers recognize that physical discomfort of all kinds– including fatigue, hunger, the need to void, as well as pain– are all very distracting for the person living with dementia. Moreover, as the illness progresses, it gets harder for the person to recognize and report the source or experience of discomfort. Imagine trying to concentrate on the class if you have a toothache. So, one of the things we need to remember is to be constantly alert to the possibility of pain of one sort or another – including psychological pain. For example, a randomly recalled painful memory (like a combat memory for a veteran or the memory of an accident) may well be experienced as a present-time event rather than something that took place in the past. Even as we work at adjusting the tasks to fit the person, that work can be defeated if the person doesn't feel rested or well – so those factors have to be considered.

This is the first time that participants will have seen this "cloud" figure. We want the participants to spend time absorbing this figure since it plays an important part in the rest of training. Here are some points:

- Contented Involvement is at the center, which you've just gone over. It is the target of our work.
- Two "enemies" of Contented Involvement are over- and understimulation. The freeway image (Session 2) is a good example of overstimulation. A good example of understimulation is what they would feel like if we asked each of them to sit alone in a room for 2 to 3 hours and read manuals about a topic they're not interested in.
- At some point, when a person is over- or understimulated, they typically begin to experience some form of distress or discomfort. This gets worse as the person becomes increasingly over- or understimulated.
- Withdrawal and/or Catastrophic Reactions. Especially with the more explosive and potentially violent catastrophic reaction, everyone involved will feel a lot of discomfort – and it takes a lot of work to bring the person back to focus afterwards. Therefore, it is an important caregiving principle to try to prevent such reactions from happening. It is also important to point out that as a dementia-related disease progresses, these reactions happen more suddenly and with less warning. People's tolerance to over- or

under-stimulation is reduced as the illness progresses. Their ability to recognize that their limit is being reached is reduced, and their ability to self-direct away from a reaction is also reduced. Catastrophic reaction is what it sounds like – an eruption or outburst that is extreme and/or intense. Such reactions are frequently sudden in onset, and caregivers often report they seem to come "out of the blue."

- Withdrawal is what we think of when we think of people who are zoned out and sitting in a corner. It's different from gazing pleasantly out a window, taking time out, or having some down time. Those are actually forms of Contented Involvement. Withdrawal is frustrating for caregivers who sense their person is missing out and not enjoying a good quality of life.

The Savvy Caregiver Concept of "Fit"

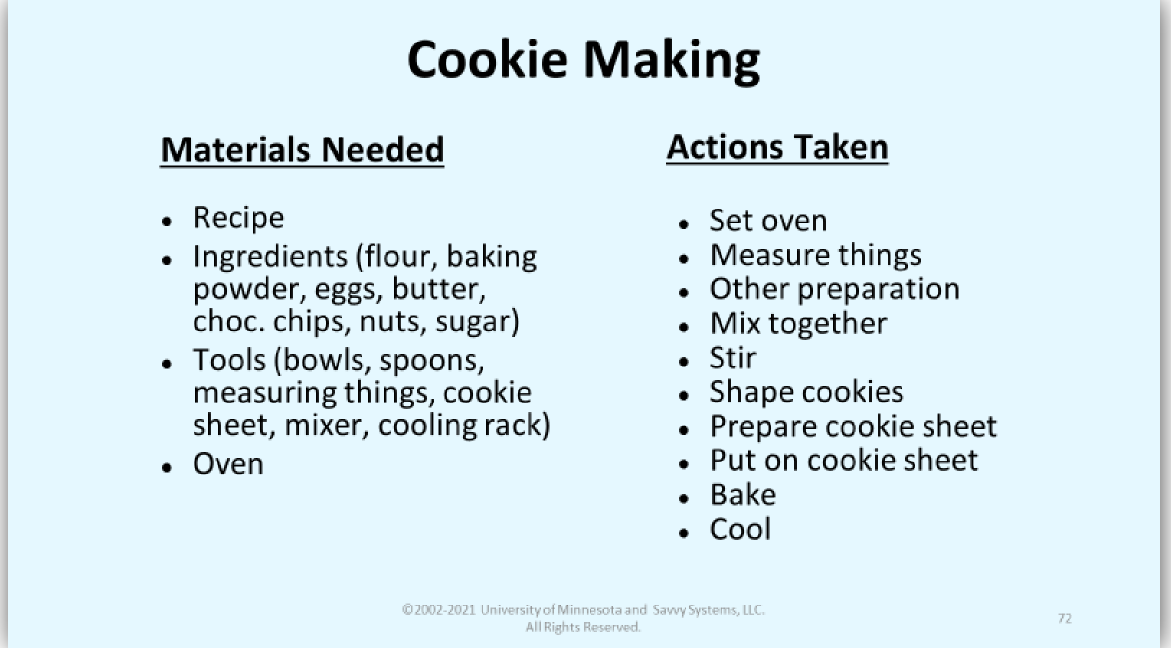
"Fit." Fit is another central idea in caregiving. It has to do with creating and maintaining a situation of Contented Involvement by establishing a match between task and ability. The Savvy caregiver works to find a fit between their person's remaining strengths or abilities and the tasks and activities the caregiver sets out for the person. Achieving Fit is a key step in helping someone to zero in on a task and to remain focused on it. The exercise that follows is meant to help participants recognize that they already know what fit means.

The Cookie-Making Exercise in this session also anticipates material you will cover in Session 4. In this exercise, you will be showing caregivers that they already know – and have an intuitive sense for – how to fit tasks to abilities. You will be illustrating how their sense of fit leads them to specific planning decisions. The exercise demonstrates that they make decisions about structuring each child's activity and how to communicate with each child and support him/her throughout the task.

What you want to have happen as a result of this exercise is that:

- Caregivers will recognize that they have an intuitive grasp of the notion of fit or match.
- They will demonstrate that they can put this grasp of the notion into effect in the exercise.
- They will appreciate that fit relates to Contented Involvement and Savvy caregiving – that if they could fit tasks to their person's ability, it would help to keep the person doing things and being content in the process.
- They will understand that knowing how to fit task to ability will also mean knowing how to set the task up and how to guide the person through it.
- They will also appreciate that there is a relationship between fit and feeling success in caregiving (and not feeling frustration).

The Cookie-Making Exercise. Imagine you have volunteered to take care of your neighbor's children – aged 5, 11, and 14 – and you've decided that making chocolate chip cookies will be an appropriate activity for them. As the slide indicates, you have all of the materials you need, and you are pretty clear about the steps that go into making cookies.
The group's task is to organize the cookie making so that the children all get to do as much as they can, that they all have as good a time as possible, and that no harm comes to anyone, especially the young ones.



Cookie Making

Materials Needed

- Recipe
- Ingredients (flour, baking powder, eggs, butter, choc. chips, nuts, sugar)
- Tools (bowls, spoons, measuring things, cookie sheet, mixer, cooling rack)
- Oven

Actions Taken

- Set oven
- Measure things
- Other preparation
- Mix together
- Stir
- Shape cookies
- Prepare cookie sheet
- Put on cookie sheet
- Bake
- Cool

- First, ask them to surface their concerns: what will they be worried about. These might include that the big kids will be bored and drift off; that the little kids will be pushed aside and feel hurt or bored; that the kids will fight among themselves; that they'll get burned or blow up the house; that they'll eat the dough and not cook the cookies. The least important concern will be that the cookies won't be particularly good.

- Next, have them decide which tasks they will assign to which child or group of children. For example, the oldest might do all of the measuring, light the oven, and supervise the two youngest. The 5-year-old might be assigned to spoon the dough onto the cookie sheet and to put margarine on the sheet.
- Have them say – briefly – why they make each assignment.
- Next, have them describe how they will set up the task for each kid. How much help will they provide (e.g., in getting things out or in hands-on help) and what kinds of directions they will give (for example, they might just hand the cookbook to the 14 year-old and ask him/her to get everything ready; they might ask the 11 year old to do the measuring and pouring and help the 5-year old to do the stirring and mixing; they might ask the 5 year old to use a measuring spoon to scoop dough onto the cookie sheet. Their directions to each kid would likely be more or less sophisticated, depending on the age of the child, and with the younger children, they might use visual cues and demonstrations more than with the older ones.
- At the end, ask them to say how they would know that they had done a good job as an adult in this situation.

The key teaching points are that the group i*ntuitively* will be able to:

- Name a set of "caregiving" concerns that they bring to the situation.

- Establish generally appropriate involvements for each child – and be able to link these to a rationale that is based on their grasp of each child's abilities (not losses, but strengths).
- Recognize that each kid could get involved in this task and that each could have a good time.
- Recognize, especially, that *fit was the thing that promoted both enjoyment and safety (and that misfit can produce very bad results)*.
- Recognize what it will mean (feel like) to have done a good job caring for this group of kids.

Behavior, Contented Involvement, Fit, and Savvy Caregiving. At this point, briefly review the points in the previous exercises and talks about Behavior, Contented Involvement, and Fit. In particular, you can make the point that the participants have all demonstrated, in the exercises, that they have a good intuitive grasp of the idea of Contented Involvement – and its opposite, the distress produced by confusion – and fit. The key points of this mini talk are:

✓ Confusion can produce discomfort, even extreme discomfort leading to an outburst (you might have wanted to punch the chatty passenger in the car exercise).

✓ Confusion is a major problem produced by illnesses like Alzheimer's, and the savvy caregiver wants to keep confusion as far away from the person as possible.

✓ Contented Involvement is something we all relate to – and it is something that remains available to persons living with dementia, even far into the disease (they will have all seen their person involved in some task or activity in which s/he was zeroed in and having a good time; and you can assert for them that this kind of involvement and enjoyment remains possible even much farther into the disease than they now experience).

✓ When tasks are fitted to abilities – as in the exercise – Contented Involvement is promoted, and confusion is prevented.

✓ When fit is applied well, the caregiver feels a sense of satisfaction or success and does not become frustrated.

The punch line of this brief talk should be that caregivers are saying, in effect, "well that's great, but how do I know how to fit things for my person?" This is the lead-in to the next part of the session, this week's home activities, and next week's session.

Effects of Dementia on Everyday Life

This is another turning point in the training. At this point, the caregivers have a lot of information:

- They have much more knowledge about the effect of dementia disorders on thought, behavior, and emotions.
- They have a central image – Confusion – to understand the situation and what's happening to the person
- They have been instructed and coached to stand back and analyze and assess their caregiving situations.
- They have learned the key concept – Contented Involvement – that provides a target for their caregiving plans and strategies.
- They have an intuitive capacity – establishing Fit – that suggests an overall caregiving strategy (match task to ability).

There are two more pieces of the puzzle left:

1. How does the caregiver know what his/her person's abilities are?
2. How, in practical terms, can the caregiver use that information (about ability level) to create and maintain a good (and enjoyably involving) fit with a task?

Performance and Staging

Performance and Staging. The rest of today's session deals with the first question. In this portion of the session, you will be teaching participants a way to think about **the stages of progressive** dementia illnesses, like Alzheimer's, and the varying effects of the disease on the person's ability to do things in everyday life. This staging system we use is grounded in an occupational therapy-based approach for thinking about losses caused by the illness but also about the person's remaining strengths for doing things. As you will cover in Session 4, the stages also provide ways for fitting tasks to abilities and for developing caregiving strategies that help the person to use their remaining abilities to be contentedly involved in everyday activities and tasks.

There are a variety of ways that have been developed to describe the progression of dementia illnesses. We use a simple **4-stage staging system: Early/ Early-Middle/Late-Middle/ Late**. We divide the middle stage into two parts in recognition of the fact that that stage is likely the one in which the great majority of community-based care occurs, and it typically occupies a very long period of time (perhaps 2-10 years, or more). During this stage, the illnesses produce substantial changes in capacity in persons living with them. So, it is important for caregivers to understand that real change is occurring, and giving name to these changes in the form of two stages is one way to help the caregiver frame his/her assessment of the person's capacity.

The main point of presenting participants with this staging system is to give them a kind of "yardstick" against which to measure the status of their person's thought and behavior. The point is <u>not</u> for the program to offer an assessment of where people might be in the stages – that is an activity that should only be undertaken by a trained professional. Rather, by the end of Session 4 (if not by the end of this Session), caregivers should have formed a reasonable estimate – <u>a ballpark estimate</u> – of where their person falls on this broad continuum of decline that we are providing. This estimate can help them as a starting point in the kind of task and activity design strategies that are described in Session 4.

As they work with these strategies and with their person, they will gradually find what works for them, and the issue of stages will recede to the background.

A Glimpse into the Future

A second important point about providing a system for staging the disease is that – hard as this may be for many participants – this will give a glimpse of the future, and how the disease can progress. It is sometimes the case that caregivers, especially those whose persons are in the early stages of the disease, can be upset by seeing the videos you will be showing in this session of persons in later stages of the disease, and you will need to prepare them for this. However, it is also critical that caregivers recognize that, as the disease progresses, the strategies they have developed for engaging their persons in tasks and activities that are pleasant will begin to need adjustment because the disease will continue to erode or decrease the person's abilities. Understanding how strategies change as stages progress can help caregivers provide increased structure and support more seamlessly over time.

This section starts with an exercise meant to help get participants thinking about what goes into "doing things." The exercise introduces participants to the notion of ***performance*** and alerts them to the three main elements involved in performance (purpose, order, and appropriate use). This introduction makes participants aware of how performance capacity erodes in stages, but that there is no clear line indicating that a particular element is now lost. The elements of performance are lost in sequence as the dementia illness progresses, but the loss is a slow, gradual process. In time, an element, such as Purpose, will appear to be lost altogether. Nonetheless, up to that time, it will come and go, be dim or bright and then just gradually disappear. These losses can be tracked on the staging system you will teach them, but the stages will have this same quality of merging into one another without a clear demarcation between them.

After the exercise, you will introduce the idea of staging systems for dementia illnesses. This, in turn, leads to a longer discussion of the staging system.

Exercise. This exercise involves participants in solving a puzzle. Tell the participants that they are standing on one side of a river and that they have the following objects:

- A chicken
- A fox
- A bag of grain
- A rowboat and oars

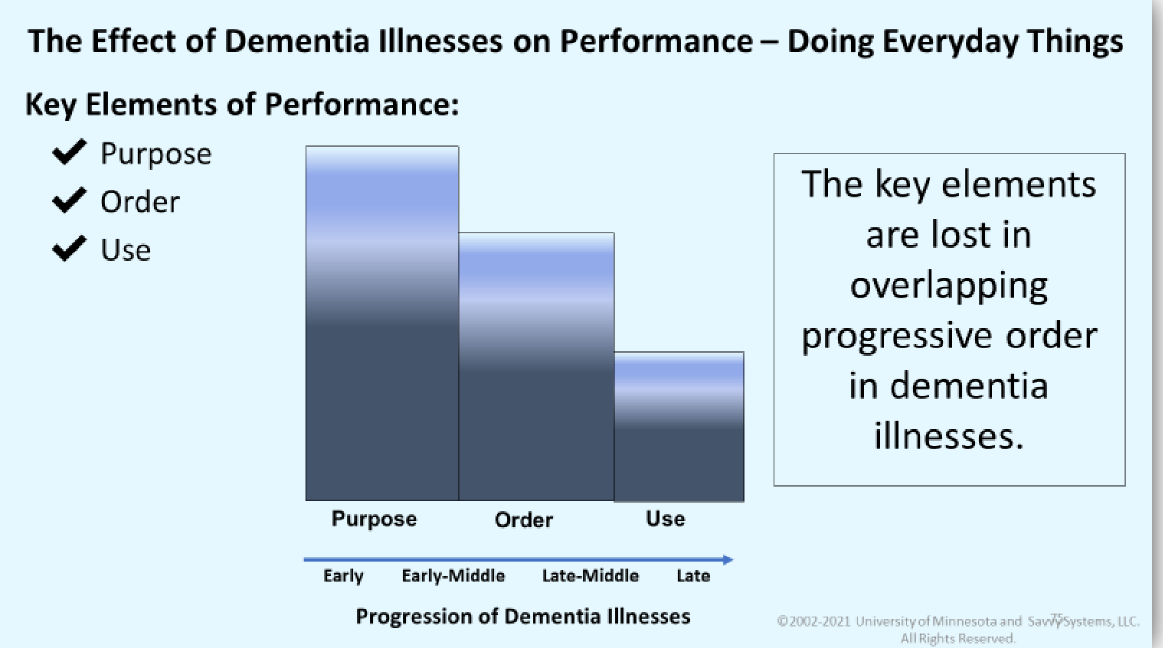
Their task is to get the chicken, fox, and grain safely and intact to the other side of the river, and the rules are:

- They can only take one thing across at a time.
- They can't leave the chicken alone with the fox or the fox will eat her.
- They can't leave the chicken alone with the grain, or she will eat it.

Ask the group to work on solving the puzzle – and ask that anyone who knows the answer not to share it!

Key Elements of Performance

Key Elements of Performance. The lead-in to the stage material is a very brief discussion of performance – doing things. All you want to accomplish here is to introduce the idea that doing things has some key elements and that the participants already know what these are. You are simply trying to make these elements explicit for them. This idea will come into practical use later in this session – and in the next session as well. But for now, all you want to do is introduce it and tell participants they'll use it later. You can use the group's experience with solving puzzles – or with organizing even simple tasks – to get at the three basic parts of performance (see slide below).



The Effect of Dementia Illnesses on Performance – Doing Everyday Things

Key Elements of Performance:

- ✓ Purpose
- ✓ Order
- ✓ Use

The key elements are lost in overlapping progressive order in dementia illnesses.

Purpose. The key to solving a puzzle is knowing and keeping an end point, goal, or purpose in mind. That helps to form and monitor the plan the person follows to accomplish the task – to perform successfully. If the purpose of the task (in this case the puzzle, but in daily life it might be "getting dressed" or "getting the mail" or "taking a shower") is lost, the task will not be completed independently. If a person cannot keep the purpose of what s/he is doing in mind, s/he will not be able to complete the task – ***without help***.

Order. Next, point out that there is an order in which things have to proceed to reach the desired end point (to achieve the purpose). In some activities, there may be multiple ways to reach the end (for example, there are two ways to solve the puzzle). In other activities, there may be only one correct sequence. The point is that there are correct ways; you don't get to a desired end point through random activity. [Note that the chicken or grain are eaten most of the time if a random order is followed.] Thus, getting dressed requires that garments are put on in a certain order; there can be variations, but the undergarments have to go on before the outer garments. Taking a shower, for example, requires several linked sequences involving undressing, adjusting water temperature, washing completely, drying, and redressing. This is an important point about performance. A task is named one thing – showering – but that one thing may really be more usefully thought of as a series of tasks, each of which has its own order. Of course, the exact order of steps doesn't always matter. It doesn't matter which sock I put on first, but it's important to do them both before putting on my shoes.

Use. Finally, the person has to be able to use the tools and objects appropriately. The objects have to register for the person as what they are and what they are for. [Thus, in the puzzle, a person who couldn't recognize or use a rowboat won't be able even to begin the task.] A person who no longer understands what a shirt or towel is or what it's used for and who can no longer even recognize the object as a shirt or towel will very likely not be able to make any kind of appropriate or ***intentional*** use of the shirt or towel. With appropriate prompting, however, it is possible that over-learned behavior (like muscle memory) might kick in an enable a person to use the object appropriately. Thus, a person whose illness has severely eroded his/her sense of the use of things may, if s/he is given a warm wash cloth to hold and has his/her hand guided to the face, participate in a form of cleansing.

Make the point that these elements are lost gradually and in order in dementia-related illnesses: the capacity to retain the purpose of activities diminishes first and is gradually lost altogether. The ability to keep track of the order of things is retained longer, but it too eventually fades and is lost. Finally, the person eventually loses the sense of what things are and what to do with them. The staging system you'll present next can be thought of as a way to stage these gradual losses in the key elements of performance

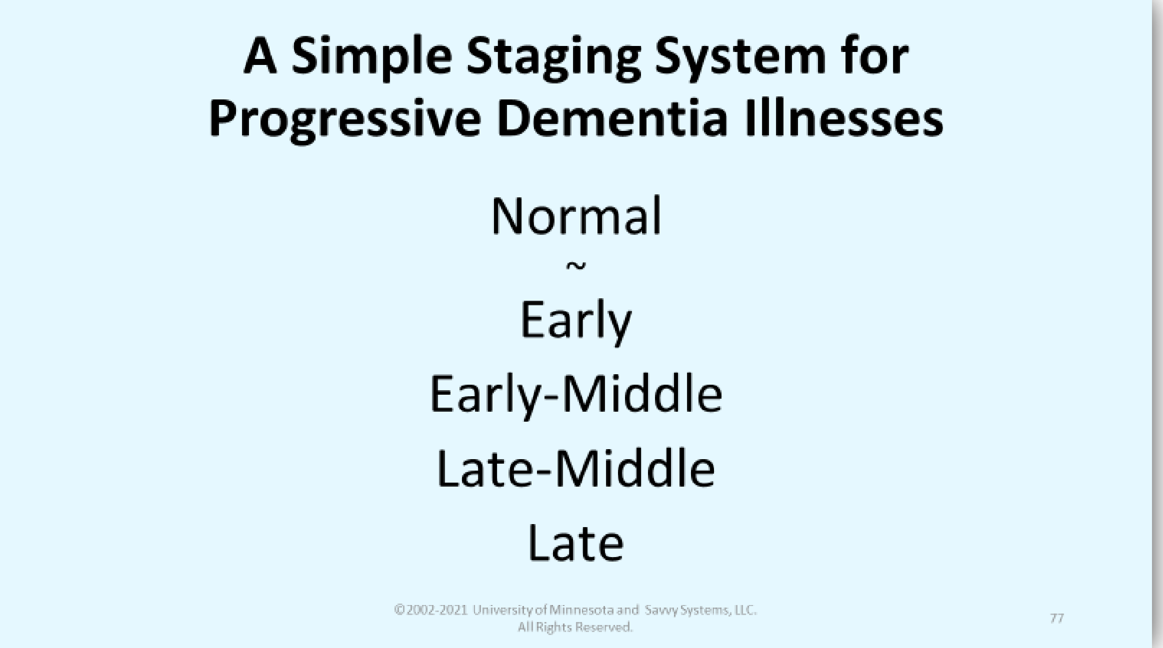
This information is useful in terms of the kinds of help and support that the caregiver has to provide. **To reiterate: as the illness progresses, the person loses capacity in the key elements of activity described above (Purpose, Order, and Use) in an overlapping and progressive manner.** The slide above portrays this concept. The way to read the slide is that the element or ability is intact until the shading begins. From that point until the column goes black, that particular element is fading. The elements are lost, roughly speaking, in order. The complexity and familiarity of a task also has an effect on how well a person will perform.

This slide above links the stages with the important elements of Performance. Thus, a person who is in the Late-Middle stage may perform relatively well if asked to put a shirt on. S/he will keep the task's goal in mind and will act in an orderly fashion and use the object effectively. And this may take only some prompting (e.g., a person who cannot bathe independently might begin washing up when handed a washcloth). That same person, if asked to leave the home to pick something up and then return may become confused by the task. With repeated prompts s/he may be able to do it, and s/he will likely know or feel that there is a goal or endpoint to what s/he's doing. S/he will keep parts of the order of the activity in mind but will likely need to be reminded of the larger order as s/he carries out the task. S/he will likely not have difficulty using objects or tools.

The sense of purpose <u>usually</u> fades out entirely somewhere in the Middle stage (Early-Middle to Late-Middle). The element of order fades more in the Late-Middle stage. And the appropriate use element fades in the Late stage. It is <u>particularly important</u> to emphasize that this is highly variable between individuals and also by the complexity and familiarity of whatever task you're asking a person to do. Also, the use and fading of these particular elements is on a continuum. This slide is only meant to give participants a broad sense of what they can expect from persons at various thinking levels.

A Staging System for Dementia

Stages of Progressive Dementia-Related Illnesses. This talk introduces caregivers to the system of staging that is used in the Savvy Caregiver program.[*] This system of stages relates to a person's ability to perform – that is, to do things in everyday life. It forms the basis for material on caregiving strategies that will be introduced in the next workshop session; that material will focus on linking the remaining abilities of a person with a progressive illness like Alzheimer's to the design of everyday tasks and activities that fit those abilities. The system describes persons both in terms observable losses and in terms of their remaining strengths and abilities. The orientation of this system is that it enables caregivers to use the stages as a way to fit a task or activity that is appropriate to the remaining abilities of the person. The material below provides caregivers with starting points for making the linkage between stage and task and activity design. It makes intuitive sense that we would use a system developed by Occupational Therapy, since that is a discipline whose very foundation is to figure out how to help people do things when they have lost capacity in some area of life.



A Simple Staging System for Progressive Dementia Illnesses

Normal
~
Early
Early-Middle
Late-Middle
Late

It is important to keep in mind as you proceed through the rest of the sessions that you and the caregivers are about to get into individual examples that may benefit from professional input. Your own knowledge of dementia illnesses, the caregivers' experience as caregivers, and the intuitive grasp they and you have of the concepts (strengths, fit, etc.) should enable the caregivers to acquire more of the skills and outlook of the savvy caregiver. However, questions of application will likely arise – "this and that is happening; now how do I get him to . . .?" Much of the time there is no clear-cut answer to questions like this. Experience,

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[*] The system is based on the work of Claudia Allen, an Occupational Therapist who worked with persons living with brain injuries and cognitive disorders, including those living with Alzheimer's or similar illnesses. You can find more information about the Allen levels at www.allencognitive.com.

a general grasp of the concepts of the workshop, and a caregiving outlook that allows the caregiver to engage in a trial and error process will often be the most helpful resources. Sometimes, however, situations will arise in which the opinion of an expert – consultation by an appropriate health care provider – will be essential. When these situations arise, urge caregivers to seek appropriate professional help. **Under no circumstances should you exceed the limits of your own experience and knowledge.**

Even if you're a physician, don't, for example, get in the situation in which you are suggesting particular medications – this is not the proper time or place. You may suspect, based on what the caregiver is saying, that the person living with a dementia illness is also depressed or is showing signs of acute distress stemming from a cause other than a dementia illness. You do well, in such circumstances, to use the leadership position to urge the caregiver to get the person to a doctor and to say what s/he thinks is happening. It would be clearly inappropriate to suggest that the caregiver ask the doctor for a particular drug for depression or to suggest that the person has a particular problem. The same is true with other specific caregiving problems. The group will help the caregiver develop knowledge and skills and should help with outlook. But many problems are beyond the scope of the group and, when you feel that you are hearing such problems, make a referral. For example:

- A Nurse can teach a caregiver how to administer medications or how to monitor any vital signs the physician wants to keep track of. S/he may also be able to provide more in-depth teaching on various topics related to dementia illnesses.

- An Occupational Therapist can provide an assessment of the person's performance capacity and suggest a more individualized plan for fitting remaining abilities to tasks. S/he can suggest devices and equipment to help the person continue to do things, and she can conduct an assessment of the home environment to see that it is safe and suggest ways to make it simpler and supportive of performance for the person.

Introduction to the Staging System. You will coordinate this talk with a showing of the sandwich-making videos. Most Savvy trainers will alternate between the descriptions of the stages with a showing of the videos. There is no slide for unaffected performance capacity in Normal functioning. That is just baseline – the way most of us perform most of the time. We are able to absorb and process information and access information from memory – and can use all of this to perform effectively in ordinary social life and in work and relationships.

There are a number of key teaching points that need to be made at this point:

- For purposes of functioning as a savvy caregiver, what's important is to think of the stages in terms of their being "ballpark" estimates. A trained occupational therapist, using multiple assessment techniques, could arrive at a more precise determination of capacity and stage. For most caregivers, a precise determination might be especially important if s/he felt uncertain about the working estimate at which s/he had arrived, but knowing more or less where the person is on the spectrum of performance will be enough to let the caregiver begin to develop effective strategies and to engage in the process of trying them out.

- The real value in having an estimate of the performance stage is that these tie in with concrete suggestions about fit. That is, knowing the performance stage allows the caregiver to begin to think tactically about how to set things up for and communicate with the person so that Contented Involvement – getting zeroed in on a task or activity – becomes a greater likelihood.

- Information about a person's stage of performance should not be interpreted rigidly. As we will go on to discuss and stress in the rest of the workshop, there are many factors that affect performance. Among the key factors that might affect performance are:

  - ✓ Size, complexity, and familiarity of task
  - ✓ Personal habits, history, and preferences
  - ✓ Other physical factors (how well the person feels; how rested; etc.) – the simple fact that we all have good days and bad days
  - ✓ Other factors in the environment
  - ✓ Other physical limitations the person may have

  Having a working estimate of the person's performance stage provides a guidepost for developing strategies of caregiving. This knowledge should help to narrow the range of choices for the caregiver and allow him/her to focus more specifically on the question of "how to" in caregiving. But knowing the level does not provide an automatic solution to the caregiving question; it just helps frame the question better.

- The stage describes capacity across the spectrum of doing. That is, in a dementia illness, particularly in Alzheimer's disease, a person is highly likely to exhibit the same kind of strengths and needs *across a very wide spectrum of activities that are of a* ***similar complexity***. The person is unlikely to function one way in one activity and very differently in another roughly similar activity (for example, need a great deal of help to feed him/herself, but dress in a completely independent manner) unless other limitations are present. This is important because it can help caregivers to understand that they can develop generalizable strategies for comparable tasks. On the other hand, the nature of the task – its complexity, in particular – may well affect performance, so that a person who can do an everyday task (like dressing or doing something in one place) without much help might need a great deal of help to perform a much more difficult task (like balancing a checkbook or engaging independently in an activity that requires moving from place to place).

  Sometimes caregivers don't recognize just how much help they are providing – it comes more or less naturally – so they may say that the person is independent in some realm but much more dependent in others. In these cases, it is useful to have the caregiver describe in great detail just what happens in the area of independence. Often, on examination, the caregiver is providing more help than s/he thought (and, sometimes, more than their person needs).

- As the dementia illness progresses, the capacity to do things declines. Because Alzheimer's and other similar progressive illnesses are long-term diseases, these changes will probably not occur rapidly. Most likely the caregiver will notice change only gradually – often as previously effective strategies start to become less effective. Sudden changes in thinking are not characteristic of dementia illnesses. Should these occur, they often signal some other physical problem – and the caregiver should confer with his/her health care provider.

The Teaching Videos. The videos used in this portion of the program shows four women diagnosed with dementia at different stages in the disease making a sandwich.[9] The teaching sequence is to give a brief talk on the stage that is being portrayed and then show the person in that stage doing the task. After each video, ask participants what they observed about the way the person did the tasks – and the way the Occupational Therapy assistant worked with the person. The sandwich making task is concrete, not abstract, likely to be familiar to the person, and all the materials needed for it are right in front of the person. The Occupational Therapy Assistant (OTA) who is guiding the persons through the task was following instructions regarding the way to work with these persons in these tasks. Because this video was made for training purposes, she was instructed not to be helpful so that the extent of the person's performance losses and strengths could best be on view. Emphasize that this is not normal practice (not a "how to" video), nor is it an example of how we think savvy caregiving should look. Rather, this is done here for teaching purposes, to illustrate where people at different levels can perform well and where they can get stuck. An activity would be done similarly for formal assessment purposes.

The main instruction was to ask the person (when she sees that the person has lost track of the task (i.e., forgotten the purpose) or is leaving something out or making a mistake): "Can you remember what I asked you to do?" You will notice that, as the people are in the later stages of the disease, this kind of prompt is not very helpful and may even be confusing or irritating to the person. In the third and fourth video, the OT assistant does go beyond this instruction and provides certain kinds of help. The use of short sentences, visual cues, and touch can be pointed out. This is also an opportunity to have participants say what they would have done differently from the OTA to provide guidance to the individuals and consider what a better fit would be for the activity. For instance, the woman in the 3rd video might be able to participate more if she were handed needed items in order. Similarly, the woman in the fourth video, might enjoy conversing while someone else made the sandwiches.

You might want to warn participants that the material they'll see in the videos will show what someone might come to look like (and perform like) in the later stages. This might be upsetting. The videos will be helpful in teaching about the stages, but they will also provide participants with a sense of the trajectory of the disease and what happens over time. This is also an opportunity to point out that each of the women, despite experiencing cognitive losses, retains strengths and personal qualities like vibrancy, humor, and a willingness to try. It can also be noted that they and their families generously agreed to participate in this so that future caregivers could benefit. Consider having tissues available; this segment can be intense.

Teaching About the Stages. Each stage is presented in terms of the effect of the disease on performance that will be visible in the person; this presentation typically covers what happens to the key elements of performance at each stage. Following the discussion of the effect of the disease, there is a section on caregiving concerns and strategies appropriate for each stage. This material will not be repeated here in the Trainer's Manual; rather, you can read through the Caregiver's Manual. In the sections that follow, commentary will be provided about the performance of the people in the four segments of the staging video – as well as about the way the OTA is working with them. General teaching points and slides will also be provided.

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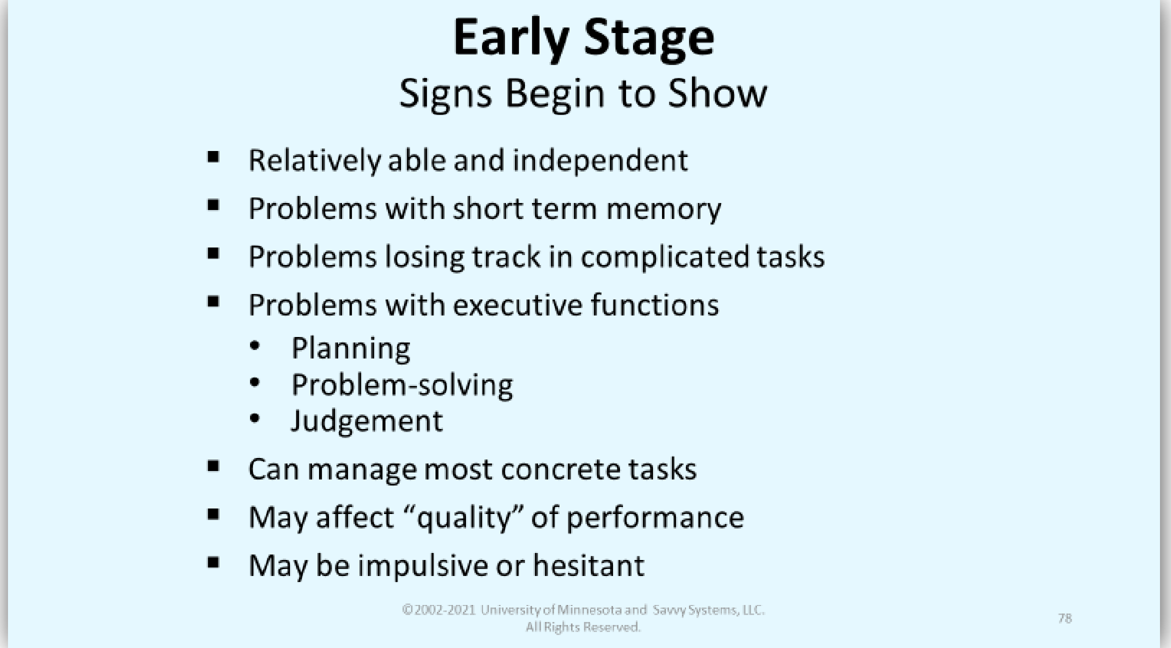
[9] The videos were filmed with the permission of the person (where possible) or her family for use in this educational purpose.

Early Stage

Early Stage: The First Signs Show. Use the slide below to outline the points you will want to make about a person in the Early Stage of a disease like Alzheimer's. Persons at this stage will be able to function independently in most areas of life. They will experience difficulty with complex tasks – tasks that require many steps and abstract thinking – for example, managing a checkbook or household finances. They may have to quit their jobs earlier than they had expected to because they can no longer handle the difficulties of the job.



Early Stage

Signs Begin to Show

- Relatively able and independent
- Problems with short term memory
- Problems losing track in complicated tasks
- Problems with executive functions
  - Planning
  - Problem-solving
  - Judgement
- Can manage most concrete tasks
- May affect "quality" of performance
- May be impulsive or hesitant

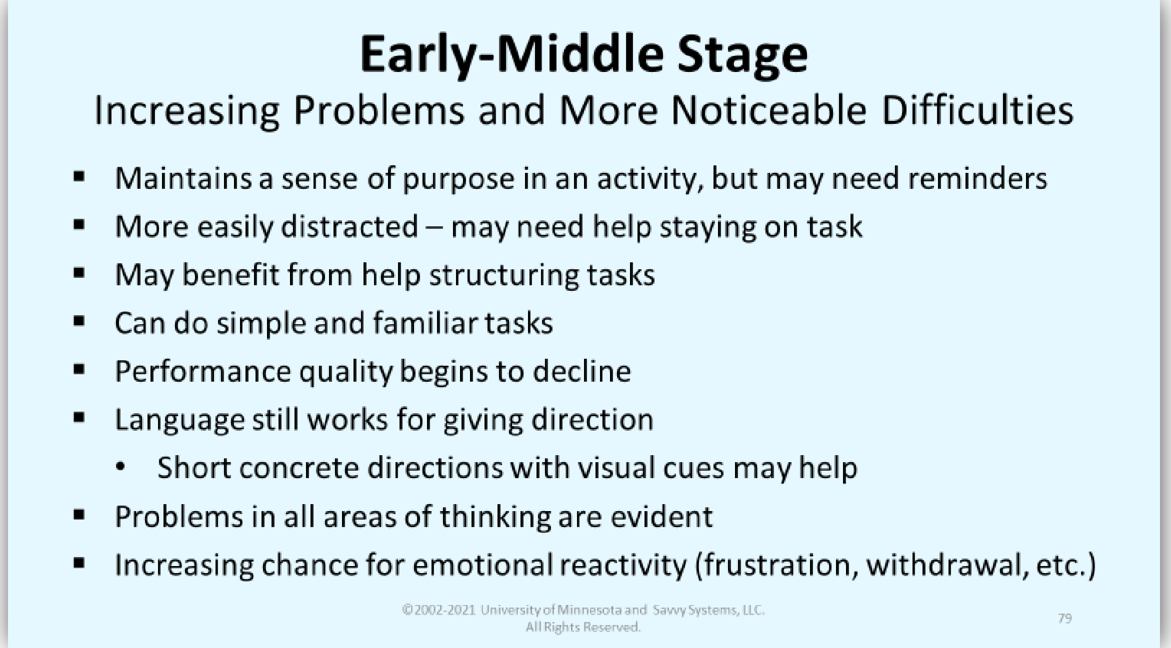
A person at this stage may appear to be functioning quite normally in a great many situations and might only show signs of a problem when under stress. People seem to vary a lot in terms of the amount of insight they have about having the disease. Some seem to understand there is a problem and are able to talk about it. Some become depressed – in fact, depression is quite common in the early stage of a dementia illness. Others might not be aware (insight, as a cognitive ability, may be diminished) – or might deny awareness.

Show the video of the first person making a sandwich. The person's performance in this task exemplifies Early stage performance.

The woman, Genny, can handle the task without difficulties – except for one possible minor bobble in memory She keeps a running conversation going while carrying out the plan she obviously made in her head to make the sandwich. It is useful to point out that, on two different occasions during the sandwich making, the person mentions her brothers and sisters. Note that each time she mentions them, the number of brothers and sisters changes. It is unclear if this is a mistake or if she is counting herself in one count but not in the other. So possibly some loss of cognitive functioning has taken place, yet she can proceed with the task in front of her with no apparent loss of effectiveness. From a caregiver's perspective, people at this stage can be pretty reliable with everyday tasks.

Early-Middle Stage

Early-Middle Stage: Increasing Problems and More Noticeable Difficulties. Depending on their own awareness of and sensitivity to their own condition, persons in the Early-Middle stage can become withdrawn unless encouraged to remain a part of things. They may show frustration at their own inabilities and take this out on themselves (putting down or making excuses for their own abilities), or on others. In other words, their lives may become more emotionally up and down. Again, depression is a frequent and serious problem – one that should be looked at by a medical expert since depression is treatable.



Early-Middle Stage

Increasing Problems and More Noticeable Difficulties

- Maintains a sense of purpose in an activity, but may need reminders
- More easily distracted – may need help staying on task
- May benefit from help structuring tasks
- Can do simple and familiar tasks
- Performance quality begins to decline
- Language still works for giving direction
  - Short concrete directions with visual cues may help
- Problems in all areas of thinking are evident
- Increasing chance for emotional reactivity (frustration, withdrawal, etc.)

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In terms of performance, individuals will still be able to relate to a sense of purpose and will be able to set up and follow straightforward sequences, especially in everyday and routine tasks. They'll be ok with using things correctly – though, since judgment is more impaired, they need to be watched more closely when safety is an issue with use. Written information may become less useful at this stage, though verbal information should still be effective; this will not be the case in certain dementias, especially in Primary Progressive Aphasia. Even now, though, the Savvy Caregiver should be simplifying verbal expression and beginning to use visual cues more. Performance difficulties may be more apparent in more complex and sophisticated tasks

Ida Mae, the person in the second set of videos, is in the Early-Middle stage of the disease. People at this stage are still relatively independent – they certainly can take care of all their own needs (dressing, eating, etc.) unless some other physical problem is present. They will make more errors and will need more prompting and reminders.

The key things to point out:

- The trouble she has opening the jar does not appear to be related to the dementia illness, but rather a problem she has with her hands. In this regard, it is important to remind participants that dementia illnesses do not protect against other health problems; in fact, other problems can make the problems of living with a dementia illness worse. She does, however, start talking around what the issue is ("I wasn't sure if I was supposed to open it"), which is not uncommon as people living with dementia illnesses are working to make sense of what is happening.

- She gets involved in opening the package of ham and seems to lose track of the purpose of the sandwich-making activity. The OTA has to prompt her to put the cheese on the sandwich.

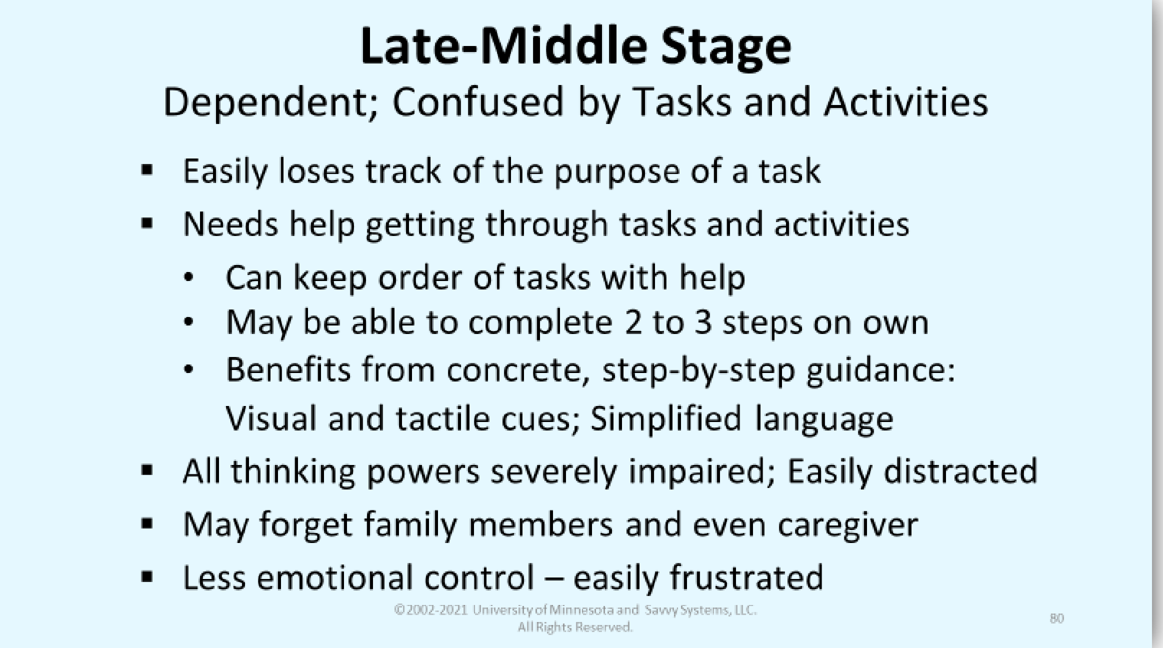
- She has an unusual way of putting mayonnaise and mustard on, but we don't know if, in fact, this is how she has always done it.

- As with the first person, she is able to keep up a certain amount of verbal interaction without getting too confused. She may be a bit impetuous – leaping into action before fully absorbing the directions.

- She seems to be having a good time in both activities.

Late-Middle Stage

Late-Middle Stage: Dependent; Confused by Tasks and Activities. Again, use the material in the Caregiver's Manual to describe this stage; the slide below highlights the issues associated with this stage. Use the slide to make the key points about persons functioning in the Late-Middle stage and to highlight the key points you will want to make about the functioning of persons at the Late-Middle stage of the disease.



Late-Middle Stage

Dependent; Confused by Tasks and Activities

- Easily loses track of the purpose of a task
- Needs help getting through tasks and activities
  - Can keep order of tasks with help
  - May be able to complete 2 to 3 steps on own
  - Benefits from concrete, step-by-step guidance: Visual and tactile cues; Simplified language
- All thinking powers severely impaired; Easily distracted
- May forget family members and even caregiver
- Less emotional control – easily frustrated

From a caregiver strategy perspective, it's helpful to note that, as the person moves into this stage of the illness, communication is shifting much more from words to sight and touch. Note, too, that one of the key elements of performance – purpose – is much less dependable at this stage and will likely be gone altogether as the stage progresses.

Point out the implications of this stage for care. The person will need help of some kind with just about everything, including activities of daily living and all other activities. The caregiver will not have to do everything (it's not total care), by any means, but s/he will have to be much more available.

It is very important to note that it is at this stage that caregivers may feel particularly inclined to do things for their person rather than to help them to do what they can do for themselves. Reinforce the idea of trying to help the person do for him/herself as much as possible.

Show the third video.

Key talking points for the video:

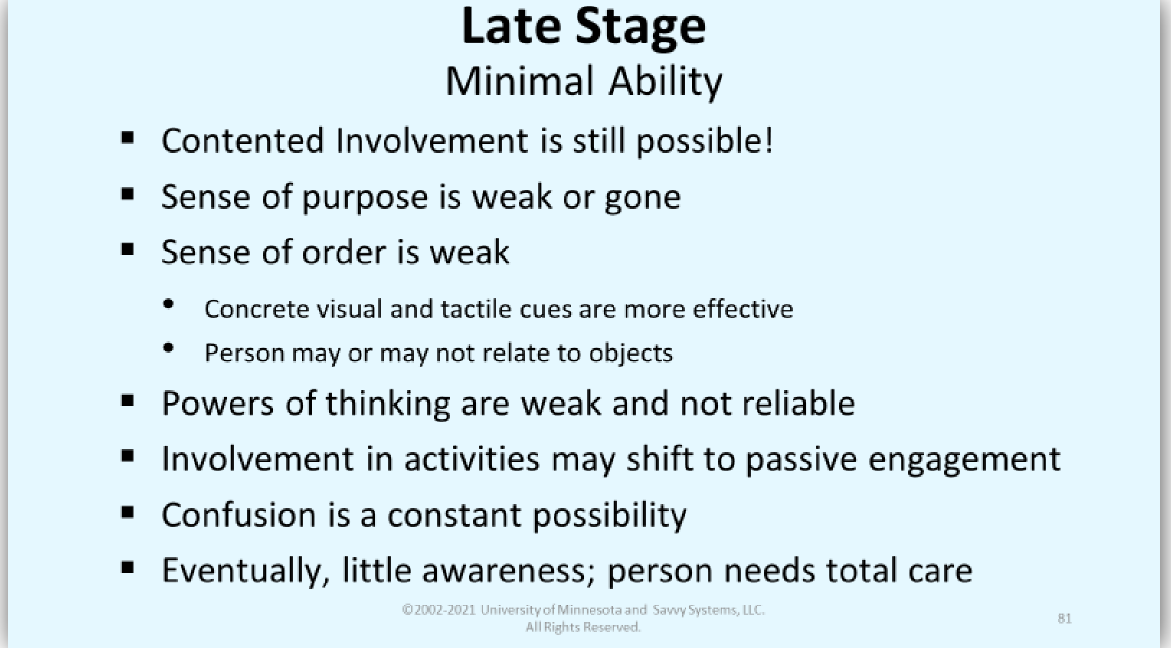
- The person, Libby, retains pretty good verbal skills. However, her performance is nowhere near as good as her speech.

- This kind of retained skill – in this case, a verbal skill – can be confusing for caregivers. They see the person doing so well in one area of function and have a hard time keeping in mind that this is a disease process that has a global effect.
- She's past the point of having much if any understanding of purpose in this action. She needs help to order the actions leading to making the sandwich. Note, for example, that she uses the table to slice the bread, rather than putting it on the plate. She does still use things relatively well.
- She gets stuck after she cuts the bread in half, having done the steps in the wrong order. Usually, cutting the sandwich is a final step, and she doesn't appear to know how to proceed from there.
- She seems confused by all the things in front of her. (Note: confounding items were deliberately placed on the table for the demonstration.)
- She appears frustrated and irritated
- She fixes on the lettuce and tries to do something with it; the OTA has to draw her back to the task and to pick up the ham.
- She seems stumped by the task, so the OTA puts the sliced bread together on the plate to create a cue for the next step (though she seems not to understand what the bread is). The OTA has to cue her to put the ham on the plate and then to put the cheese on the bread.
- The OTA completes the task for her by putting the second slice of bread on top
- She does seem to take pleasure in being praised for doing a good job of making the sandwich.
- Note how patient the OTA is with her throughout the task – she doesn't expect her to do any more than she does. Also, she adjusts what she does to her abilities.
- Because she doesn't expect her to perform above her stage-specific ability, the OTA seems able to remain warm and encouraging and to accept the person's functioning without any kind of blame or frustration.
- Note that the woman does get the job done (in some fashion) and has taken part throughout. It might be easy for her to feel some sense of failure or inadequacy, but the way the OTA is working with her allows her to do things. And even when she is being very directive, she's using a neutral or positive tone and never blames or scolds him. Again, at the end, there is delight in the praise.
- Discuss with participants what a better approach might be with her. Could she perform one step at a time with cues? What if all unneeded items were removed from the table?

Persons at this stage of the disease need more or less constant attention. This is full-time care. Many at this stage are in an organized help-providing setting.

Late Stage

Late Stage: Minimal Ability. Use the slide below to highlight the key points about functioning in the Late stage of a dementia illness.



Late Stage

Minimal Ability

- Contented Involvement is still possible!
- Sense of purpose is weak or gone
- Sense of order is weak
    - Concrete visual and tactile cues are more effective
    - Person may or may not relate to objects
- Powers of thinking are weak and not reliable
- Involvement in activities may shift to passive engagement
- Confusion is a constant possibility
- Eventually, little awareness; person needs total care

This is late into the disease; it is not impossible that someone in the group is caring at home for a person whose illness is this far advanced. It is important to make it clear that when persons reach this stage, caregivers will very likely not be able to care for them at home, at least not without a great deal of help. They may have to move to more of a full care facility. Persons at this stage and the next require almost complete care and are no longer capable of doing much for themselves except cooperate passively. However, it is important to emphasize that even passive participation can promote Contented Involvement.

As this stage progresses to more of an end-stage condition, persons would almost certainly be in a care center and would require round the clock total care. An appropriate care goal for persons at this Level is comfort – freedom, as much as possible, from pain and confusion. Persons at this Late-Late stage will likely not be able to communicate at all, so if there is anything wrong with them, it will probably go unnoticed until it is at a critical state. Thus, infections are seen only when they are very serious. Death from pneumonia – or other infections – is quite common.

Show the final segment of the video – the portion with Catherine – to illustrate the Late Stage of the disease.

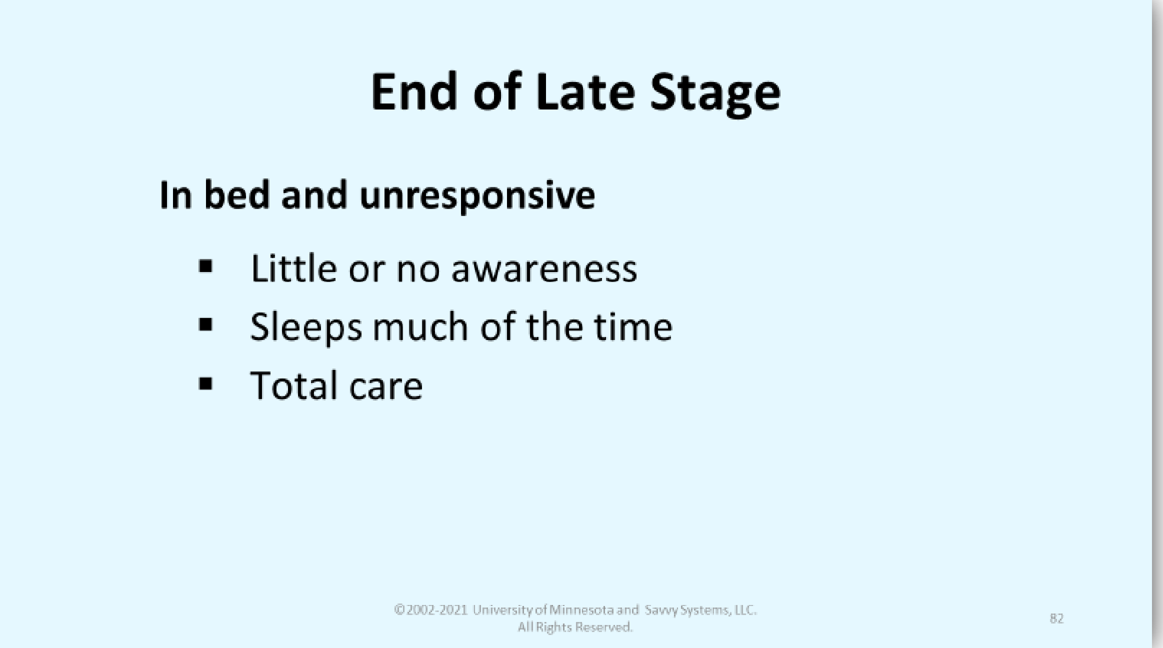
Some talking points about this segment:

- This person has a very expressive face, and the sense of distress and confusion are apparent in her face at a number of points in the video.

- She appears to enjoy being with the OTA and has a wonderful come-back to her ("Why don't you pick on that girl I was sitting next to . . .") that seems to represent some kind of understanding of the situation – and possibly of her own limitations. Regardless, it is one of those moments when pleasure appears to be experienced in an interaction, and where she demonstrates some strong remaining verbal skills. Catherine – the essential Catherine – is still very much present.
- She is very well dressed and groomed; this suggests that someone with good skills has helped her and that she was likely cooperative.
- In particular, her having manicured nails suggest that this is an activity in which she can be contentedly involved. If it were not, there would be no reason for someone to do it.
- Note that she doesn't seem to relate to the things in front of her and explores the objects by touching them.
- Catherine parrots the phrase "make a sandwich" repeatedly but without comprehension.
- When it's clear to the OTA that Catherine doesn't understand the task (make a sandwich), she, in effect, changes the task: "Can you get two pieces of bread?"
- When she cannot do that, the OTA gets the bread out for her, puts it on the plate, and uses it as a visual cue for her next request, "Can you put ham on the bread?"
- Note that Catherine's verbal response ("Yeah, I think so") isn't carried out in an action; the response is more of a reflex reaction to what is perceived as a question. It's a good example of an over-learned behavior masking the substantial losses that have occurred.
- Toward the end of the sandwich-making task, it appears Catherine is getting a bit upset or disturbed, though she does complete a portion of the task with continued direction.
- Another wonderful moment: Catherine's "Didn't I though" response to the OTA's saying she had done a good job with the sandwich making.

End of Late Stage

There is no video of a person in the Late-Late stage of the illness. The majority of persons living at this stage need to be in an institutional setting with round-the-clock care. It is possible that some of the caregivers in the group will be able to sustain this kind of care at home, but those will be rare cases. The person basically needs total care, but it is still important to emphasize that, even in this profoundly affected state, passive forms of Contented Involvement are still possible.



End of Late Stage

In bed and unresponsive

- Little or no awareness
- Sleeps much of the time
- Total care

Strengths. The brief section on strengths serves a number of purposes. **First, it gives the caregivers a concrete way to relate to the process in a dementia illness by which performance is less and less in the control of the person and relies increasingly on external factors.** The exercise below asks the caregivers to make relatively fine distinctions about the amount that the person can do for him/herself and the kinds and amount of support, direction, and direct assistance that the caregiver contributes to the successful completion of an activity. (Make sure to point out to the caregivers that “assistance” comes in at least three forms: planning (thinking through the task with/for the person and then leading him/her through it); supervision and direction or advice; and direct, hands-on help. Remind them how the person, others, and the surroundings influence behavior and performance.

Second, it presents the caregivers with the idea that persons living with dementia illnesses retain abilities throughout the disease. Their abilities are diminished – progressively – by the disease, but it is both possible and reasonable to describe persons living with dementia in terms of their remaining abilities. This is especially important because, as the workshop moves, in the next session, to using Structure and Support to keep the person Contentedly Involved, the caregivers should feel that these strategies are built on an appreciation for – and depend on – the person's remaining strengths. In that way they are not manipulative, but appreciative; that is, they are not forcing the person to do something, but setting things up so the person will be able to do something – and to derive enjoyment from doing it.

Third, the exercise reinforces the material on the stages to help caregivers consider, if only on an intuitive level, that there is a kind of order to the losses that occur (or the strengths that remain). It also allows them to see that the level of strength tends to be consistent across activities. This last point is particularly important and should be emphasized in the workshop at this point. It's important because a key message from the staging material should be that if they have an idea of where their person is in the disease, they should have a pretty good idea where to start in designing their structure and support strategies *for almost all tasks and activities*. You can suggest that understanding where their persons are with respect to stages and abilities allows them to take fuller advantage of being *with* and *for* them in a positive, effective way and to maximize opportunities for positive, peaceful shared time together for as long as possible.

Exercise on Strengths. This is an exercise in which the caregivers are asked to think about how their person does very complex and simple things – manage finances, handle travel, wash up in the morning, comb/brush hair, get to the bathroom, and eat. This exercise should help participants to grasp – in a way that emphasizes that the person retains abilities throughout the course of the disease – the way in which the responsibility for even these fundamental behaviors is already shifting to the caregiver.

Tasks and Activities Grid

The Tasks and Activities grid below gives participants a way to think globally about their person's performance in daily life. The grid is linked to the staging system that was just described.

Note that the Tasks and Activities Worksheet is in their handout packet.

Have the participants look at the grid while you point out the following:

- In the second column, general descriptions are provided regarding the overall level of capacity (strengths) that can be thought of in a person at that stage.
- In the third column, examples are provided of performance that caregivers might observe in their person at various stages in the progressive dementia-related illnesses.
- The examples in the Early stage include activities that call on more executive functions. These are complex activities, like managing finances. For the most part, the focus of the examples is on common self-care activities – eating, fixing hair, getting to the bathroom, and washing up in the morning and evening.

Now, ask them to reflect spontaneously on their person's performance in light of the descriptions provided: *Where does their person seem to fit?*

Have them take 2 to 3 minutes to look at and make notes on the Tasks and Activities Worksheet.

This exercise links with watching the videos in the workshop. It is useful for participants to “get a feel” for the stages and to estimate into which stage their person falls. People may say that their person looks like one stage in one activity and another stage in another activity (e.g., needs more help getting washed up than eating).

The stages merge into one another, and it is not unlikely that persons will exhibit behavior that straddles stages. The point is that if the caregiver can say: “Well s/he’s somewhere between Early-Middle and Late-Middle,” that is a starting place for appropriately designing and helping with tasks and activities – the main focus of the next Savvy Caregiver session.

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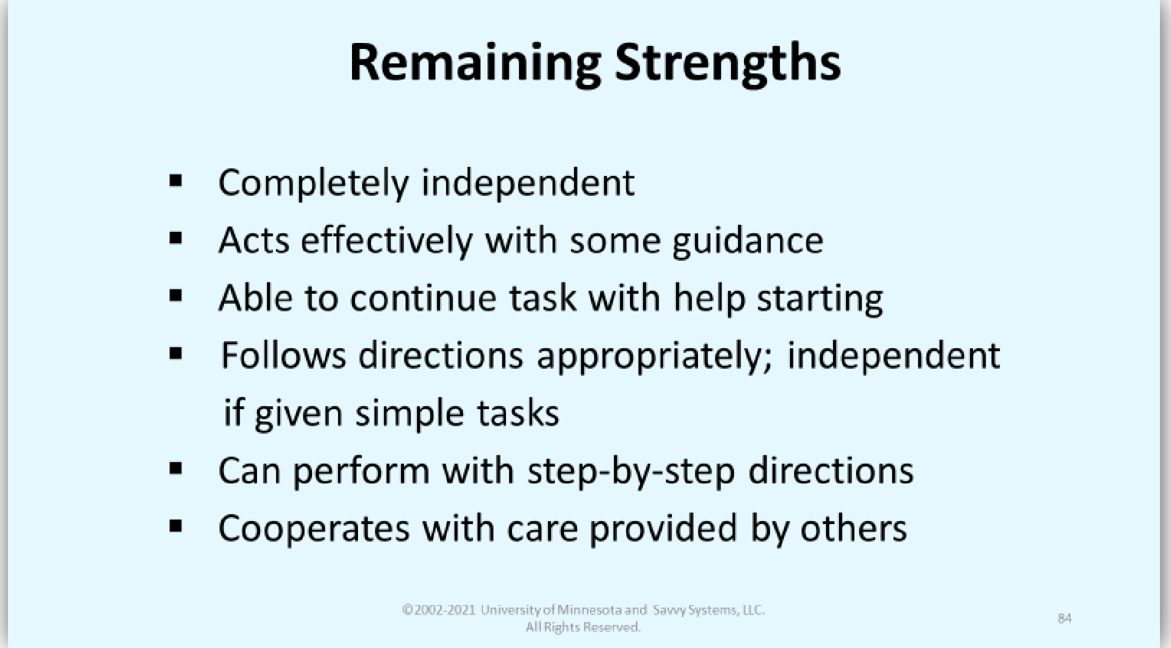
Tasks and Activities Grid Handout

Stage	Description	Examples
Normal	Independent in all activities, including complex cognitive tasks requiring intact executive function	▪ Managing a checkbook ▪ Making and following shopping lists ▪ Planning and taking a vacation ▪ Taking care of all daily needs (dressing, eating, toileting, hair care, etc.)
Early Stage	Independent in most daily activities, but may make errors in complex tasks. **NOTE:** Errors in complex activities are more serious, and often higher risk, than those in daily care activities.	▪ Makes mistakes with finances (checkbook doesn't balance; impetuous purchases), where he/she used to be able to manage. ▪ Difficulties in complex activities (problems on trips or in unfamiliar places; difficulties navigating while driving in unfamiliar places; confusion carrying out complex tasks such as preparing a large meal), where he/she used to be able to manage. ▪ May need reminders (e.g., to come to dinner, wash up, comb hair, or get to the bathroom).
Early-Middle Stage	Able to participate in daily care and activities with cuing and direction. May be able to do some steps, with guidance, in more complex activities.	▪ Cannot manage checkbook or finances reliably; cannot successfully plan complex activities. ▪ Occasionally becomes lost or confused in places outside normal routine. ▪ Makes occasional errors with daily care activities (e,g, spill food, make a mess, toilet accidents) ▪ Needs help starting or continuing with daily care tasks (e.g., prompt to keep eating; hand hair brush, washcloth, etc.) to him/her; reminders to finish brushing, eating, washing, etc.). ▪ May still perform overlearned activities well (knitting, gardening, letters).
Late-Middle Stage	Remains able to participate in everyday care activities, with increasing amounts of assistance and guidance.	▪ Must be handed things (grooming objects, dinner utensils) to perform task. ▪ Needs prompting and cuing in a step-by-step way to complete tasks (remind person to do each step of the task; serve just one thing at a time at meals; remind person to finish the task). ▪ May need direct assistance (help finishing cleaning up after toileting; having food handed to him/her; having washing-up materials handed one at a time and being cued on their use). ▪ May still perform simplified, overlearned activities with cuing and support.
Late Stage	Able to enjoy passive engagement. May cooperate or be fully passive during care provided by others.	▪ Can be passively engaged/involved in activities performed by others. ▪ May enjoy passive activities, such as listening to music, watching birds. ▪ May cooperate during everyday care (e.g., move head while being washed, having hair combed, having incontinence products changed, or while being fed by another). ▪ May give no response while someone else does his/her daily care activities

Note: Even in early stage, when the person seems to be performing well, issues of safety must be addressed. Caregivers can't take safety for granted at any time.

Once the participants have completed the brief exercise, use the slide to below to make the summarizing points for this section of the workshop regarding strengths and support activities.



Remaining Strengths

- Completely independent
- Acts effectively with some guidance
- Able to continue task with help starting
- Follows directions appropriately; independent if given simple tasks
- Can perform with step-by-step directions
- Cooperates with care provided by others

The main points to emphasize are the following:

- There is a kind of general order or hierarchy to the strength profile, and there will be a general pattern of retained strength across activities.[*]
- The person can be described in terms of remaining strengths (s/he's lost powers, but s/he has also retained some).
- It is important to note that the final strength, the ability to cooperate with care, is a strength. To be passively involved is to be involved.

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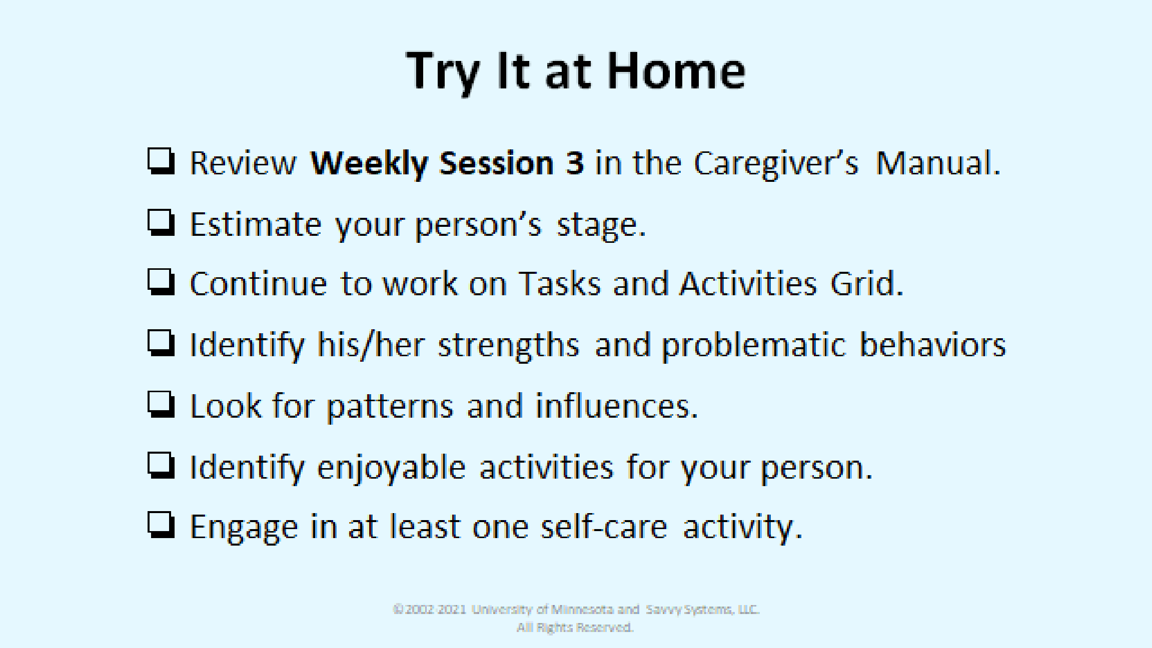
[*] This is a general rule, not an inflexible one.

Home Assignments

Things to Try at Home.



Try It at Home

- ☐ Review **Weekly Session 3** in the Caregiver's Manual.
- ☐ Estimate your person's stage.
- ☐ Continue to work on Tasks and Activities Grid.
- ☐ Identify his/her strengths and problematic behaviors
- ☐ Look for patterns and influences.
- ☐ Identify enjoyable activities for your person.
- ☐ Engage in at least one self-care activity.

- Review the performance and staging material in the Caregiver's Manual.
- Estimate stage of person's illness.
- Continue work on the Tasks and Activities grid (above).
- Continue to describe their person's strengths.
- Identify behaviors that have been problematic in caregiving. Look for patterns: Do they occur at certain times or under certain circumstances? Does anything bring them on or calm them down?
- Identify activities that are enjoyable to the person – what kinds of things does s/he become easily involved in?

Also, continue to engage in self-care: **Everyone should do at least 1 self-care activity.**

Coaching Tip: Stress to participants that they are now halfway through the program (only 3 sessions left). So make the most of the home exercises. The more they practice and experiment at home, the richer their learning will be. **Make the pitch: *Change takes practice*!**

Weekly Session 3 Notes

Weekly Session 4

"Human behavior flows from three main sources: desire, emotion, and knowledge."

Plato

Session Agenda

Savvy Caregiver Program
Weekly Session 4 Agenda

Instructional and Topic Areas	Content Included In Topic Area	Approximate Time
Coaching and Review	• Reading on Stages • Review Tasks and Activities Grid and Personal Care Worksheet • Discuss Stage Estimate for Person • Self-Care Activities	40 Minutes
Teaching: Guiding Day-to-Day Behavior	• The Anchors of Contented Involvement: Structure, Support, and Personal Preferences (25 min) • Understanding the Design of Tasks and Activities (10 Min) • Linking Design to Stages (15 min) • Adapting Communication Skills to Support Effective Interaction (10 min) • Two Models of Behavior (15 min)	75 Minutes
Home Practice	• Assigned Home Readings and Practice Tasks	5 Minutes

Program Leader's Overview of Session 4

This session continues the Savvy program's focus on developing caregiving strategies. Up to this point, almost all of the material dealt with discrete or particular effects of a dementia on the person – and with strategies that the caregiver could develop and employ to work more effectively with the person as behaviors occurred. By now, the group discussions and practice at home should have encouraged participants' active learning and participation.

In this session, the learning should feel more global. In other words, the way participants discuss and evaluate their situation should reflect a more comprehensive and holistic understanding. Their comments should reflect an appreciation of the effects of these illnesses on the whole person – and the implications of these effects for them as caregivers. The introduction of the staging system and the home exercise to estimate the stage of the care recipient's illness should make this material more specific and personal. The teaching material you will use in this session is also more personal.

This 4th session will really focus on the daily work of Savvy Caregiving – how to support and interact with the person living with a dementia so that s/he will be as content and involved as possible throughout the day. The keys to doing this will be establishing a linkage in caregivers' minds – and in their practical behaviors – between the stage of disease (and level of performance) of their person and the way they set up the day. The session will focus on the design of tasks and activities. It will build on the idea that people living with dementia will likely continue to enjoy doing things they enjoyed before they were affected by the disease. It will introduce the concept of **Structure** as a critical component for how caregivers can design tasks. It will also introduce the concept of **Support** – the way they communicate about and help the person with tasks. Together, these skills can affect how well the person becomes and remains involved in them.

Review the Home Practice. Note that the review and coaching time is somewhat longer in this session than in the previous three. There is much to review:

It is useful to get an initial sense of which participants have read the materials in the manual, reviewed the Tasks and Activities grid, and done the stage estimation. This will give you an indication of how to pitch this session. If there are some who haven't yet engaged in practicing at home, keep referring, during the session, to what they will learn by reading, viewing, and completing the estimate.

Ask participants if they have thought about the stage of their person's illness. It is quite possible that some caregivers may not have tried or wanted to try to make an estimate of the person's stage. For some participants, estimating the stage will confirm and give name to what they already knew. For others, the exercise can be difficult in a number of ways:

⇒ For those whose acceptance of the disease has been incomplete to this point, looking at the videos, reviewing the tasks and activities grid, and trying to come up with a stage estimate may clash with their own efforts to deny the reality of what is happening.

⇒ For those caregivers and/or family members who are denying the disease, estimating the stage might cause them to look clearly at the situation for the first time.

⇒ For other caregivers, seeing the progression of the disease – in terms of seeing persons who are further along in the disease process – may be something they didn't want to look at or that they find hard (distressing) to look at. You may have some reactions like this in the group.

In many families there is disagreement about what is happening to the person. The exercise may serve to rekindle and intensify those disagreements. It may also help to address their reality in a positive or more productive way. It is always useful to encourage other family members to look at the material from the Savvy Caregiver program as a way to promote agreement.

Emphasize the point that all that is happening with the process of estimation is that it is providing caregivers with a place to start their own process of figuring out the kinds of structure and support work best with their person. Mention again that they should take advantage of professional help if they can. A professional assessment – for example one done by an Occupational Therapist skilled in judging the level of a person's cognitive performance – and professional guidance in working out the strategies of day-to-day life will be most beneficial.

Continue the coaching session by asking:

- Were there any additions or changes to the caregivers' reflections on remaining strengths?
- **Identifying and Guiding Behaviors.** Have caregivers report on their efforts to identify, analyze, assess, and work with behaviors they found difficult or challenging.
- **Identifying Preferences.** Did they come up with lists of things the person enjoys doing?

In each case, make sure to have the caregivers describe the behaviors and involvements in terms that fit the behavior model covered in Session 2. Be sure that caregivers look at the role played by Person (i.e., personal preferences and interests), by Others (e.g., the caregiver) and by the Setting (environment) in both positive and difficult behaviors.

- **Self-Care Activities.** Ask the group to report back on activities aimed at dealing with their own feelings related to caregiving (identifying and transforming "negative powerless" feelings to more positive and powerful ones) and at taking some time to do something for themselves.

Finally, before moving to the new material, ask if participants have any questions about the material they read in the Caregiver's Manual.

Today's Session. The main learning objective of today's session is to introduce participants to the concept of Contented Involvement and to have them begin to see how they can apply this concept to their day-to-day caregiving.

Anchors of Contented Involvement

Guiding Day-to-Day Behavior:[10] **The Anchors of Contented Involvement**
This is the "how to" part of the program. We now fully focus on how to fit tasks to abilities and how to help the person to get and stay involved in those tasks and activities. The tasks and activities we speak of may be things to do during the day to keep occupied – such as hobbies, entertainment, diversions, even chores. Or, the activities may be everyday tasks, like getting washed up, using the toilet, or getting dressed. It is during this portion of the program that you will help participants understand important terms that you will continue to use throughout the program. These terms are: **Person, Structure, and Support**.

The foundation of the brief talk you'll provide is that there is a basic inter-relationship between 1) the caregiver's knowledge of what the Person likes (or liked) to do (or how s/he has always done something), 2) the kinds of Structure and Support the caregiver provides, and 3) the stage of the person's disease. This inter-relationship circles back to the idea of "Fit" that was introduced in the last session. A task or activity that enables a person living with a dementia illness to be content and involved taps into their own personal preferences. It is shaped in a way that matches his/her remaining abilities and is guided by help that also matches the person's abilities. The talk is based on this key principle:

> **Contented Involvement = Meaningful Engagement**. For persons living with dementia, the basic human capacity persists for enjoying doing things that they like to do and/or that they are comfortable doing and/or that they have done habitually and easily. All individuals retain an ability for doing things, and they can enjoy and be content in doing them. This lesson emphasizes that it is the caregiver's skill in designing and helping the person into tasks and

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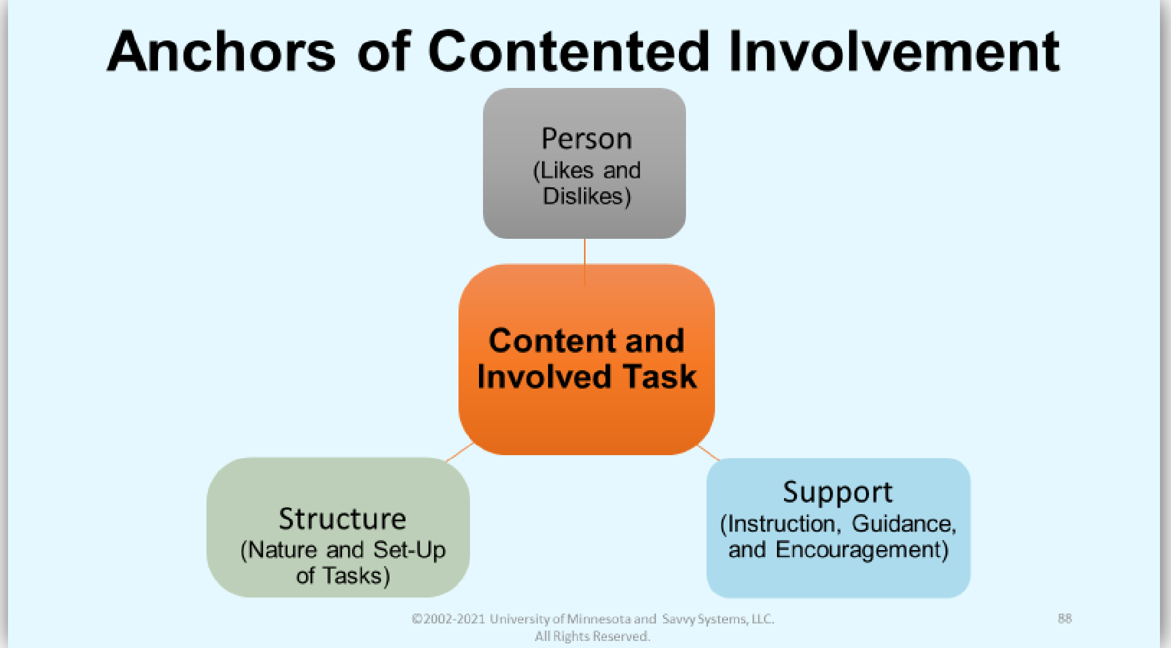
[10] It is very possible that – once the topic of behavior is introduced – participants will want to discuss the opposite of this topic. They will want to engage in conversations about how to get the person to stop doing certain things –behaviors the caregivers find concerning. Recall that a portion of Session 2 – along with sections of the manual – dealt with this topic; also portions of this session will cover this as well. However, once participants get the idea of Structure and Support, these sources of information will mean even more. It is important that the topic of quelling difficult behaviors be understood through the same framework that encouraging positive involvement is understood. Therefore, **ask them to hold off further questions on difficult or troubling behaviors until you've completed the part on Structure and Support.**

activities that fit the person's strengths and capacities that opens the door to Contented Involvement.

The estimate of the person's disease stage and level of performance provides a starting point for designing appropriate tasks. Using the materials that will be provided and described in the next part of this session, participants will be helped to select tasks and Structure and Support strategies that fit the person's remaining abilities. The expectation is that participants' observations of their persons doing tasks that are structured and supported in this way will provide them with information that will help them to refine their estimate of the person's stage and level of performance. Over time, caregivers should come to a surer sense both of the level and of how to tailor the structure and support information to best fit their person.

The Anchors of Contented Involvement. The slide below illustrates the point that, in almost any activity we can think of, there is a process of ongoing assessment that is necessary to maintain a condition of Contented Involvement. This is as true for our own involvement in things as it is for the involvement of a person with a progressive dementia disorder. The Anchors stand in dynamic relationship to one another. To guide a person to a place of Contented Involvement and to help him/her remain there for as long as possible, it is necessary to **harmonize the three factors of Person, Structure, and Support**.



Anchors of Contented Involvement

Person
(Likes and Dislikes)

Content and Involved Task

Structure
(Nature and Set-Up of Tasks)

Support
(Instruction, Guidance, and Encouragement)

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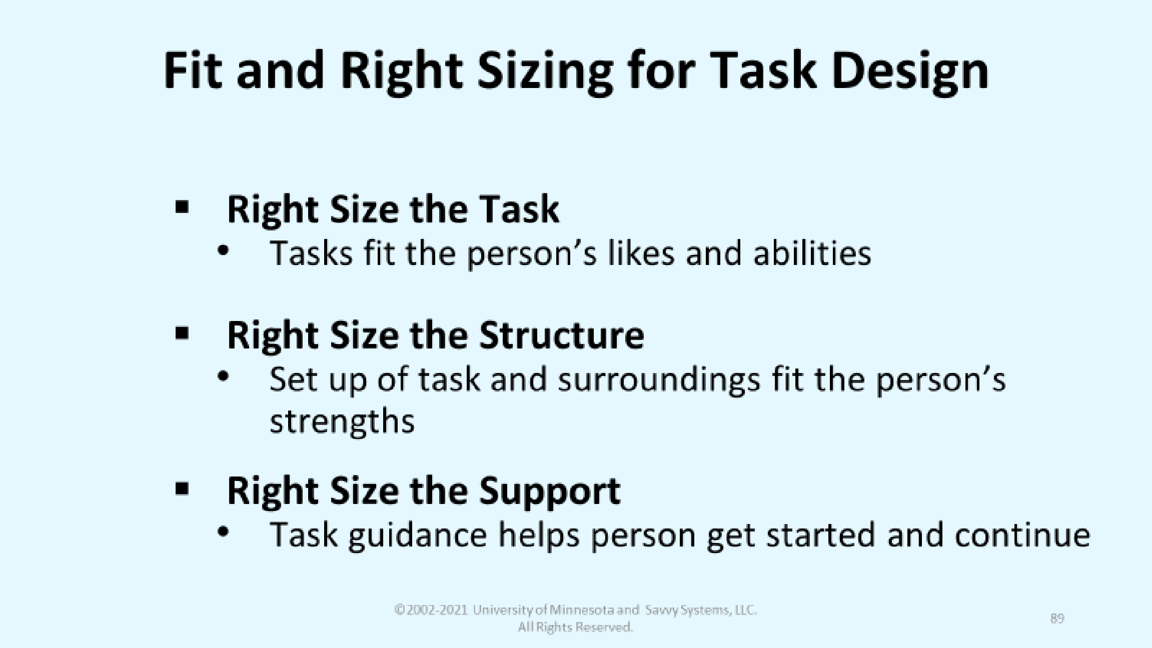
This is always a dynamic process. Caregivers use their observation of how the person reacts to a particular activity on a given day to readjust their estimate of the person's overall ability to perform tasks. However, caregivers always have to address the three "Rights" of involvement:



Fit and Right Sizing for Task Design

- **Right Size the Task**
  - Tasks fit the person’s likes and abilities
- **Right Size the Structure**
  - Set up of task and surroundings fit the person’s strengths
- **Right Size the Support**
  - Task guidance helps person get started and continue

Right Task; Right Size [*Person*]. Caregivers will need to pick tasks that are based on the person’s likes and that are scaled to the right size and complexity for their person’s current strengths (linked to the stage of the person’s illness).

Right Set-Up [*Structure*]. The nature of the task and environment in which the task or activity takes place should accommodate the person’s capacities.

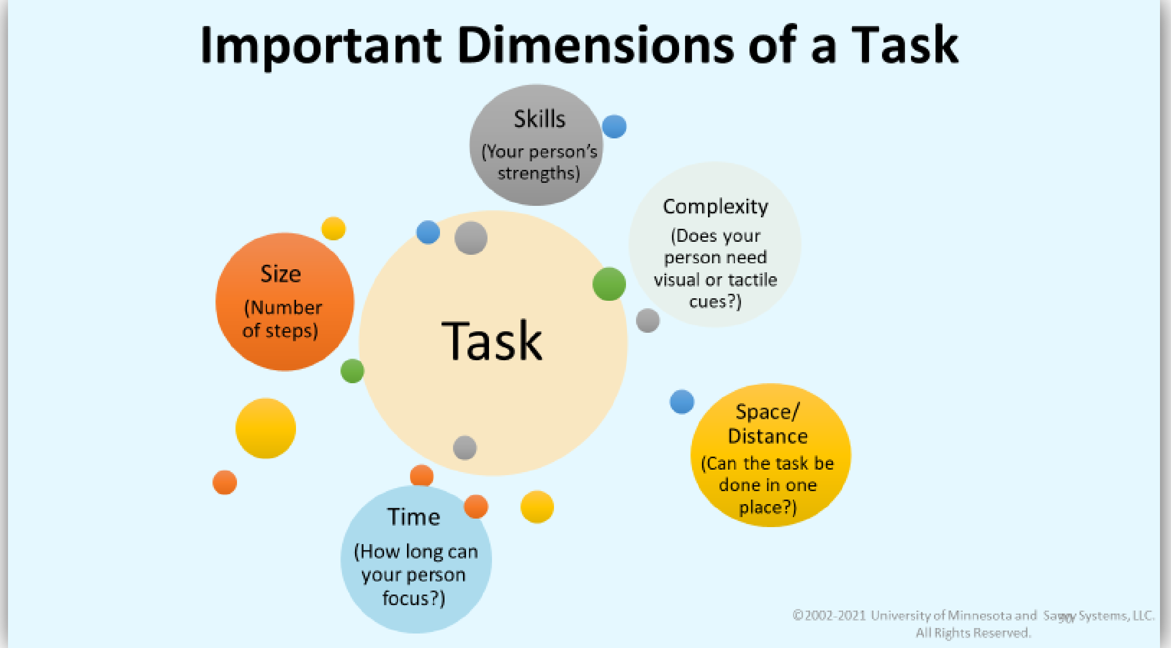
Right Guidance [*Support*]. Each person will require different kinds and amounts of help to get started with and keep going in their parts of the task. This will entail understanding which kinds of communication strategies are likely to be effective with the person’s current capacities.

To get these “Rights” right, caregivers will benefit from understanding the three Anchors:

Person. Caregivers benefit from starting with using what they know about a person to design the kind of task or activity in which they seek to involve him/her. Personal preferences – what the person likes or dislikes and the way the person most likes to do things – should strongly affect the choice of tasks. The starting point of task or activity design is the question: what does the person like or enjoy? What did s/he like or enjoy? How does s/he like to do certain everyday tasks (like washing up or getting dressed). Lifetime habits and preferences remain important starting points for task/activity design.

Structure. Structure is simply the total manner in which a task, activity, or event is presented to a person. Appropriate Structure considers the abilities of the person to whom the task is presented. The Structure of a task or activity concerns the nature of the task and the way in which it is set up.

Key Dimensions of Tasks. Use the slide below to talk about the key dimensions that have to be considered in task design. These dimensions relate to the choices caregivers have to make to provide appropriate Structure for the activities, tasks, and events in which they hope to get their person contentedly involved. They should have some kind of framework for analyzing tasks so that they will have a systematic approach to tinkering and experimenting with them to try to arrive at an appropriate fit for the person.



Important Dimensions of a Task

Skills
(Your person's strengths)

Complexity
(Does your person need visual or tactile cues?)

Size
(Number of steps)

Task

Space/ Distance
(Can the task be done in one place?)

Time
(How long can your person focus?)

Size relates basically to the number of steps that are involved in a task.

Complexity has to do with the amount of abstract thinking that is involved in completing the task. Are the purpose of the task and the order of performance apparent? Are there nested sub-tasks whose relationship is unclear, except in the abstract? Are things needed for the task present and visible or does the person have to find them?

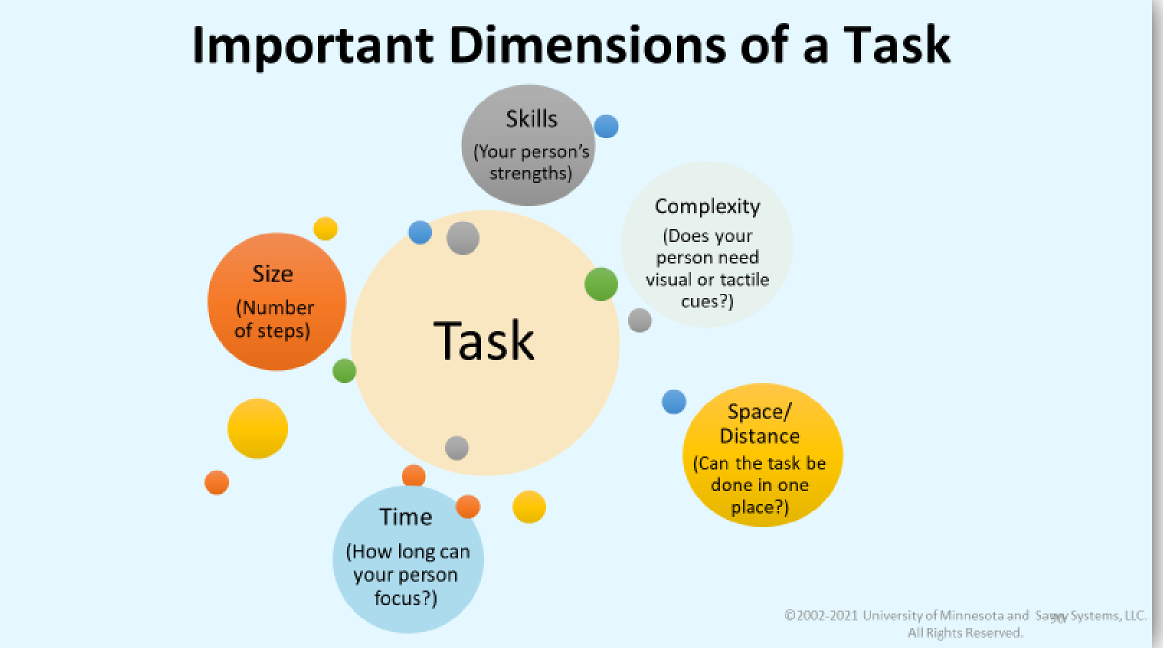
Space/Distance relates to the geography of the task. Does everything take place in front of the person or in the same room – or does the person have to travel out of the room to finish the task?

Time is probably just another way of talking about size. It has to do with both the amount of time it takes to do one repetition of a task and with the amount of time you can expect the person to stay with repetition of the task.

Skills relates to whether the person has the basic skills required to do the job. Calculating the orbit of the moon around the earth may be child's play for an astrophysicist, but virtually impossible for the rest of us. Cooking a fancy dish or dessert may be easy for some and mysteriously difficult for others.

> One of the things people ought to come away with is a greater appreciation for what is meant when they say something is a simple task or something is hard. It's the combination of all these dimensions.

The slide below provides a concrete representation of the relationship between disease Stage (and level of performance) and Structure. It suggests starting points for the basic relationships between disease stage and the key dimensions of tasks. It relates to Support and Structure Considerations (above and in the handouts).



Important Dimensions of a Task

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Size (Number of steps)

Task

Space/ Distance (Can the task be done in one place?)

Time (How long can your person focus?)

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Walk through the chart, stage by stage. Try to use some examples to illustrate how this is done. For example:

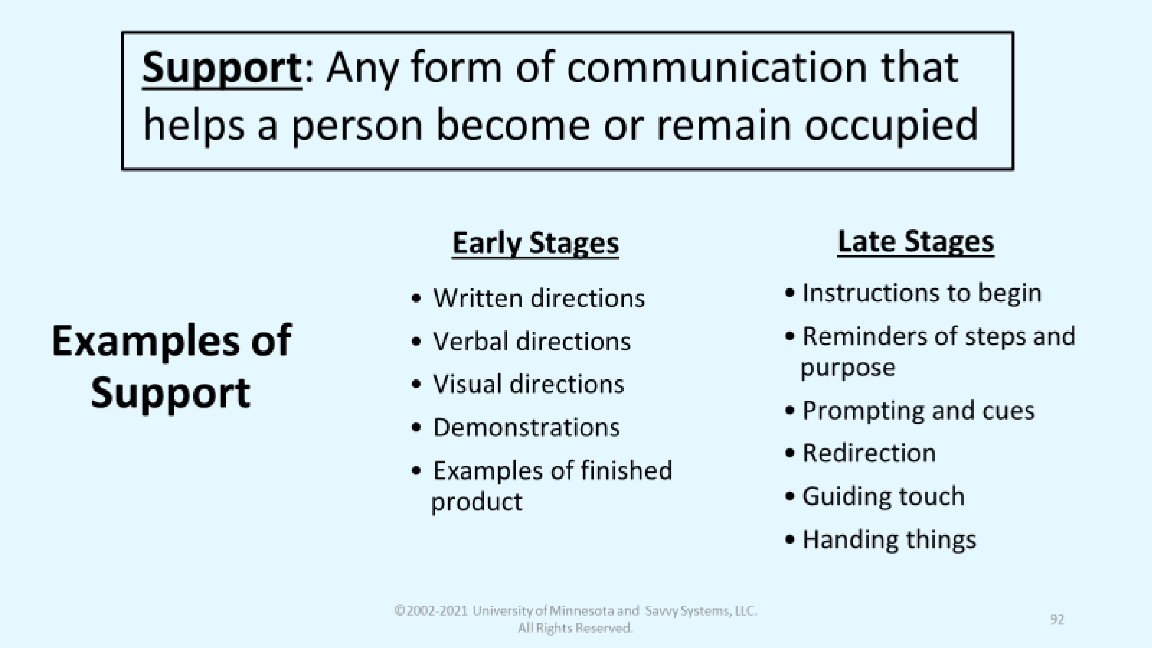
- A person whose illness is in the Early stage and who is functioning relatively independently might be able to do chores around the house, and possibly run errands in the immediate neighborhood.
- As the person's disease worsens and s/he enters the Early-Middle stage, the person would likely be able to navigate a large room easily and might go outside the room – but s/he may function better at this with a companion.
- A person whose illness has progressed within this Early-Middle stage might be more comfortable and less distracted doing something in just one part of the room and that doesn't involve too much moving around.
- A person whose illness is in the Late-Middle stage will likely do better at a small table with a 1-2 step task. As this person's illness progresses within the Late-Middle stage, s/he may

become easily distracted, so remove excess stimuli – perhaps have him/her facing a bare wall and do a 1-step task.

- A person whose illness is in the Late stage might enjoy watching an activity and taking part passively in it.

The selection of a task is a particularly important element in Structure. Make the point that tasks can often be broken down into smaller subtasks: Making breakfast involves making toast and coffee. Making toast involves toasting and putting butter on, etc. Persons can be given parts of any task that fit their ability. Tasks, events, and activities also tap into the areas of habit, experience, and personal preference. Thus, a person is more likely to feel drawn to a task s/he has done before or has shown interest in before. **Thus, it is important to consider the person's life experience when designing tasks or events for him/her.**

Support*.* Support – the third anchor of Contented Involvement – has to do with the help a caregiver provides – and the manner in which s/he provides this help. The nature of support to a person living with a dementia-related illness will help him/her to become and remain involved in a task, event, or activity. Use the slide below to talk about kinds of support.



Support: Any form of communication that helps a person become or remain occupied

Examples of Support

Early Stages

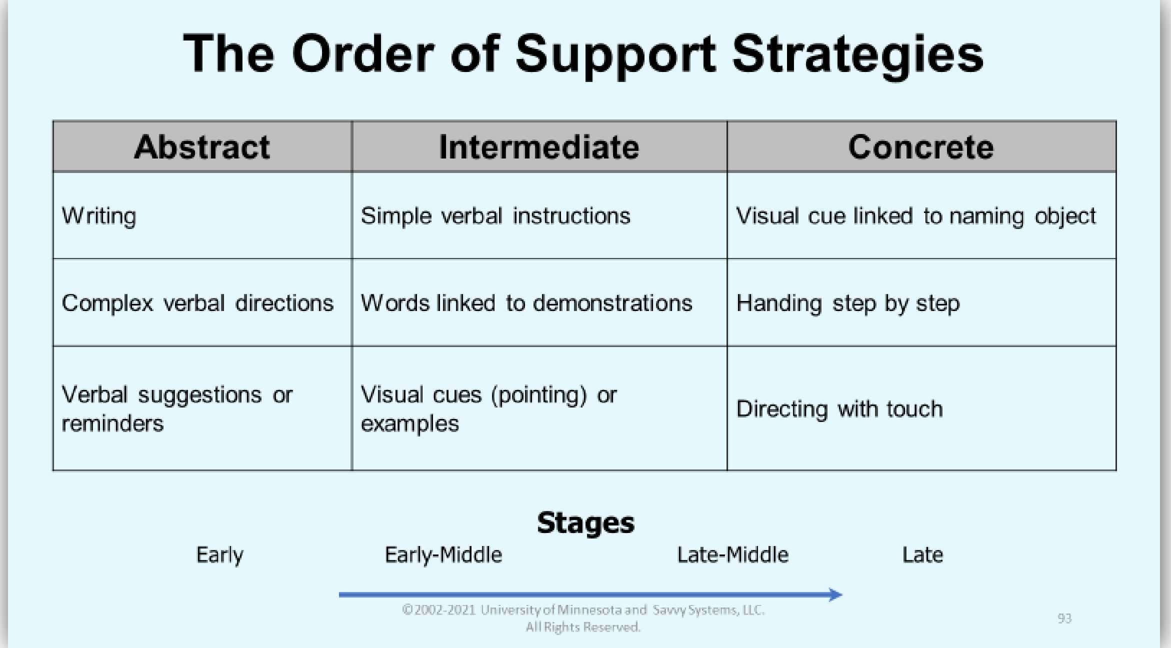
- Written directions
- Verbal directions
- Visual directions
- Demonstrations
- Examples of finished product

Late Stages

- Instructions to begin
- Reminders of steps and purpose
- Prompting and cues
- Redirection
- Guiding touch
- Handing things

This introduces the idea that all support strategies are not equal – that they are of different sorts.

Ask the group to try to differentiate among the support strategies. This leads to the next slide.



The Order of Support Strategies

Abstract	Intermediate	Concrete
Writing	Simple verbal instructions	Visual cue linked to naming object
Complex verbal directions	Words linked to demonstrations	Handing step by step
Verbal suggestions or reminders	Visual cues (pointing) or examples	Directing with touch

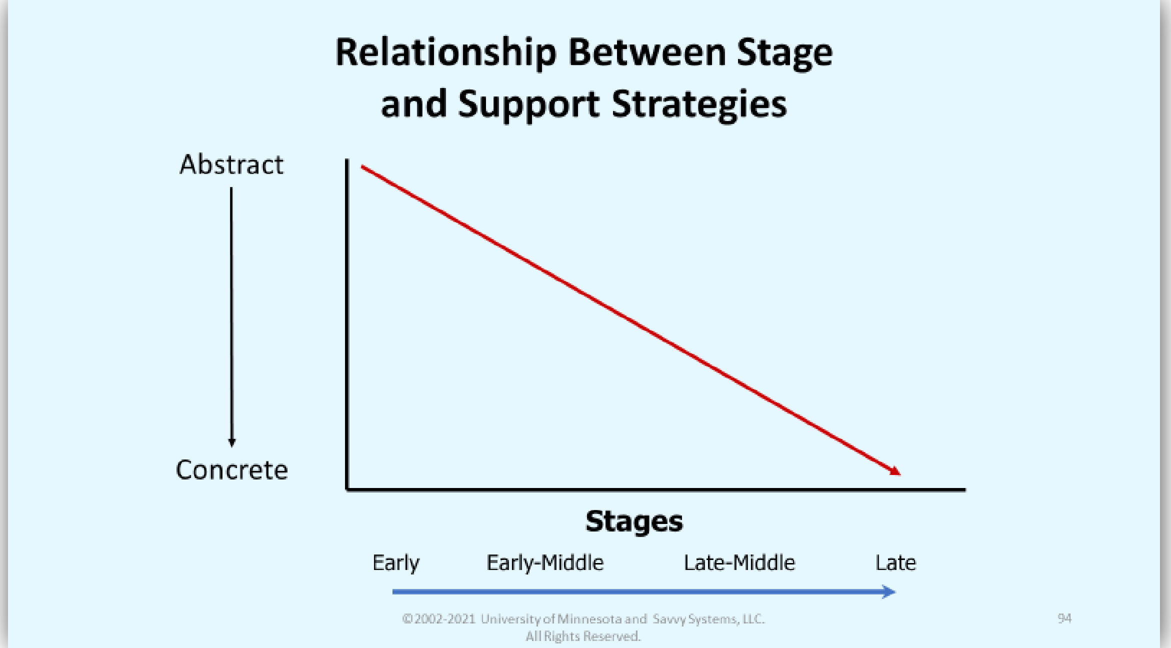
Stages

Early → Early-Middle → Late-Middle → Late

Some forms of help and communication are more complex than others, while some are more concrete. As Alzheimer's or similar illnesses progress, **the kind of Support and communication caregivers use should be matched to the person's abilities**.

In the Early Stage of the disease, ordinary forms of communication – forms that rely on language – will remain effective. But as the disease progresses, other forms of communication that are more direct and concrete will need to replace language. Thus, pointing to things becomes an important support strategy in the Middle stages (think back to the stage videos that were shown last session; recall that with the later participants, the Occupational Therapy Assistant often used pointing and tapping on things (like the ham) to call the participants' attention to them). Eventually, more tactile methods are needed. In some dementia illnesses, such as variants of Frontotemporal Dementia, language skills diminish much earlier in the process, and compensatory strategies are needed sooner. Participants should be encouraged to think about how they can make their interactions increasingly clear and concrete with their family member.

The slide below makes the point that the continuum of support must be related to the person's disease stage (and level of performance). As a person's dementia illness progresses, the kind of help s/he will need has to progress from abstract to concrete. As the illness progresses, interventions – structure as well as support – have to shift to match those changes. Tasks are scaled down and simplified, and support strategies become more concrete.



Relationship Between Stage and Support Strategies

A Few Basic Notes About Communication. Take a moment, while dealing with Support, to make some comments about communication strategies. There are a few basic points to emphasize about communication with a person living with dementia:

- **Make sure you have the person's attention**. Don't assume the person's attention is on you. Give the person time to recognize you are there and to focus on you before you start talking or engaging in any form of communication (e.g., touch).

- **Try not to startle the person.**_Don't come upon the person from the back or side. Have the caregivers imagine what it's like to have someone touch them from behind when they don't know that anyone is there. Usually, people jump. There is research that indicates that the visual field of persons living with dementia shrinks as the illness progresses. Gradually, peripheral vision weakens, and the person sees an increasingly narrow band directly in front. As a result, persons approaching from the side may seem to appear suddenly, producing a startle reaction.

- **Make sure the environment is not working against you**. Many things in an environment can distract the person. Too much clutter and a bright light behind you are two of the main problems. Similarly, too much noise – the TV, a computer, or even music in the background – can easily distract the person.

- **If possible, deal with sensory deficits**. If there are hearing and/or vision problems for the person, make sure that they have whatever aids (glasses, hearing aids) that s/he needs to correct the problem. Hearing aids are tricky. They amplify sounds. A person living with dementia may no longer be able to filter out background noise from meaningful sounds, so a hearing aid may make matters worse by just making things louder. Also, if the person is not used to wearing a hearing aid, putting it on/in may prove difficult – it could even become a source of struggle. Moreover, most hearing aids need batteries, which can wear out. A person living with dementia will not remember or be able to replace them, or manually adjust them when needed.

- **Use appropriate techniques**. Issues of pitch, tone, and volume of voice are important. The person has to be able to hear you, and you don't want to sound like you're angry. Beyond this, choice of words and length of sentences is important as the disease progresses. Savvy Caregivers have to learn to rely less on language and to begin to use visual and tactile signals as an integral part of communication.

Have the participants take out the **Structure and Support handout** (see next page). Go through it stage by stage and discuss the various support strategies for each stage.

⇒ Keep pointing out how the strategies become more concrete as the disease progresses.

⇒ Relate the chart back to the discussion and related readings from Session 3 on the Stages and Performance Levels.

⇒ Relate the Structure portion back to the point made earlier in this session about the important elements of a task and note how, as thinking declines, task size, complexity and geography all need to be decreased (i.e., made smaller and more immediate).

⇒ Note, too, that the chart refers back to the point made in Session 3 about the three elements of Performance (Purpose, Order, and Use) – as dementia progresses, these capacities are lost, in order. As a result, when providing Structure and in thinking about a Support strategy for a task or activity, you need to keep in mind what parts of performance are still present and what parts will you have to substitute for.

Session 4 – Structure and Support Handout

Stage	Structure (Set Up of a Task or Activity)	Support (Communication and Help)	Steps
Early Stage	• Can do many things independently • Consider removing complex parts • Think about breaking tasks apart and assigning parts • Check this, but should be able to move from place to place	• Use fairly normal directions • Give verbal help; use notes or labels • Be ready to help with the next step or missing word • Watch for frustration and be positive and supportive	4-6 Steps depending on complexity
Early-Middle Stage	• Can successfully participate in activities if you: • Take Over: do the planning for the task; establish a routine • Simplify: break larger and more complex tasks into parts • Structure: Get things ready and set them up • Make the environment work for the person by removing distractions • By the end of this stage, do the activity in one room	• Begin to be more directive because reason and explanation may not work • Verbal help still works, but simplify and begin to use visual cues • Fill in with next steps and words • Be ready to help and redirect • Frustration and irritation very possible	2-5 Steps Reduce the number of steps as the disease gets worse.
Late-Middle Stage	• Can participate in steps of an activity when: • You are in control; you are making decisions • Continue to simplify by breaking tasks into fewer and fewer steps • Set everything up • Only show the things needed to do the task • Do the task in one place • Remove distractions • Be prepared to do the task yourself	• Help the person start and with each step • Use short verbal directions • Rely more on showing and physically guiding the person • Demonstrate the steps • Expect frustration; end the task and move on when you sense it • Do not force a step • Be positive and reassuring	1-2 Steps or Passive
Late Stage	• Able to enjoy passive activities and observation • You are fully in control • Very simple, one-step tasks may be possible • Focus mainly on comfort and calm environment • Think about the senses: What might s/he like to watch, feel, smell, hear, or taste?	• The tone of your voice will convey more than words • Your emotional tone is also likely to be picked up • Guide the person physically and use visual cues	1 Step or Passive

Exercise Time! This talk has thrown a lot of material at the participants. Caregivers will be able to read and re-read it if they need to, but now would be a good time for them to get some practice in applying the ideas. The exercise will ask the participants to use the information about Stages and levels of Performance as a key to designing tasks (i.e., deciding on the kind of Structure and Support they might provide) for a number of persons living at various stages of Alzheimer's and similar illnesses.[11]

Ask the participants to imagine that they are volunteer visitors for a number of people living with dementia. Have them use the Structure of Tasks slide above and the Structure and Support Grid (above) to design tasks for the following people (part of the design task should involve taking into account who the people are – what interests and abilities might participants draw on to try to get them involved in tasks or activities?):

- Mrs. L. is a retired librarian. She had been an avid traveler and a prize-winning gardener. She is in the early stages of her illness and has been assessed in the Early stage of the disease.
- Mr. B. is a retired engineer. In addition to his interests in the details of elaborate projects, he was a life-long tinkerer around the house and still has a big and well-stocked tool shop. He has been assessed at the Early-Middle stage.
- Mrs. J. had a career as a homemaker, parent, and grandparent. She was a good and enthusiastic cook and a doting grandparent. Her illness has progressed considerably – to Late-Middle stage.

The group's task, with each of these people, **is to design an activity that might keep each involved for a short period of time. The questions to ask/answer are:**

- ✓ What activities might interest the person?
- ✓ How should the activity be Structured? What should the dimensions of the task/activity be? How many steps, what kind of space/geography, how complex, what kind of environment?
- ✓ What kind of Support should you provide? Will the person be able to understand the whole task or just the steps? Will s/he be able to get started on his/her own, or will you have to give help? How much step-by-step help might

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[11] It's possible that, by the time you get to the third example, the point of the exercise will have been made and you will be able to move over it quickly.

To promote participation, some facilitators break the group into dyads or small groups, assigning each example to a different group; the assignments might be by the stage the participants have identified for their persons. Each group presents its ideas and the larger group enters in. If there's enough time, it's possible to ask the group how they would adapt their ideas as the dementia progresses. One experienced trainer suggests telling participants that it's always easier to fix someone else's problems than our own. So, here we are going to practice our new skills and knowledge on some fictional people. This trainer does this as a larger group to reinforce that they are all "experts" and build peer-to-peer support.

you need to give? What form of communication might work best with the person?

Here are some examples of the kinds of things the group might try for the three people:

Person	Possible Task	Structure	Support
Mrs. L. Early	▪ Looking through travel photos ▪ Sorting things (uses a librarian's skills) ▪ Some kind of gardening task (e.g., repotting)	▪ Can handle multiple (4-6) steps and can move from room to room ▪ Will likely understand purpose of task ▪ Might need help setting things up or finding things	▪ Once attention is engaged, she will likely begin task on own ▪ May become distracted and need verbal refocusing ▪ May chat during task
Mr. B. Early-Middle	▪ A simple assembly task ▪ A shop task (e.g., sanding) ▪ A sorting task (e.g., putting nuts and bolts into jars)	▪ Things will have to be all set up in front of him. Have him at a table. He may not be too clear on the nature/purpose of the task. ▪ Not too many steps (2-4)	▪ Provide visual cues ▪ Help him get started (hand objects and give start cue) – might need to demonstrate ▪ Be prepared to help him refocus throughout the task if distracted
Mrs. J. Late-Middle	▪ A food preparation task (e.g., peeling) ▪ Reminiscence – looking at family pictures	▪ Everything in front of her; minimize distractions ▪ May actively do a 1-step task or may participate passively	▪ Hand objects and show what you want her to do ▪ Go slow – make sure she's focused on task/activity ▪ Keep focus with visual and tactile cues

The linkage between Stage (and Level of Performance) and caregiving strategy (Person-Centered choice of task or activity, Structure, and Support) is central to Savvy caregiving. The main "home activities" for participants this week and next will be for them to try to apply these ideas at home.

Summarize the main points:

1. **A key target of the Savvy caregiver's work is to help the person get and remain content and involved in things during the day.**

   ⇒ Several words of caution here. Caregivers have to be careful not to become slaves to this. It doesn't mean that they have to worry that the person is content and involved every minute of the day. Few of us can claim that. Both they and the person would find this exhausting. But it does mean that they should have the mindset that even a person living with dementia can get involved in things and can enjoy them.

   ⇒ It also means that they can use their new skills (taking disease stage and performance level into account in designing the Structure and Support for tasks) to help the person become involved. Point out, too, that if the person can become involved – and/or if caregivers can find a small set of things that they can use to get the person occupied when s/he is becoming agitated or confused – the caregiver may find s/he has a bit more space for him/herself as well (and has also had a caregiving success – a feeling to place in the upper righthand feeling quadrant).

   ⇒ Remind them of the point made in Session 2 about the power of Confusion and of the person's need for security. The Savvy Caregiver establishes a routine that provides comfort and security. If the caregiver can figure out a set of activities that characterize everyday life – things the person does (either to help the caregiver with things around the house or on his/her own), that set of activities constitutes a routine. In the same way, if the caregiver can have a repertoire of activities s/he knows the person likes, the caregiver can call on these in times when s/he (the caregiver) needs a break or when things are starting to get out of hand.

⇒ It is also the case that knowing this set of preferred activities will help the caregiver to use outside help. The caregiver can instruct someone else – for instance a member of the family or a paid helper – about a set of activities they can give the person to do, activities the person is likely to enjoy and become involved in.

2. Interest in involvement starts with the Person. What did the person like to do and what was s/he good at? What interests did s/he have, and which ones does s/he still show?

This may seem obvious and intuitive, but amidst the stresses of caregiving, the caregiver may sometimes lose sight of the principle. The appropriate perspective here is that these skills and interests are important entry points for task design. Keep in mind that the point isn't the quality or effectiveness of the performance. The person who had been an expert at some craft (knitting or woodworking) or some sport or was a good musician or loved to read can likely still do those things, but just not as well and perhaps only passively. The activity may need to be simplified and adapted, or they may enjoy a more passive observer role.

What are some examples? Listening to the music of one's youth; sitting turning the pages of a newspaper or book – regardless of understanding or being able to discuss it; peeling carrots, beating (whipping) eggs or cream, and shredding lettuce; saying prayers or watching a religious service on TV; watching (over and over) a video of the granddaughter's choir performance or a sports event.

There are online videos of everything. Caregivers can find song, dance, and orchestral performances. There will be videos of a person's favorite singer. There is a nearly infinite number of adorable kitten, puppy, and baby videos. Museums post images from their collections. A knitter who can no longer manage complex stitches might still enjoy winding a ball of yarn. The list can go on and on. The caregiver's choice of an activity starts with the person; the design of the activity starts with the person's current capacities for engaging with and becoming contentedly involved in the activity.

It is worth mentioning to the caregivers that persons living with dementia can sometimes become involved in tasks or activities in which they had had no previous interest. As a result, they should feel free to experiment with some different things. For example, a man who had never cooked or laundered might be persuaded to help with some parts of these tasks (like peeling carrots or potatoes, shredding lettuce, drying or stacking dishes or sorting silverware, sorting laundry or folding clean clothes – even vacuuming). Similarly, a woman who had never shown any mechanical inclinations might be happy to sort through a jar of nuts and bolts and separate them into piles. At worst, the person will show no interest; at best, the caregiver might discover another activity for the daily repertoire.

3. **Be aware of the disease Stage.** Having a good ballpark estimate of the disease Stage (and level of Performance) helps the caregiver to decide on the kind of Structure and Support that might help the person become and remain enjoyably involved in the task/activity the caregiver selects.
4. **Understanding habits is important.** Over a lifetime, people become set in certain ways of doing routine tasks. Some shower and dress before breakfast; for others, life doesn't begin until after coffee. Lunch for some is the main meal; in the evening, a small snack and salad will do. Others always skip lunch, but snack at 10 and 2. Patterns and methods of personal routines are just that – personal. Building guidance for engagement in these daily necessary activities benefits from knowing and following – to the extent possible – these habits and preferences.

As caregivers begin to apply these principles in their caregiving, ask them to keep a couple of guidelines in mind:

- **Be flexible**. The guidelines that are in their readings and handouts are broad in nature, and the estimate of the stage that they have arrived at is only a ballpark estimate – it's probably pretty close, but it's not as accurate as if it were a professionally done assessment. So, use the guidelines in a relaxed manner.

- **Be experimental**. Try different kinds of tasks and activities – even things the person might not have done much or at all before, as mentioned above.sks). But most importantly, experiment with the kind of Structure and Support you provide. Just because you think your person is living at the Early-Middle Stage of the illness, don't limit tasks to the 3-5 step range that is suggested. Try tasks with more or fewer steps; **see what fits.** The same holds true for Support. Maybe a person living in the Early Stage of his/her illness will benefit from more visual cueing as well as the verbal help you provide. Perhaps a person estimated to be living at the Late-Middle Stage of his/her illness is happier as a passive participant, or maybe s/he still gets more from verbal information that one might expect.

  This is like adjusting an old color television. You've got several dials – for color, tint, contrast, and brightness – and it is finding the right balance among all of them that will produce a clear picture with good color.[12] You've got to fiddle around until you get it right. The added problem of caring for a person living with dementia is that, once you get it right, you know that something will happen that will cause you to have to readjust. The person's condition will change over time, or the person will have a good day or a bad day and somehow be different from how s/he was on the day you got all the settings right.

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[12] It's possible younger participants won't have any experience with or understanding of the old color TVs, so provide another example of how one needs to "fiddle around" to get something right. Cooking can provide an example.

- **Recognize you are developing a skill**. Keep working at this. It may be that you won't get it right the first time, but you should begin to see elements of success in your efforts. Try to learn from what works and what doesn't, and give yourself credit for even partial successes.
- **Link successes to Self-Care**. Remember that every time something works, that's an accomplishment – an upper right quadrant feeling (positive and in control). And even when something doesn't work, you're taking action – moving from not being in control to being in control. Trying something out moves you from powerless toward powerful on the feelings grid.

Two Models of Behavior

Understanding Behavior. This section of the manual provides you with a way to add to participants' understanding of behavior, introduce key issues of behavior in dementia-related illnesses, and tee up a major reading assignment in the Caregiver's Manual. There are two new models for under-standing behavior presented below.[13] The models offer ways to expand on the simple model of behavior that was covered in Session 2. The home practice assignment you will make at the end of this session asks caregivers to identify typical behavior problems they face and use their appreciation for how behavior happens to design and implement strategies for dealing with the

The ABC Model

The ABC Model. The main point to make here is that **All Behavior has Meaning**. Any observed behavior – an action taken – is the middle point in an ongoing process. Typically, the action that is observed – the behavior – is a reaction to or result of something that occurs beforehand. Usually, what occurs beforehand is something the person is seeing, sensing, or feeling, or thinking about, and the action is taken deliberately and with an intended or expected outcome in mind. For example, a person who is crossing a road sees a bus coming at him/her and jumps out of the way (that's the behavior) in response to this thing that's happening (in the model, the antecedent). Something happens as a result of this behavior; in this case it might be that the person will be more cautious in crossing streets or that s/he puts on a reflective vest. A caregiver, observing that the person seems upset (behavior) – apparently by something seen through the window (antecedent) – realizes that the person is seeing his/her own reflection but doesn't recognize it, so

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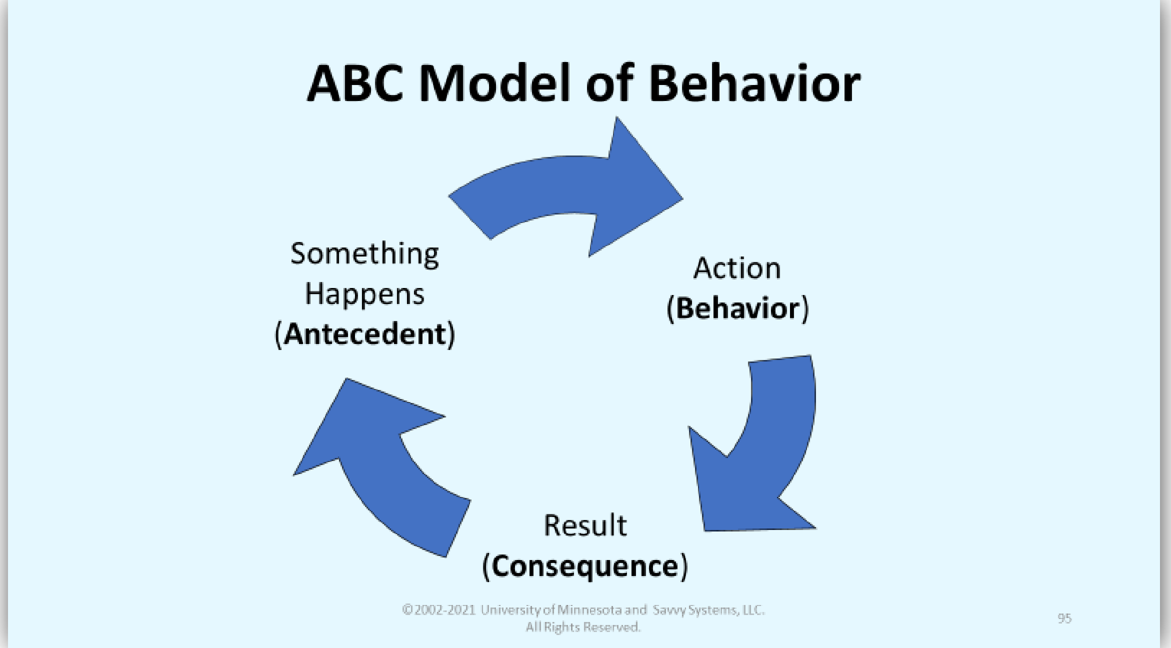
[13] Time may not permit you to cover both models in this session (though you should be able to pick it up in the homework review next time). Use your judgment about how much, if any, of this to cover in the group setting.

the caregiver closes the blinds (consequence) which changes the antecedent (person sees closed blinds, not the reflection) which, in turn, changes the behavior (person becomes calm).



ABC Model of Behavior

Something Happens (**Antecedent**)

Action (**Behavior**)

Result (**Consequence**)

From what participants already know from the program about the way dementia affects thinking and about the central role of confusion in these illnesses, they should be ready to accept the notion that, while the behaviors that people living with dementia engage in are responses to antecedent stimuli, the behaviors themselves are not necessarily self-directed or connected (in a straight-line fashion) to the antecedent stimuli.

So, it is left to caregivers to figure out what the behaviors mean. Actually, people are quite good at this, and the next exercise is meant to remind caregivers of their skill at discovering the meaning of behaviors – and in dealing with them.

Another Guided Image Exercise. You can use this exercise to make participants aware of the ways in which they usually handle unusual behavior. The exercise involves a very simple guided image.

Ask the participants to imagine that they are at a family gathering:

- It is a large family event, and the house is very crowded and very noisy.
- Loud music is playing.
- The noise level is intense. People are crowded together.
- Little kids are running around, chasing each other, screaming and giggling.
- Out of the corner of your eye you see your 3-year-old niece – sitting alone in a corner. She is crying frantically, but no one seems to hear her or to pay attention.

- You decide to help her.

Ask the participants to brainstorm about what they will do. Make a list of the things they say. After they finish responding, point out that the list will almost certainly include the following:

- They will try to figure out what is troubling the girl (though this will be intuitive, since the child will likely not be able to provide much useful information).
- They will try to calm her and offer reassurance, perhaps putting an arm around her.
- They will try to get the girl to feel trust in them.
- Only after this will they try to do something about the situation – go looking around to find her parent(s).
- They would probably not leave the child alone until the parent happened along.

The point of the exercise is to get the participants to recognize that they have a process that they use when they encounter a situation that is rooted in confusion:

- They look at the situation and analyze it – behavior is occurring. What are the antecedents?
  - The child is frightened and confused by all the bustle.
  - She is separated from her parents.
  - She doesn't have the capacity to figure out or correct the problem – it is beyond her abilities.

- They seek first to establish some kind of calm in the situation. They can turn the "result" of understanding what is going on (what the behavior means) into a new antecedent for the child, making themselves the new "something happens" to try to produce a new behavior, the child calming down.

  - Get the child to focus on them.
  - See if they can get her to stop crying and calm down.
  - See if they can get her to feel – at some level – that they will make the situation alright.

  Never underestimate the power of reassurance. Even if it isn't clear why a person is upset, words like, "I'll help you" and "I'm here" can have a strong calming effect.

- Only after calm is established will they try to remedy the larger problem.

This pattern – figure out the disturbance, re-establish calm, and deal with the larger problem (if possible) – is the basic pattern suggested in the Savvy Caregiver's Manual for handling the troubling behaviors they may face. The first session of the program has provided information about cognitive losses, and this should help caregivers to understand that the person cannot think his/her way out of situations that may be confusing. The portion of the program on Confusion should help participants to appreciate the emotional state that persons living with Alzheimer's or similar illnesses find themselves in. With this understanding of the situation, caregivers need to approach troubling behaviors with the general framework they applied to the situation above.

The Progressively Lowered Stress Threshold Model

Too Many Balls in the Air. Prior to introducing the next model of behavior (the difficult-to-say academic name is the Progressively Lowered Stress Threshold Model[14]), it is useful to remind participants about the important role that confusion plays in shaping the behavior of persons living with a dementia illness. In terms of the previous model, confusion is often the antecedent – the “something happens” – that precedes a behavior that seems to be uncomfortable for the person and can be troubling or disturbing for the caregiver.

As a preface, you might have participants call to mind their own ability to keep lots of “balls in the air.” At the same time, they also have the capacity to know when they’re reaching a limit and likewise have strategies for backing off some of the things that are putting them under pressure – thereby staying within their own limits and avoiding some kind of meltdown. The slide should draw participants’ attention to the idea that, as a dementia illness progresses, the person’s capacity to handle lots of things at once, perceive approaching a limit, and produce a measured response by backing off, is progressively diminished. So, the caregiver has the task of figuring the behavior out. To do this, they should follow the same pattern they followed in the exercise above: Observe; Analyze; Seek for Calm; Work toward a Larger Solution. This pattern is covered in detail in the Caregiver’s Manual.

The lead-in to the slide below is to ask participants to reflect on three capacities most people share. First, most of us are able to juggle a number of tasks and concerns at one time. Second, we generally know – or have a feeling we recognize – when we are approaching the limits of what we can handle. We know when we’re coming close to the threshold of our tolerance for stress. And finally, most of us have strategies – compensatory mechanisms – that we can draw on to back away from the stress threshold. We take some of the balls we’re juggling out of play for a while.

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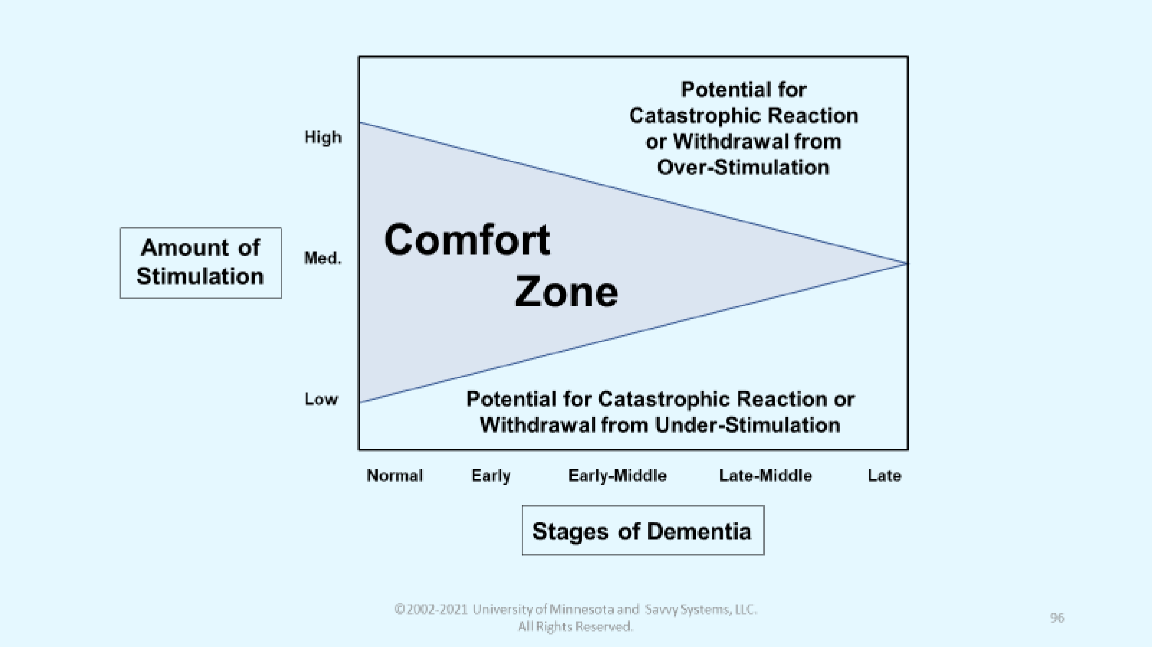
[14] Hall, G., & Buckwalter, K. (1987). Progressively lowered stress threshold: A conceptual model for care of adults with Alzheimer's disease. *Archives of Psychiatric Nursing, 1*(6), 399-406.



Potential for Catastrophic Reaction or Withdrawal from Over-Stimulation

High

Med.

Low

Amount of Stimulation

Comfort Zone

Potential for Catastrophic Reaction or Withdrawal from Under-Stimulation

Normal

Early

Early-Middle

Late-Middle

Late

Stages of Dementia

The slide should draw participants' attention to the idea that, as a dementia illness progresses, the person's capacity to handle multiple stressors, recognize an approaching limit, and respond practically by deliberately reducing the stress situation is progressively diminished. So, the caregiver has the task of either figuring out a stress-based behavior while it's happening or – better – of monitoring situations and environments to prevent too many stressors from entering into the picture. To do this, they should follow the same pattern they followed in the exercise above: Observe; Analyze; Seek for Calm; Work toward a Larger Solution (which also reflects the Savvy process model: Assess, Plan, Implement, Evaluate). They can also take the scenario of that exercise – a family gathering – and think of ways to reduce the stress that such gatherings might place on a person living with dementia.[15]

Common Behavior Concerns. There are a number of behaviors frequently associated with dementia-related disorders that caregivers often find disturbing or concerning. Included in these are, for example: wandering, repetitive questioning, shadowing, and sundowning. The Caregiver's Manual discusses a number of these behaviors and relates them basically to the problem of confusion and to the emotional needs (for security, control, and calm) that stem from confusion. You should again assure them that – whether they know it or not – they have a framework that they typically use to analyze behavior – one that involves trying to figure out what the behavior means and then responding appropriately.

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[15] One possible exercise is to ask participants to think of ideas for how to continue traditions in ways that reduce stress – or demands – on the person. One family, for example, continues Thanksgiving traditions not by one big family gathering, but by a series of much smaller family get-togethers spaced out over several weeks.

Home Assignments

Things to Try at Home

Try It at Home

- ☐ Review **Weekly Session 4** in the Caregiver's Manual.
- ☐ Review the **Managing Daily Care and Complicated Behaviors** worksheet.
- ☐ Pick a behavior and design a Structure and Support™ strategy.
- ☐ Try it out.
- ☐ Consider tasks and activities your person might enjoy. Design an activity for involving your person in the morning or afternoon.
- ☐ Continue self-care activities.

- Read the material in the Caregiver's Manual regarding Dealing with Daily Care and Complicated Behavior.

- Pick one behavior you would like to work on and, using materials from the program, design the Structure and Support strategy you think might work to accomplish the goal. And, then: **TRY IT OUT!**

- Work on designing a task or activity in which to involve your person in the morning or afternoon. Use the Structure and Support guide to help you design the activity and to get and keep your person involved.

- Continue Self-Care activities related to the identification and transformation of negative powerless feelings and to taking time for yourself.

- Think about tasks and activities your person might enjoy.

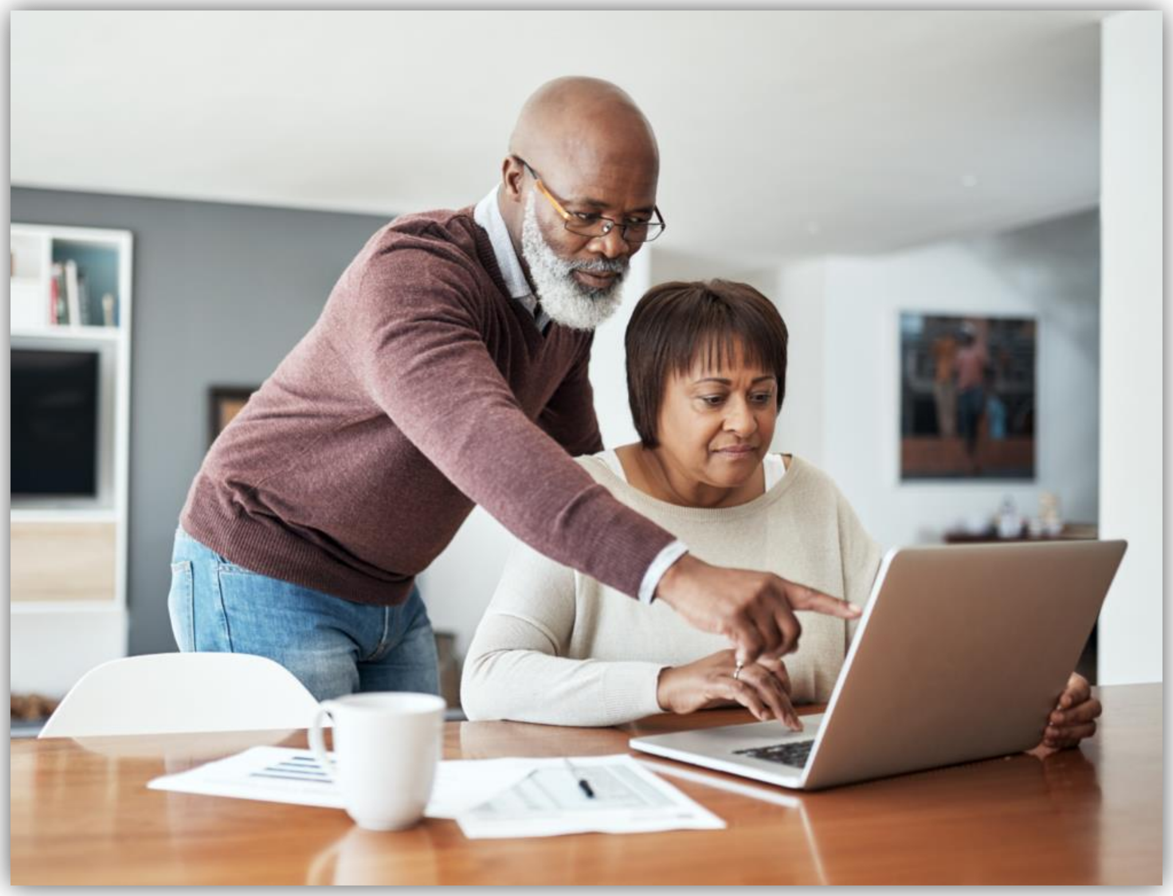
This is an important – perhaps the most important – moment in the program. Some – if not many – caregivers may have, up to this point, been content to see this as a more passive experience. **You've got to continue to make it clear that they really need to attempt to practice what you're teaching them in order for this to work.** Let them know that the sessions in the next two weeks will center on their reports from home – and that the upcoming learning will be based on this for everyone.

At the same time, emphasize that they can work on a small thing, not necessarily the thing (behavior) that is bothering them the most. For example, they might see if they can get the person to engage in some kind of activity that s/he has not done before – e.g., helping with chores or meals. Or see if they can find something that the person might be content to do on his/her own, even for 10 or 15 minutes. They might try to see if they can do something about a small thing that is bothering them (e.g., the person always wants to wear the same thing). If the person always asks the same question, they might try strategizing about an answer they want to give.

Basically, what you want them to do is to try to make some basic change in strategy. It might even be a change in the way they talk to or provide information to the person. Might, for example, talking in shorter sentences or providing less information until a time at which it is absolutely useful change the way the person behaves (for example, might it change the questioning the person does during the day)?

Weekly Session 4 Notes

Weekly Session 5



"The universe has no fixed agenda. Once you make any decision, it works around that decision."

Deepak Chopra

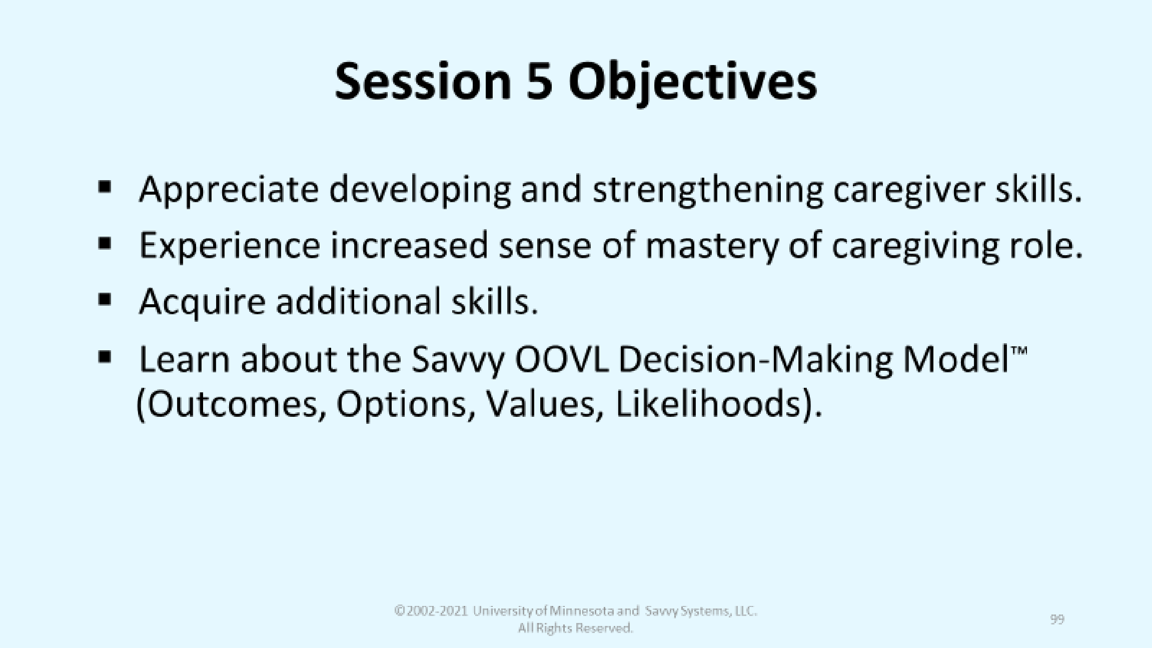
Session Agenda

Savvy Caregiver Program
Weekly Session 5 Agenda

Instructional and Topic Areas	Content Included In Topic Area	Approximate Time
Coaching and Review	• Work on Issues of Behavior • Self-Care Activities	30 Minutes
Teaching: Managing Day-to-Day Behavior	• Linking Structure, Support, and Levels of Performance • Taking Care of Daily Needs • Facilitating Contented Involvement	35 Minutes
Teaching: Decision-Making and Finding Help	• A Model of Decision-Making for Family Caregivers	30 Minutes
	• Resource Mapping	20 Minutes
Home Practice	• Assigned Home Readings and Practice Tasks	5 Minutes

Program Leader’s Overview of Session 5

A shift takes place in this session and continues through session 6. Last week’s home assignments were aimed at having caregivers put the main lessons of the program into practice. This week and next, you will want to spend significant time during the session debriefing with the caregivers about their efforts to put instruction into practice.



Session 5 Objectives

- Appreciate developing and strengthening caregiver skills.
- Experience increased sense of mastery of caregiving role.
- Acquire additional skills.
- Learn about the Savvy OOVL Decision-Making Model™ (Outcomes, Options, Values, Likelihoods).

A goal of this session will be to have caregivers describe their efforts at putting caregiving strategies to work. In addition, there are two new “classroom” segments in this session. The first one gives more examples of using Performance, Structure, and Support to anchor Contented Involvement. The second topic introduces participants to a model of decision-making that they can use both with larger, long-term decisions and with making choices about day-to-day management.

Review and Coaching Segment
Questions about readings or previous weeks’ materials. As always, begin by asking if any of the participants has questions. This provides a chance for you to clarify material – and also to see where coaching might be useful.

Home Application Debriefing

Issues of Behavior. The main assignments were to try to change some behavior that was bothering the caregivers and to try to design a morning or an afternoon activity the person would enjoy.

As usual, have the caregivers volunteer to describe what they did. Those who tried and met with success will usually want to step forward to talk about their experience. Those who tried and did not meet with success – or at least what they had in mind that success might look like – will also likely step forward. You may find that you will need to prompt caregivers' participation, so it may be useful to remind them of the home activities (work on a behavior that bothers you and work on finding a morning and an afternoon task or activity that the person gets involved in and likes doing). Then try asking them (for example):

- ✓ Tell us about your efforts and successes in trying to influence some behavior of your person last week – efforts to encourage the person to do something – or to stop doing something.

- ✓ Tell us about something that was bothering you and trying to use what you know about the Levels of Thinking and the ideas of Structure and Support to do something with the person about that?

- ✓ Did you try to design things the person might do in the morning or in the afternoon?

- ✓ Did anybody try things but find they didn't work? What did you learn from it? Did you make any adjustments?

This exercise involves a particularly important facilitation task, and it is important that you know what you are expecting. There may not be a lot of reports of success. The distribution of caregivers' experience with this home activities assignment will likely look something like this:

- ➢ One or two will have tried the assignment in a way that suggests they really understood a lot of the program principles and ideas, and they will have met with success. That is, they will…
  - ⇒ Describe what they did in terms that reflect the content of the program (applied, for example Structure and Support strategies appropriate to their person's stage (level of performance)
  - ⇒ Report that their person's behavior changed in ways the caregivers both anticipated and appreciated, and
  - ⇒ Demonstrate a sense of pride or accomplishment in what they did.

At least one or two caregivers will have tried to apply the principles and ideas of the program, but they will seem not to have worked. Point out that trying things moves them from powerless to powerful on the feelings grid.

- ➢ The others will report that they did not try to do the assignments (change behavior or develop a morning or afternoon activity).

Be sure that you "call on" all of the caregivers. Those who didn't have much success or those who didn't do the home activities – or who think they didn't – should be asked what they did or tried during the previous week. You are likely to find that even those who say they didn't do the home activities did, in fact, put some of the lessons of the program into play. Try to draw this out of

them – they may not have realized at the time that they were doing this but the class conversation – particularly the part where they are hearing what others did – may make them aware that they did try some things, even if not consciously. So, encourage all to report on their home activities. Every caregiver can offer something to the group discussion.
Think of each report – whether of success, failure, or not trying – as an opportunity to teach the Savvy Caregiving model. You will have a number of different kinds of opportunities to support caregivers' attempts at applying the new information and strategies.

It may be that success came from application of some of the ideas presented earlier in the program. For example, we have found that for some caregivers an appreciation of the concept of Confusion has been particularly important in their becoming more understanding of and patient with some troubling behaviors of the person. This understanding has, in turn, allowed them to develop responses that are effective but that also allow them to be less drawn in by the person's behaviors.

- A good example is with the issue of repetitive questioning. Seeing that the questioning is driven by a need for security – rather than not paying attention or a desire to annoy or be difficult – might help the caregiver to develop one or two responses that are meant to address the feeling and to reassure rather than to directly address the question.

- Another example goes back to the material on cognitive loss presented in the first session. A caregiver who comes to see the impact of diminished capacity in language and reasoning might, for example, consciously decide not to present too much information.

    ⇒ S/he may, for example, not tell the person what the whole day will be like but to deal with things only as they come up or are about to happen.

    ⇒ S/he may decide to change the way in which s/he speaks to the person.

    ⇒ S/he may have decided to shorten sentences or to use declarative sentences rather than to ask questions and involve the person in decisions. So, for example, instead of saying, "would you like to go for a walk after lunch?" the caregiver may now say nothing about the walk until it is time for it and now say, "Come with me. We're going for a walk."

Those who put the principles into play and met with success should be acknowledged, and they should have an opportunity to talk about how they feel about the success they met with. Their success also provides you with an opportunity to review how they approached the task. This lets you go back over it and make whatever the appropriate points might be about the way in which the caregiver used knowledge of the stage (performance levels) or of the design principles (Support or Structure) to achieve success. Use this as a chance to review the steps the caregiver took – to go back over the ground s/he covered in putting together the Structure and Support steps to achieve the end s/he achieved.

A problem you might encounter is a too rigid application of the principles. The first place you might see this is in a too fixed estimate of the person's stage. The caregiver may be thinking of the person as being more or less impaired than s/he actually is. This, in turn, would cause the caregiver to be applying management principles from the Structure and Support worksheet that don't actually fit the situation. A simpler example might be that the caregiver is applying the ideas from the grid presented in Session 4 that links stages to structuring and providing support for tasks too mechanically – "It says 5-6 steps, and that's what I tried."

Even with the class exercises and the readings, the material is not always easy or easily understood. For all the caregivers who are reporting, listen for how they talk about what they did and how they used the information from the program. Make sure that their understanding of the ideas and principles is correct, and if it is incorrect in any way, take this as a teachable moment, a chance to review the material and help the individual to be clearer about it.

Remember, too, that even if the effort didn't yield the desired effects, the caregiver should be appreciated for making the effort. The experimental attitude is especially important and should always be encouraged.

Particularly for those who reported that they didn't do the home activities, this portion of the program should be used to encourage them to do the home activities this week (it will be virtually the same assignment). Provide an opportunity to those who did not volunteer a report to talk about what they did do during the past week to put some of the Savvy Caregiver principles into effect.

Some participants will choose to wait to report to the group until they have what they define as a clear success. Until that time comes, they may report that they didn't do anything – or at least not anything very much. See if you can get them to talk about what they did do. It may be they really did not try anything, but there is a good chance that they did make some attempts, and this will give you an opportunity to affirm them for their analysis and to encourage them for their efforts.[16]

Review Self Care Activities. Ask the group to report back on activities aimed at dealing with their own feelings related to caregiving (identifying and transforming "negative powerless" feelings to more positive and powerful ones) and at taking some time to do something for themselves.

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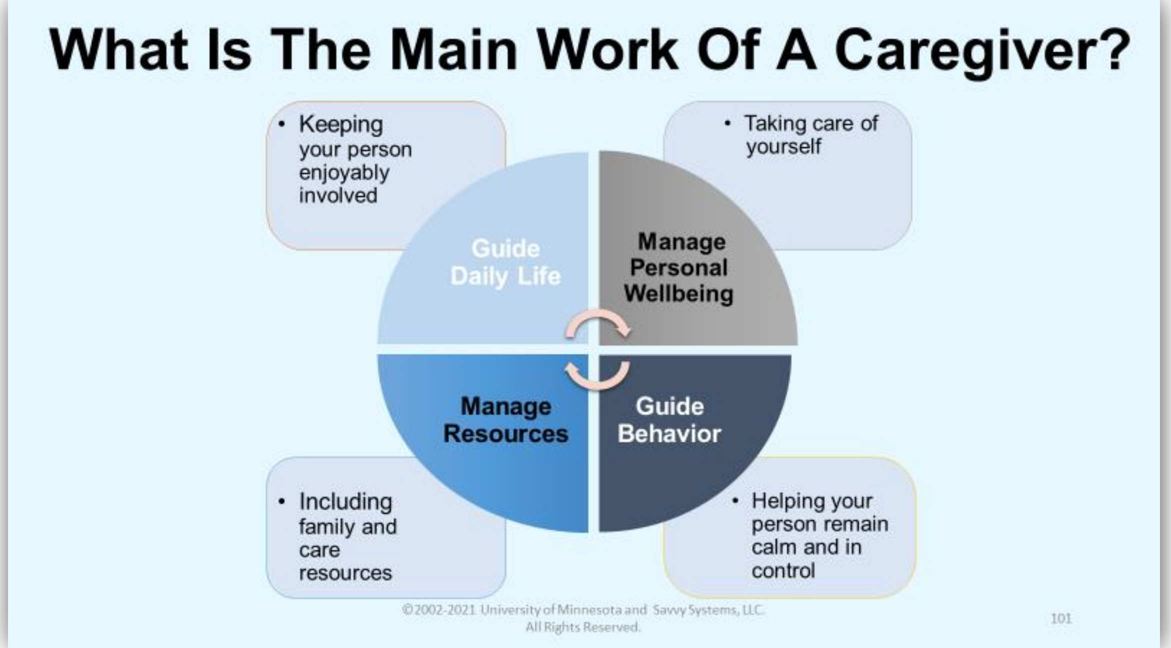
[16] Some tips from experienced Savvy trainers: Always encourage and elicit responses, but respect individual limits to how much people are willing to participate. Passive participation also leads to learning, and they will all demonstrate their learning in their own way. Not everyone cares to brag. Ask the caregiver who doesn't seem to be doing the home assignments what they're observing with their person. Ask if they've changed anything about themselves, i.e. self-care, are they letting things go, are they feeling more patient, etc. Some don't identify as doing anything when they actually are. That acknowledgement often encourages them to actually try and report on a strategy the next week.

Anchors of Contented Involvement, Revisited

Anchors of Contented Involvement, Revisited. This portion of the program focuses on strengthening caregivers' understanding and use of the Anchors of Contented Involvement, Structure, and Support – as well as on their ability to make practical use of these tools in their caregiving. By this point in the program, caregivers should be relatively comfortable thinking and talking about what they do as a "job," or at least recognize that caregiving requires a set of skills, knowledge, and strategies. It might be useful to use the diagram below as a way of reminding them about the main components of the job they have undertaken.



What Is The Main Work Of A Caregiver?

- Keeping your person enjoyably involved

Guide Daily Life

- Taking care of yourself

Manage Personal Wellbeing

Manage Resources

- Including family and care resources

Guide Behavior

- Helping your person remain calm and in control

Remind participants of the information on guiding behavior that they learned earlier (Sessions 1-4). The discussion on Confusion was a key part of that – focusing on the roots of the kinds of behaviors that caregivers often find troubling or difficult. Readings in their manual relate to the issue of dealing with or avoiding troubling behaviors.

Caregivers may be making their first efforts to apply the principles of the program to managing life around the home with the person affected with a dementia illness. In its simplest form, the idea of managing daily life comes down to two big categories:

- Taking care of the person's personal daily needs (keeping clean, getting dressed, eating, etc.).

- Getting the person appropriately involved in things so the day is as safe, calm, and pleasant as possible. The rest of this portion of this session will focus on exercises designed to get participants to apply what they have learned about the design of tasks and activities.

This session is “looser” than the previous four sessions; it is less scripted and relies more on your engaging participants in the spirit of the exercises; the video you’ll show is meant to exemplify the application of the Anchors in a real-world setting. The exercises are meant to provide participants with practice in applying the Anchors of Contented Involvement to three tasks and activities. This is meant both to review (and, if necessary, clarify) the concepts (Person/Structure/Support) and to remind participants of the linkage between the anchors and the stage of illness in which they estimate the person to be. Depending on the size of the group you’re leading, you might want to group participants by the stage estimates of their care recipients (match Early stage caregivers with other Early stage caregivers – and so on).[17] In each of the exercises, use a strategy of asking those caring for persons at the different stages to respond to lead questions, and then ask the rest of the group to contribute their thoughts.

Linking Design to Stages

Two Exercises: Washing Up – and Getting Dressed – in the Morning. In the first exercise, caregivers will be asked to design and specify the kinds of Structure and Support strategies they would use to involve persons at various stages of dementia-related illnesses in a task related to personal daily needs. In this case, ask them to think about helping a person to wash up and get dressed in the morning. Have the participants review the handout on washing up. This handout brings together all of the key concepts you have introduced and focuses them on the issue of managing a daily task to meet personal need.

The first part of the exercise is to walk participants through the handout. You will not be asking them to “do” anything during this part, just to be following along and noting how the grid works.

Show caregivers how the handout works. Note that the columns relate to stages and corresponding levels of performance – each column focuses on working with a person at a different stage of the illness.

- The first row identifies a range of capacities at various stages.
- The second row relates to Structure.
- The next two relate to components of Support.

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[17] This is not a frequently employed strategy. Most facilitators do this as a whole-group exercise.

So, reading down any column, the table provides an outline of information about how to Structure the washing up or dressing task for a person at that stage and level of performance and then how to Support the person through the task – what kind of help to expect to give and how best to provide the information that conveys the help.

After reviewing the handout, **have the caregivers focus on the matter of helping a person to get dressed in the morning (the second exercise,** which is also found in both manuals and can be provided as another handout)**.** By now, participants have all settled on an estimate of their person's stage.

- ⇒ Go around the group and have each person say what s/he thinks her person's stage or level is. Let participants working with persons at the same stage describe – in a fuller way than is in the handout – just what they would do to provide Structure and Support for helping their person to dress in the morning.
- ⇒ Ask them to describe the set-up, the needed assistance, and the cues they'd provide.
- ⇒ **OR**, you could have one person in each stage group take the lead for the group and have the others chime in.

Use the larger group to provide comment – offer additional suggestions for what might be done at each stage – on the way in which the stage-specific participants had set up and carried out the Dressing task. You might have to prompt the group to provide feedback and comment. They may feel they are criticizing their colleagues, so here are some prompts you might try:

- ⇒ What do the rest of you think about the way they set things up for that person at (fill in) stage?
- ⇒ Would you have done it the same? Might you have done more – or possibly less?
- ⇒ What about the way they plan to help the person through the task? What might you add or take away from what they're planning?
- ⇒ How would you suggest communicating what you want the person to do?
- ⇒ Are there other ways you might help the person to get through the task?

The key is that participants appreciate that they are developing a kind of fluency with the Savvy Caregiver principles – that they see the relationship between stage of disease and level of performance and the way they work with the person (through Structure and Support).

In addition, it is especially important that caregivers begin to recognize that keeping the person's disease stage in mind provides them with a strategy for helping the person that can be generalized across most tasks and activities.

Getting Washed Up in the Morning Worksheet

Stage	Early	Early-Middle		Late-Middle		Late
Activity/Role	Able to wash up, shower and groom by self.	Able to wash up, shower and groom by self, but may lose track of the task at times.	Can perform the physical activities involved in morning washing up, but may need support to stay on task.	Able to perform discrete actions (wash, brush, etc.). Will need structure and support for keeping the goal and sequence in mind.	Able to perform gross actions (wash, brush, etc.). Will need assistance to be effective and not repetitive.	Might perform some gross tasks by self (e.g. using washcloth on face) with support. Can comfortably accept care.
Set-Up	Be sure the wash up area is accessible and ready.	Be sure the wash up area is accessible and ready.	Make the wash up area accessible and ready. Have materials (cloth, soap, tooth paste, toothbrush, comb, towel) laid out and remove distractions.	Make the wash area comfortable. Lay out specific materials (cloth, soap, toothbrush, towel, etc.), preferably in the order they'll be used. Remove distractions.	Make the wash area comfortable. Lay out specific materials (cloth, soap, toothbrush, towel, etc.), preferably in the order they'll be used. Remove distractions.	Make the wash area comfortable. Specific materials (cloth, soap, toothbrush, tooth paste, comb, towel, etc.) laid out for caregiver convenience.
Assistance	Able to do by self (unless another issue interferes); check back for task completion.	Give overall direction, check back more than once to redirect if necessary.	Set stage (it's time to wash up), give directions (okay, wash your face); return frequently to check and prompt.	Focus on the individual actions that make up the washing up task; remain with person to cue.	Each sub-task is an end in itself. Hand the equipment needed, start on task, refocus and redirect as needed.	Each sub-task is an end in itself. Person can do as much as able. Likely mostly done by caregiver.
Cues and Communication	Usual greeting and general direction: "Time to get going; I'll need your help with breakfast; wash up then come help me."	Specific direction (don't offer larger context): "It's time for you to wash up." Then specific cues: "have you… (washed, brushed, etc.)?'	Have all equipment laid out and in sight; provide reminders to stay on track; may need to direct for each sub-task.	Verbal and visual cues (pick up washcloth and hand it; say "wash your face," pointing to the face.) Take the person through all steps.	Verbal, visual, and tactile cues (pick up washcloth, hand it, say "wash your face," point to or touch face.) Help the person get started with hand over hand help. Take through all steps for each sub-activity.	Simple verbal cues with emphasis on visual and tactile. Hand over hand help may enhance participation. Communicate what is being done.

Getting Dressed in the Morning Worksheet

Stage	Early	Early-Middle		Late Middle		Late
Activity/Role	Able to dress by self; able to choose own clothes and put them on without error or assistance	Able to dress self; able to choose and put on clothes, but may make poor choices (e.g., want to always wear same thing or not dressing for the weather).	Can perform the physical activities involved in dressing, but may need support to stay on task.	Can perform discrete actions (put on items) but may need structure and support for keeping the goal and sequence in mind	Able to perform gross actions (putting on clothes), but may need assistance to be effective (e.g. managing zipper) and not repetitive	Might perform some gross task (e.g. putting arms into a shirt) with support, and visual cues. Can comfortably accept care.
Set-Up	No set up really necessary	Consider beginning to simplify clothes closet to limit choices and avoid confusion	Focus on clothes closet. Simplify, hang outfits together	Set out the clothes in order of putting on. Remove or greatly limit choice. Close the closet door.	Set out the clothes in order they will be put on. Don't offer choices.	Set out the clothes in order of putting on. Hand each in order.
Assistance	Able to do by self (unless another issue interferes); check back	Able to dress with overall direction. Check back more than once to redirect if necessary	Able to dress with structure and support. Set stage ("It's time to dress"); give directions ("Put on your pants."); return frequently to check and prompt	Able to perform the individual actions that make up the task of dressing. Remain with person to cue through steps.	Able to perform individual steps in dressing process. Each sub-task is an end in itself. Hand the garment, start on task, refocus and redirect as needed	May be able to perform some individual steps with help. Each sub-task is an end in itself. Help the person to take part, as able. Likely done primarily by caregiver.
Cues and Communication	Usual greeting and general direction: "Time to get dressed now." However, person may not need cue at all.	Specific direction (don't offer larger context): "It's time for you to dress." Then specific cues: "Are you dressed yet?"	Might need to have clothes laid out and in sight; provide reminders to stay on track; may need to direct for each part of getting dressed	Verbal and visual cues (pick up garment, hand it; and say "put this on," perhaps mimic the action.) Take through all steps.	Verbal, visual, and tactile cues (pick up garment, hand it, say "put this on," Mimic action.) Get them started with hand over hand help. Take through all steps for each sub-activity.	Simple verbal cues with emphasis on visual and tactile. Hand over hand help may enhance participation. Communicate what is being done

Exercise: Contented Involvement in Everyday Tasks. The next exercise focuses on a major management issue facing caregivers – helping the person to be content and involved in things during the day. The issue is straightforward. There is just so much of the day that is given over to basic personal activities, like dressing, grooming, and eating. After that, what does the person living with a dementia-related illness do with the rest of his/her day?

As the disease progresses, getting their persons involved in activities or tasks falls more and more on caregivers. Being involved will help keep the person focused, and that may help to keep Confusion – and the adverse effects of Confusion – at bay and may improve the person's quality of life. Doing things can be enjoyable. Additionally, if caregivers can get their persons involved in things, there is a greater chance that caregivers will find some time and space to do things that they want or need to do, thereby possibly improving their own quality of life.

Start the exercise by asking participants to list all of the things that go into making a meal.[18] Below are some possible answers you can use to prompt the discussion.

Meal Preparations	Preparing and Cleaning the Dining Area
▪ Mixing ingredients together ▪ Measuring ingredients ▪ Stirring ▪ Peeling – carrots, potatoes, fruit, etc. ▪ Shredding – e.g., tearing lettuce for a salad ▪ Chopping and dicing– cutting things up for a salad or to prepare for cooking ▪ Shelling peas or preparing string beans ▪ Rolling (cookies) ▪ Pouring – e.g., water or juice into glasses ▪ Buttering bread/toast ▪ Putting sandwiches together ▪ Putting food in containers ▪ Helping to cook things [e.g., spaghetti sauce, chili] ▪ Cracking eggs into a bowl ▪ Pouring syrup into containers ▪ Frosting cakes or cookies	▪ Getting things from the kitchen and other areas (e.g., the laundry room for tablecloths and napkins) ▪ Arranging tables and chairs ▪ Folding napkins ▪ Setting the table – putting on tablecloth ▪ Putting silverware on tables ▪ Putting napkins on tables ▪ Putting condiments on tables ▪ Putting water/juice on the table ▪ Putting flowers into vases for centerpiece (e.g., one rose into a small bud vase for the table) ▪ Putting flowers/other decorations on table ▪ Bringing things from the kitchen ▪ Taking things from the table to the kitchen ▪ Sponging down the table ▪ Sweeping or vacuuming under and around the table ▪ Rearranging the room ▪ Doing and/or drying dishes

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[18] If you sense the group is caring for individuals who won't be interested in preparing a meal, have them choose another more likely household task and brainstorm a list of steps and tasks.

Then have the group members focus on their own persons. Have them say – for the specific stage – what kinds of mealtime tasks they might try to involve their person in and what kinds of Structure and Support help they would give. **Make the point that this isn't about what they are currently doing but about what they might do.** Get them to try to loosen up here – even if the person doesn't help now (and even if s/he never helped) what might the person do? Reiterate that tasks should only be delegated where the caregiver will find the outcome acceptable.

Stage	Structure and Support Considerations	Suitable Mealtime Tasks
Early	▪ Should be able to perform tasks involving moving about the home ▪ Should be able to do 4-5 step tasks ▪ Will likely keep the purpose of task in mind ▪ Provide clear verbal direction	▪ Getting things from other areas ▪ Arranging an area ▪ Measuring and mixing things together ▪ Taking things back to the kitchen and other areas ▪ Helping to cook
Early-Middle	▪ Should be able to perform tasks involving moving about the home ▪ Should be able to do 3-5 step tasks ▪ Will likely keep the purpose of task in mind ▪ Provide clear verbal direction ▪ Check a few times; may have to remind	▪ Getting things from other areas ▪ Arranging an area ▪ Taking things back to the kitchen and other areas ▪ Measuring and mixing things together ▪ Sweeping/carpet sweeping under/around the table ▪ Doing and drying dishes ▪ Helping to cook; making sandwiches
	▪ Needs a more contained area of work (e.g., the dining room) ▪ Can do a 2-4 step task; repetition is good ▪ Make sure materials are ready and out ▪ Give directions and visual demonstration; show end product if possible; help to start on task ▪ Check regularly; provide reminders to stay with the task; correct positively ▪ May need to be redirected	▪ Putting silverware and condiments on tables ▪ Making sandwiches ▪ Putting food in containers ▪ Preparing string beans; shelling peas ▪ Putting on napkins and/or tablecloths ▪ Putting water/juice on the table ▪ Putting flowers/other centerpieces on tables ▪ Taking things from the table ▪ Sponging down the table; drying dishes ▪ Rearranging the room
Late-Middle	▪ Needs a task that is right within reach – a sit down task is best ▪ Can manage a 1-3 step task – needs repetition; likely won't recall purpose ▪ Demonstrate; visual directions; show end product; start on task ▪ Will need frequent checks to redirect and keep going on the task.	▪ Wrapping silverware in napkins ▪ Putting flowers into vases ▪ Peeling, shredding, chopping, and dicing ▪ Rewashing things ▪ Stirring; rolling (cookies) ▪ Cracking eggs into a bowl ▪ Buttering bread/toast
	▪ Don't worry about quality, only involvement ▪ Keep task in sight and reach; remove distractions (face a wall at a table) ▪ Needs a very simple task ▪ Repeated visual demonstrations; hand object to person; give simple command ▪ Check back often for comfort and task	▪ Rolling (cookies) ▪ Simple folding (napkins in half) ▪ Stirring ▪ Frosting
Late	▪ Likely can only enjoy passive activity	▪ Wiping surface in front of him/her

	▪ May do single step task, if simple	▪ Spreading butter already placed on bread

After the group members have brainstormed about what they would do to involve their person (at a specific Level of Thinking) in mealtime activities, have the other group members chime in with additional suggestions both for activities and for Support and Structure ideas. Once everyone has reported, use the grid above to provide additional feedback and suggestions in response to the exercise. Also, use the grid to look at ideas about stages not covered in the group exercise. Note that tasks listed in later stages could be equally appropriate for a person in an earlier stage (but not vice versa).

Using the mealtime example gives you an opportunity to deal with an issue that often comes up when trying to get caregivers to try to involve their person in various activities – the idea that certain activities are "off limits." Caregivers may say, for example, that a male living with a dementia illness had never done certain household tasks (like cooking or laundry) or that a female had never done other kinds of chores (for example, yard work). While these kinds of activities might not reflect a strong association with the Person anchor (these were not things in which they had shown much if any interest in their lives), there might be another element of the Person anchor that they can tap into – the interest in helping and/or being with the caregiver. Urge caregivers not to be too quick to dismiss an idea for an activity just because it was something "s/he never did." A wife caregiver might, for example, at least try to see if her husband could get involved in a food preparation task or a cleaning task just to be of help to her.

Brainstorming Exercise. The final exercise of this part of the session will be to involve participants in a brainstorming exercise.

Have the participants brainstorm as many tasks or household activities as they can come up with that they might try to involve their persons in. Note that these “activities” may not always result in a “useful” outcome. The goal is to engage the person, not to make him/her productive.

Keep track of the responses and use the list below as a stimulus for additional ideas.[*]

- Making the bed
- Straightening up around the home
- Hanging up clothes in the closet
- Folding their own clothes
- Putting clothes back into drawers
- Rinsing and drying dishes and glasses
- Polishing
- Dusting
- Watering plants
- Setting up and cleaning before and after various activities
- Using a vacuum cleaner and broom
- Helping with personal laundry
- Helping with tasks in the kitchen
- Weeding
- Keeping the outside clean
- Mowing the lawn
- Raking leaves and grass clippings and sweeping walkways
- Tending plants and flowers – including vegetable garden

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[*] **Point out that the discipline of Occupational Therapy offers many insights into keeping persons with dementia contented and involved in tasks and activities. It might be helpful to refer participants to work done by Jitka Zgola, an Occupational Therapist. Two of her books, *Doing Things* and *Care That Works*, are published by Johns Hopkins University Press; she is easily googled.**

The Cherry Tart Video. The third Savvy Caregiver program video is of an Occupational Therapist who is highly experienced in working with individuals and groups of individuals who are living with dementia-related disorders. The video is of this OT working with four women who are each at different stages in their illnesses. She is modeling the use of the Anchors of Contented Involvement. The video is segmented so that the task of making cherry tarts is presented from beginning to end. There are a number of key teaching points:

- The OT is operating from the perspective of understanding the strengths of each participant; this understanding derives from her appreciation of the person's stage of illness.
- She gives each person a task that fits her strengths (stage) and sets up the tasks in a way that takes best advantage of these strengths.
- She directs each person in a manner that is appropriate for her strengths (stage) – note how the combinations of tailored speech and visual/tactile guidance vary for each individual.
- Note the level of engagement of individuals: some talk to one another as the activity proceeds; others are focused only on the task in front of them and don't seem to interact.
- Note, too, the apparent pleasure each member of the group is taking in the cooking activity – one that seems familiar to each of them.

The video serves both to reinforce the first exercise (fitting activity of daily living task to individual abilities) and provide some reassurance for encouraging participants to engage with their person in one or more of the activities identified in the third exercise.

OOVL Decision Making Guide for Families

(pronounced “oval”)

Decision making is an essential part of caregiving, and offering participants a decision-making guide is one of the important Savvy Caregiver concepts and strategies. This section of the training describes the OOVL Decision-Making Guide, an approach that includes the four major aspects of decision making: Options, Outcomes, Values, and Likelihoods (OOVL), which are further described below.

Caregiving for a person living with Alzheimer’s disease and other dementia-related illnesses includes both the day-to-day caregiving tasks and a full range of decisions that need to be made. These decisions relate to everyday concerns (such as how much help to provide in daily activities like bathing or dressing) to long-term decisions (such as how best to use financial resources, and whether to use a adult day program or help the person move to a residential setting). When people are faced with making decisions day in and day out, they may feel burdened, frustrated, and even in conflict with other family members.

For some dyads, decision making was previously shared; spouses/partners may have developed ways of jointly making decisions – or perhaps one of the two took on more responsibility. When the dyads involve adults caring for parents or other relatives or friends, there was likely not a history of any shared decision making. When a spouse or parent is diagnosed with a dementia-related illness, decisions still have to be made even though established patterns of making those decisions may be disrupted. A new method of making decisions has to be established.

For some people, major decision-making is a new experience and an added role and responsibility. Sometimes other family members can provide support in making decisions, but often they have different opinions about what to do, lack all of the facts, or live too far away to provide practical assistance or help.

The OOVL Guide was developed to assist caregivers in the decision-making task. This tool helps caregivers break down any decision into manageable and meaningful parts, and then review their input to make a decision. The OOVL Guide enhances people’s decision-making skills in general.[19] Therefore, it is applicable to many decision-making situations, not just dementia-related decisions.

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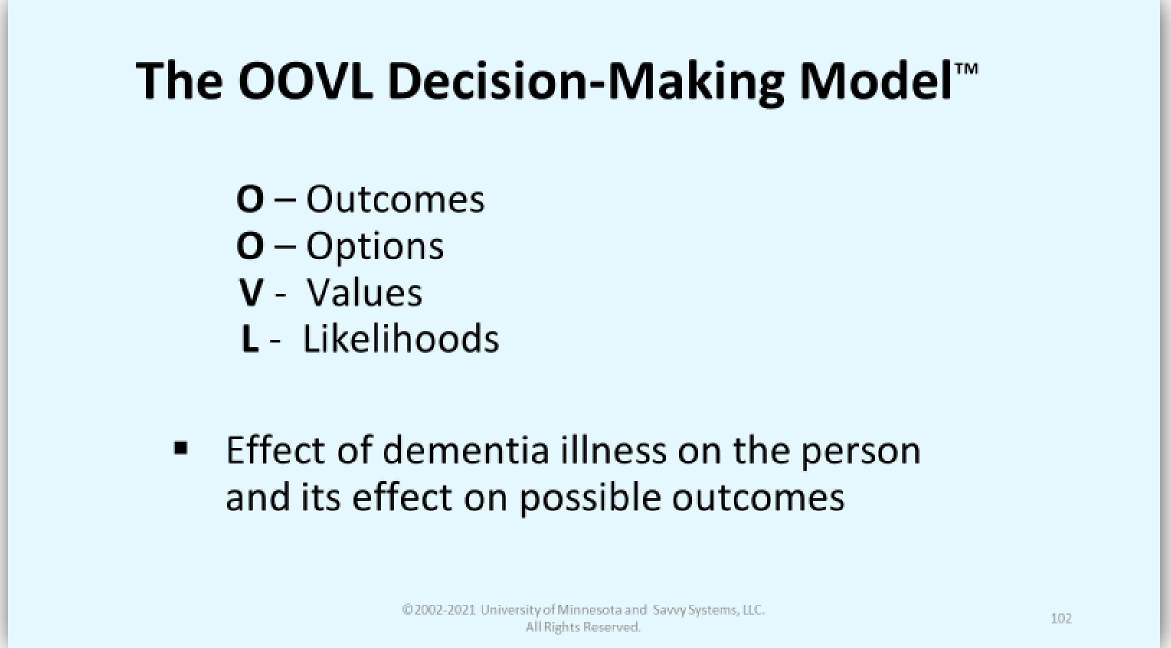
[19] See: Lewis, M., Hepburn, K., Corcoran-Perry, S., Narayan, S., & Lally, R. M. (1999). Options, outcomes, values, likelihoods decision-making guide for patients and their families. *Journal of Gerontological Nursing, 25*(12), 19-25. doi.org/10.1080/01634372.2013.859201



The OOVL Decision-Making Model™

O – Outcomes
O – Options
V - Values
L - Likelihoods

- Effect of dementia illness on the person and its effect on possible outcomes

Caregivers have to make decisions every day. So, as you introduce the topic of decision-making and as you teach this segment, keep pointing out to participants that decision-making is not just about big, long-range decisions like selling a house or moving a person to a more protected environment. Caregivers have to decide about how to involve the person in activities, and they have to decide how much to involve their care recipients in those decisions. Every part of caring for a person whose cognitive powers are eroded by illnesses like Alzheimer's involves making decisions. So, this segment of the program is about both big decisions and smaller, everyday decisions. Decision-making is a tool for day-to-day management.

The OOVL Guide provides caregivers with a structure and procedure for making choices for themselves or others. The procedure is a series of questions – presented in Table 1– for working through the decision-making process. You have some teaching options here. You can use the instructional video (Dr. Lewis guiding caregivers through the OOVL model) alone or in conjunction with your own presentation of this material or you can just teach the method without the video. The video uses the same example (Mrs. Murphy) as the Trainer's Manual and the Caregiver's Manual, so the elements should reinforce each other.

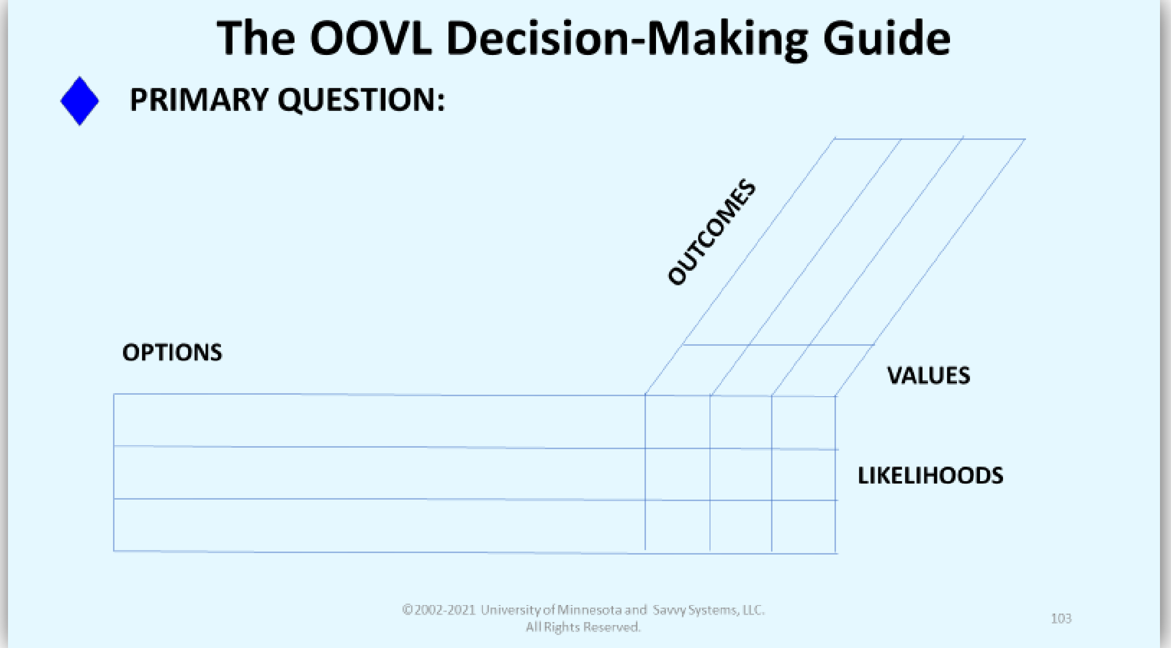
After you teach the OOVL method and illustrate how it works with the Mrs. M. example, draw from the group at least two examples of decisions they are facing. Participants may have already mentioned something they are trying to sort out and may be willing to have the group help problem-solve. Search for an example of a long-range issue but also search for an example of something that is more short-term and day-to-day. If time permits, have the participants work through both examples. (Prepare blank OOVL grids on a flip chart or white board ahead of time to record ideas.) This will provide them with confidence that they can use the grid, and it might actually demonstrate the utility of the grid to caregiving. If participants have blank copies of the decision grid, it makes it easier for them to work through the examples, so provide as a handout.

Questions to Guide the OOVL Decision-Making Procedure

1. What do you need to make a decision about? (**Primary Question**)
2. What actions are you considering? **(Options)**
3. What are the consequences of the decision about which you are most concerned? **(Outcomes).** Emphasize that all the outcomes should be framed as positive for the weighting to work correctly.
4. How important are each of these outcomes to you? **(Values)**
5. How likely is it that each option will lead to each of the outcomes? **(Likelihoods)**
6. What option is most likely to achieve the best outcomes?

Outcomes are the expected results or consequences of each option. **Values** are defined as the importance assigned by the decision maker to the outcomes. **Options** are defined as the various actions being considered in making a decision. Finally, **Likelihoods** are the probabilities that outcomes will occur.

The blank OOVL form is pictured below representing each component: **options, outcomes, values, and likelihoods**.



The OOVL Decision-Making Guide

◆ PRIMARY QUESTION:

OUTCOMES

OPTIONS

VALUES

LIKELIHOODS

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The grid and questions enable the decision maker to work through different scenarios associated with the options under consideration. In order to keep the process manageable, it is recommended that persons limit the number of options and outcomes under consideration. An example of a decision situation that a family caregiver might encounter illustrates the structure and procedures of the *OOVL Guide.*

Illustration

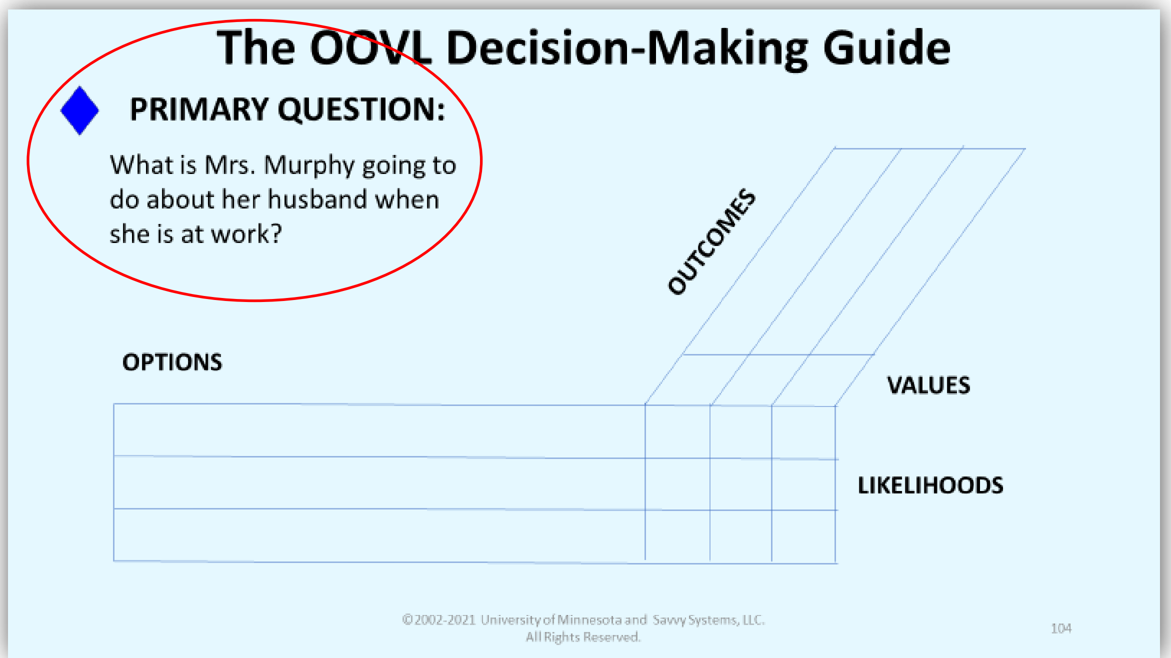
> Mrs. Murphy works every morning at a florist shop. She enjoys the work and the time away from home, and the extra money helps. Mr. Murphy, who has Early-Middle Stage of his illness, has remained at home alone. Lately, Mrs. Murphy has become concerned about Mr. Murphy's ability to stay by himself after an incident in which she came home to find the front door unlocked and the gas stove on. Mrs. Murphy feels that she must decide what she is going to do about her husband when she is at work.

Questions to Guide the Decision-Making Procedure

1. What does Mrs. Murphy need to make a decision about (Primary Question)?

The decision situation is what Mrs. Murphy is going to do about her husband when she is at work.

The slide below illustrates the completed OOVL guide as you walk through the steps of the decision-making process.



The OOVL Decision-Making Guide

◆ **PRIMARY QUESTION:**

What is Mrs. Murphy going to do about her husband when she is at work?

OUTCOMES

OPTIONS

VALUES

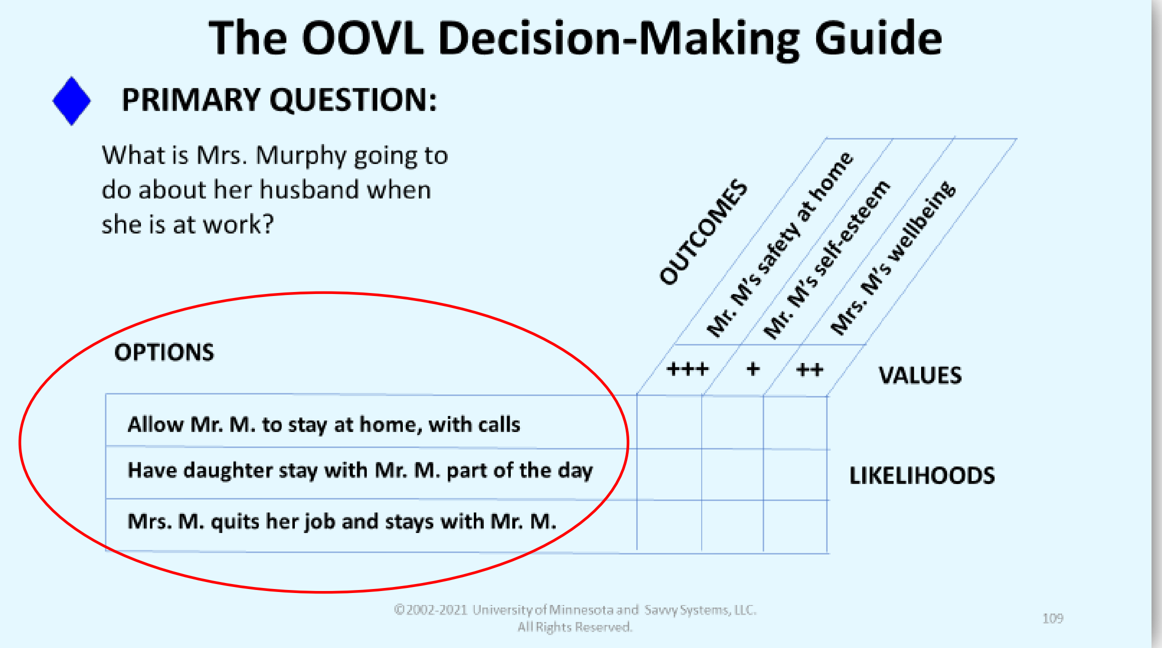
LIKELIHOODS

2. What options is Mrs. Murphy considering (Options)?

Mrs. Murphy identifies numerous **options**, but narrows them down to three specific ones:

(1) Allow Mr. Murphy to stay home alone, but call him every hour;
(2) Ask her daughter to come and stay with him during the morning; or
(3) Quit work.

(The three options are listed on the left side of the decision guide illustrated in the slide above.)



The OOVL Decision-Making Guide

◆ **PRIMARY QUESTION:**

What is Mrs. Murphy going to do about her husband when she is at work?

OUTCOMES

VALUES

LIKELIHOODS

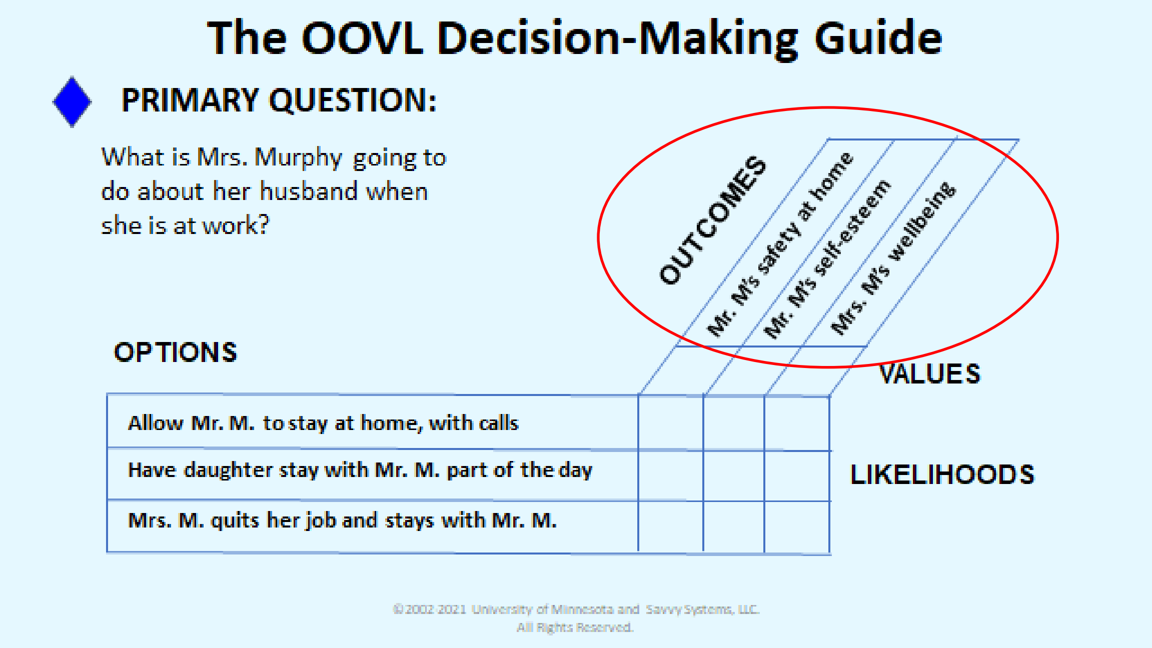
OPTIONS	Mr. M's safety at home	Mr. M's self-esteem	Mrs. M's wellbeing
	+++	+	++
Allow Mr. M. to stay at home, with calls			
Have daughter stay with Mr. M. part of the day			
Mrs. M. quits her job and stays with Mr. M.			

3. What would Mrs. Murphy like to have happen as a result of her choice (Outcomes)?

Any option that Mrs. Murphy chooses will have some **outcomes**. She needs to think about what she wants to have happen for herself and her husband, and what she wants to avoid happening. In this situation, Mrs. Murphy identifies three important results she wants to consider in choosing an action:

- She wants Mr. Murphy to be *safe* while she is at work.
- She wants to *maintain Mr. Murphy's pride and dignity*, because he says he is fine alone.
- She wants to maintain – or at least acknowledge the importance of – *her own sense of wellbeing*. She really enjoys working in the flower shop. She brings in some needed extra money, she loves talking with people, and the work gives her a sense of accomplishment.

The three outcomes of greatest concern to Mrs. Murphy are listed on the slide.



The OOVL Decision-Making Guide

PRIMARY QUESTION:

What is Mrs. Murphy going to do about her husband when she is at work?

OUTCOMES

VALUES

LIKELIHOODS

OPTIONS	Mr. M's safety at home	Mr. M's self-esteem	Mrs. M's wellbeing
Allow Mr. M. to stay at home, with calls			
Have daughter stay with Mr. M. part of the day			
Mrs. M. quits her job and stays with Mr. M.			

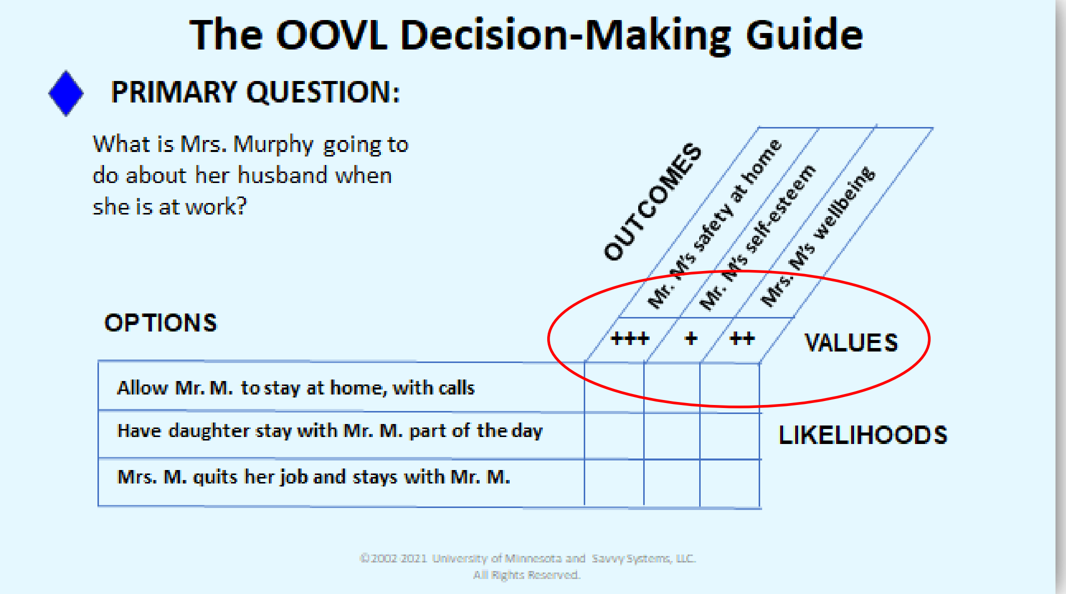
4. How important is each of these outcomes to Mrs. Murphy (Values)?

One way to identify what is important is to assign **values** to the outcomes. Some outcomes are things that the person wants to have happen (i.e., positive outcomes). Others are outcomes that the person hopes will never happen (i.e., negative outcomes).

A simple way to assign values to both kinds of outcomes is to use one or more plus or minus signs. For example, positive outcomes can be assigned a value of +++ (most important positive outcome), ++ (second in importance), or + (third in importance). Likewise, the negative outcomes can be assigned a value of --- (most important negative outcome), -- (second in importance) or - (third in importance). Another way to represent the different values is to rank order the outcomes (e.g., a value of 1, 2 or 3).

Mrs. Murphy considers the three outcomes she has listed.

- She ranks Mr. Murphy's ***safety*** as the most positive outcome, assigning it +++.
- She ranks ***her sense of wellbeing*** as a ++, because she knows that if she feels okay about herself she is better able to take care of her husband.
- Lastly, Mrs. Murphy considers the outcome of ***maintaining her husband's pride***. Mr. Murphy has always been a proud, independent person, but lately Mrs. Murphy has noticed that he allows her to do more for him and sometimes even asks for help - none of which seems to disturb him. Mrs. Murphy continues to be concerned about his feelings, however, and assigns a + to this outcome.



The OOVL Decision-Making Guide

◆ **PRIMARY QUESTION:**

What is Mrs. Murphy going to do about her husband when she is at work?

OPTIONS	Mr. M's safety at home	Mr. M's self-esteem	Mrs. M's wellbeing
VALUES	+++	+	++
Allow Mr. M. to stay at home, with calls			
Have daughter stay with Mr. M. part of the day			
Mrs. M. quits her job and stays with Mr. M.			

5. How likely or possible is it that each option will lead to each of the outcomes (Likelihoods)?

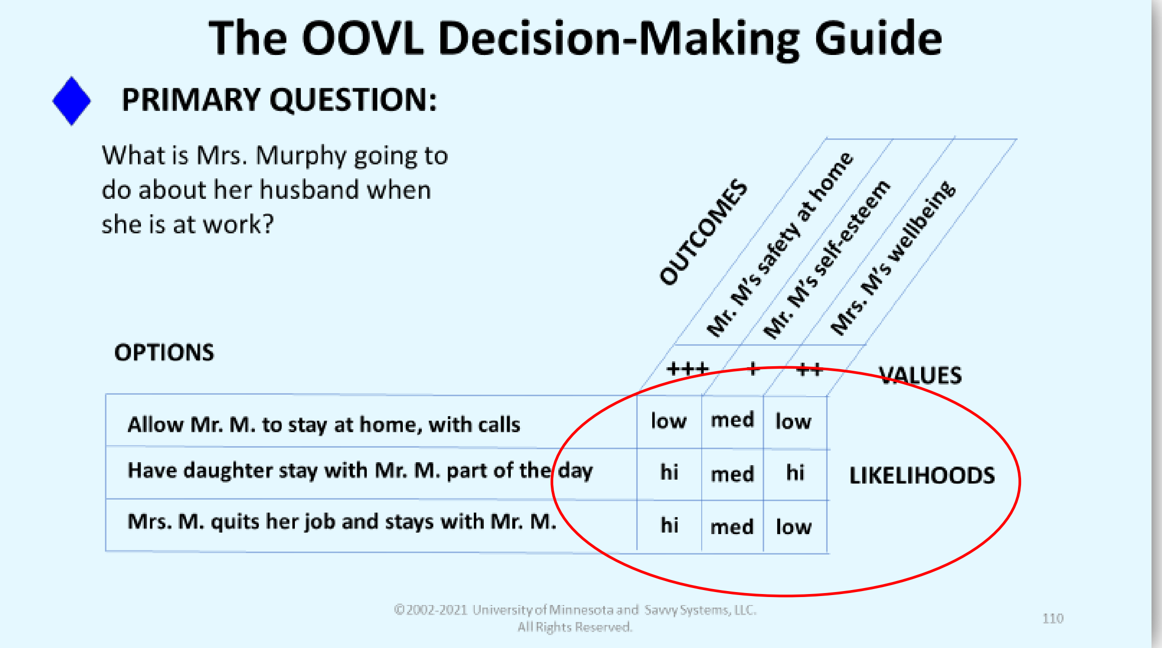
Decision making also involves looking at each option and determining, to the best of one's ability, the **likelihood** that the option will lead to the outcome. In the context of caregiving, determining likelihoods is based primarily on personal experience as a caregiver, as well as information available from other resources, such as family health care providers, written materials, and community agencies. Having a sense of the person's stage in the disease is linked importantly with the likelihood that an action will achieve a desired outcome. For example, persons in the Late Middle stage of the disease will most likely not be very self-aware. As a result, issues of self-esteem might no longer be pertinent for them, so outcomes involving promoting or retaining self-esteem are not likely to be accomplished – because the disease will have made them no longer relevant.

One way to rate the likelihoods is to use words such as *high, medium,* or *low*. In the example, Mrs. Murphy thinks about the likelihood of the various outcomes. For example:

- When Mrs. Murphy thinks about the likelihood of Mr. Murphy being safe at home if he is allowed to stay alone, she knows that he has left the stove on and the door unlocked. If she calls him, will he be able to tell her if something is wrong? What if he doesn't answer the phone? Therefore, she rates the chance of him being safe at home alone as ***low***.

- When considering the likelihood of her husband's pride being hurt if she quits work, she remembers some information she learned about persons living with dementia illnesses: they become less able to understand the meaning of events happening around them. Therefore, she speculates that he won't understand that her being around more means that she quit her job to care for him; consequently, he won't be as upset as he might have been in the past. So, she rates the chance of his pride being hurt if she quits her job as ***medium***.

- Mrs. Murphy continues this process of rating the likelihood of a chosen outcome occurring for each of the options she is considering. The likelihood ratings are found in the cells on the decision grid in the slide above.



The OOVL Decision-Making Guide

◆ **PRIMARY QUESTION:**

What is Mrs. Murphy going to do about her husband when she is at work?

OUTCOMES

OPTIONS	**Mr. M's safety at home**	**Mr. M's self-esteem**	**Mrs. M's wellbeing**
VALUES	**+++**	**+**	**++**
Allow Mr. M. to stay at home, with calls	**low**	**med**	**low**
Have daughter stay with Mr. M. part of the day	**hi**	**med**	**hi**
Mrs. M. quits her job and stays with Mr. M.	**hi**	**med**	**low**

LIKELIHOODS

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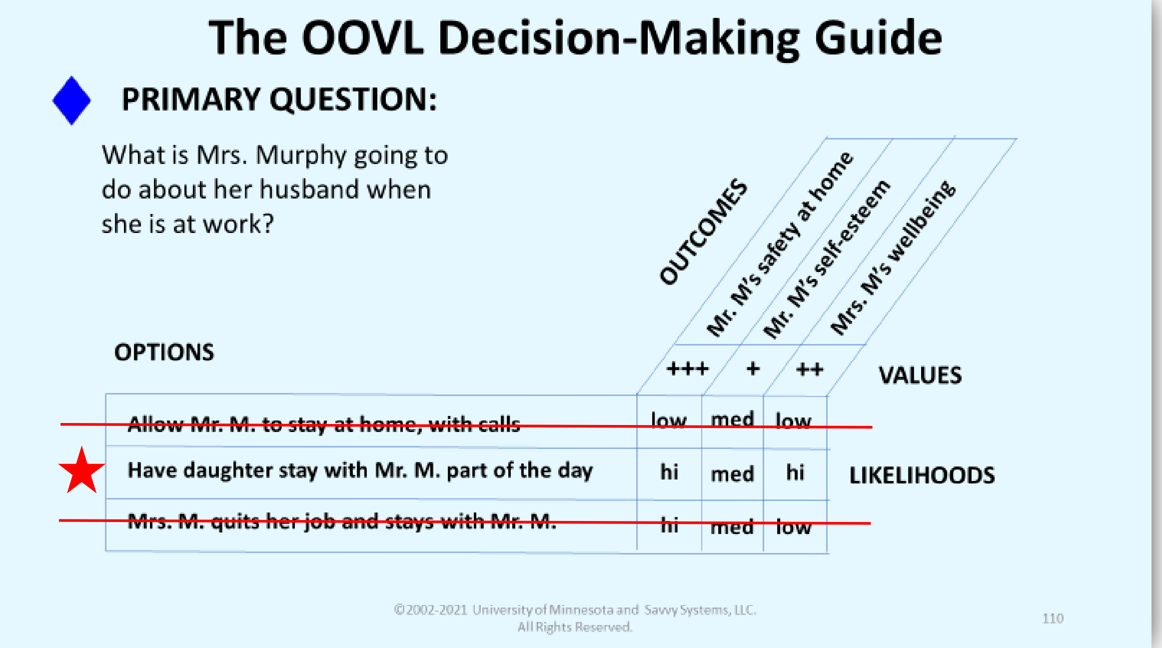
The Decision Most Likely to Achieve the Best Outcomes

Once the decision grid is completed, the decision maker chooses an option by relating the information about each option and then comparing the options. The grid serves as a guide in the process.

Mrs. Murphy ponders the grid. She quickly eliminates option 1 (allowing Mr. Murphy to stay alone with hourly phone calls) because it has a low probability of keeping Mr. Murphy safe, the outcome that is most important to her. In comparing option 2 (ask daughter to come and stay with him during the morning) and option 3 (quit work), Mrs. Murphy notices that they both have a high likelihood of keeping Mr. Murphy safe. Now Mrs. Murphy can choose between these two options by examining their likelihood of achieving the remaining two outcomes.

Mrs. Murphy relates the two options and the two outcomes on the basis of the values and likelihoods she assigned. Earlier, Mrs. Murphy assigned a ++ to her own wellbeing. She continues to feel that it is important for her to have a sense of accomplishment in her job, and to have contact with other people in order for her to provide the best care she can for Mr. Murphy. The option that is more likely to achieve this is having their daughter stay with Mr. Murphy. In addition, their daughter offered to help in any way she can. So for now, Mrs. Murphy decides to ask her daughter to stay with Mr. Murphy during the morning when she is at work.



The OOVL Decision-Making Guide

◆ **PRIMARY QUESTION:**

What is Mrs. Murphy going to do about her husband when she is at work?

OUTCOMES

OPTIONS	**Mr. M's safety at home**	**Mr. M's self-esteem**	**Mrs. M's wellbeing**	
	+++	**+**	**++**	**VALUES**
~~Allow Mr. M. to stay at home, with calls~~	~~low~~	~~med~~	~~low~~	
★ Have daughter stay with Mr. M. part of the day	hi	med	hi	**LIKELIHOODS**
~~Mrs. M. quits her job and stays with Mr. M.~~	~~hi~~	~~med~~	~~low~~	

Decision Example #2: Actual Decision From Your Group

As a next step, ask if there is a decision any member of the group is facing that he or she is willing to share with the group. (You might suggest a driving scenario, if no one immediately has a decision to discuss.)

Use the blank OOVL Guide above to go through the steps:

1. What is the decision the caregiver is facing?
2. What outcomes are important to the caregiver?
3. How important is each of these outcomes (what is the value of each)?
4. What options appear available?
5. How likely is each of the option to yield the specified outcomes?

Optional Decision About Susan and Bill (if no one volunteers a decision)

If no one is facing a decision or willing to share one, then you can use the following example. Although the example is rather specific (recovery from a medical emergency), the situation can be generalized to cover the many situations in which a caregiver has to leave the caregiving situation to deal with some other important issue (e.g., a family emergency elsewhere).
Susan is the primary caregiver for her husband Bill, who is in the Early Middle stage of his illness. Bill is still active but needs assistance to manage daily tasks successfully. He cannot manage daily tasks reliably or without support and structure.

Susan has been putting it off but now needs to have hip surgery. She will be in the hospital for several days. After that, she will require physical therapy several days a week for 2-3 months, depending on her recovery. Her recuperation may be slow but is essential to her recovery and long-term mobility. Susan also has a moderate heart condition for which she takes daily medication. During Susan's recovery, she will be unable to provide care for Bill or manage the house and the bills in the way she has done until now. She gets very frustrated and upset when things get disorganized, but she will be unable to oversee their affairs during her recuperation.

Susan and Bill have three children – two daughters and one son, and grandchildren who are in high school or college. Their son, Tom, lives about 45 minutes away and works remotely from home. Their daughters, Lisa and Beth, live in the next state. Lisa works and Beth is looking for a new job. Tom visits more than his sisters, but none of the three adult children have played an active hands-on role in assisting with Bill's care.

1. **What do Susan and her adult children need to decide?**

    - How can Bill be cared for while Susan is in the hospital and undergoes physical therapy? There is no decision needed about Bill's need for care. That is a given, so the overriding context of the decision is Bill's on-going care and safety.

2. **What are the outcomes about which Susan is most concerned?**

    - (Fill in with the group)

3. **How important is each of these outcomes to Susan?**

    - (Fill in with the group)

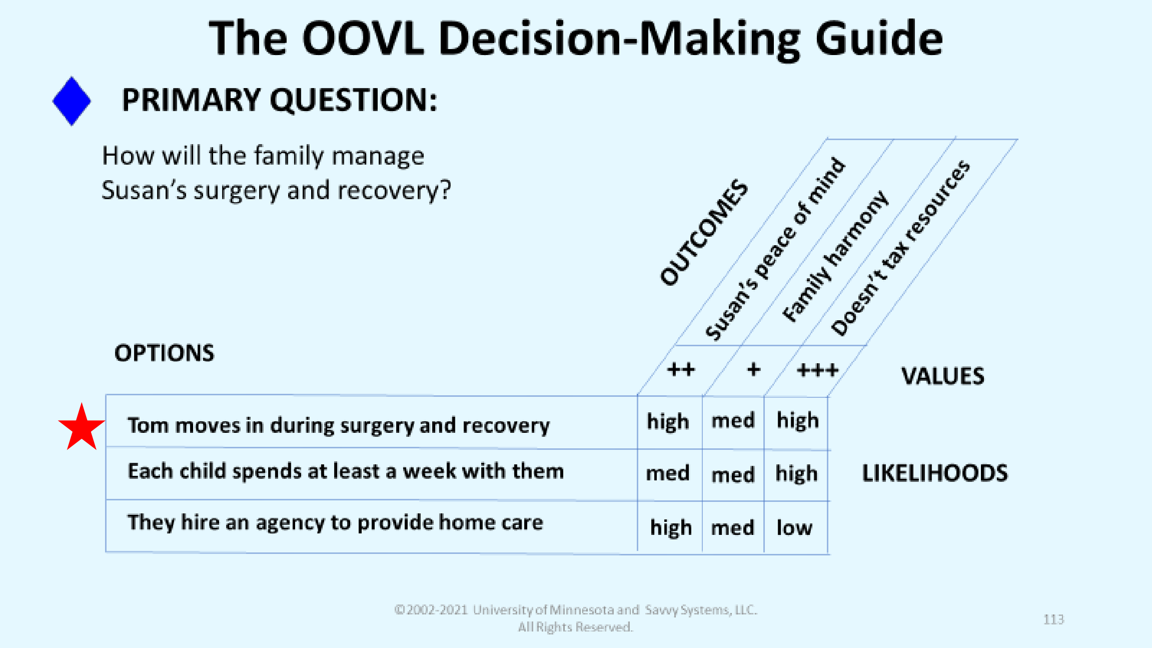
4. **What options seem available to Susan?**

    - (Fill in with the group)

5. **How likely is each of the outcomes to occur if each of the options is pursued?**

- (Fill in with the group)

You can use the slide below to address each of these questions. In broad terms, the outcomes about which Susan are most concerned are her own wellbeing, the wellbeing of her family, and the condition of their finances (which would be severely taxed by the out-of-pocket expense of in-home care for Bill. The advantage of this example is that it points out how non-clear-cut many decisions are. There are clearly competing demands in this situation, and they are all important. Even though family harmony seems to come in third on the “Values” scale, it is still of importance.



The OOVL Decision-Making Guide

◆ **PRIMARY QUESTION:**

How will the family manage Susan’s surgery and recovery?

OPTIONS	OUTCOMES: Susan’s peace of mind	Family harmony	Doesn’t tax resources
VALUES	++	+	+++
★ Tom moves in during surgery and recovery	high	med	high
Each child spends at least a week with them	med	med	high
They hire an agency to provide home care	high	med	low

LIKELIHOODS

These examples were selected to illustrate the structure and procedure of the *OOVL Guide.* Mrs. Murphy’s situation and her values influenced her decision making. Other people may face more complex decision situations and may think of different options and outcomes, assigning different values and likelihoods because of their unique situations and perspectives.

Early on, as they are learning how to use the Guide, Savvy Caregivers are encouraged to think about decisions using all the components of the *OOVL Guide*. Be assured, however, that you do not have to fill out the entire grid for each decision you face. Many times, just considering options, outcomes, and values will stimulate enough reflection to make the best option obvious. Not every decision requires this type of analysis. The kinds of decisions that are worth putting the time and energy into using the *OOVL Guide* include serious and complex decisions, recurring decisions, and those that are troublesome, perplexing, or uncomfortable. Decisions may need to be made more than once, particularly as changes occur in the situation or in the condition of the person living with a dementia illness. For example, a day-to-day management option that worked in the past may no longer be appropriate or the importance attached to an outcome might change.

The *OOVL Guide* can be useful in situations where the decision makers and family members' values or preferences differ. This approach promotes systematic and consistent evaluation of options. Share the decision grids with other family members. One of the benefits of the grid is that families can discuss a decision situation, see where they may differ in their desired outcomes or the value they place on outcomes, and develop greater tolerance for each other's views. Participating in developing options may prompt some family members to offer more help.

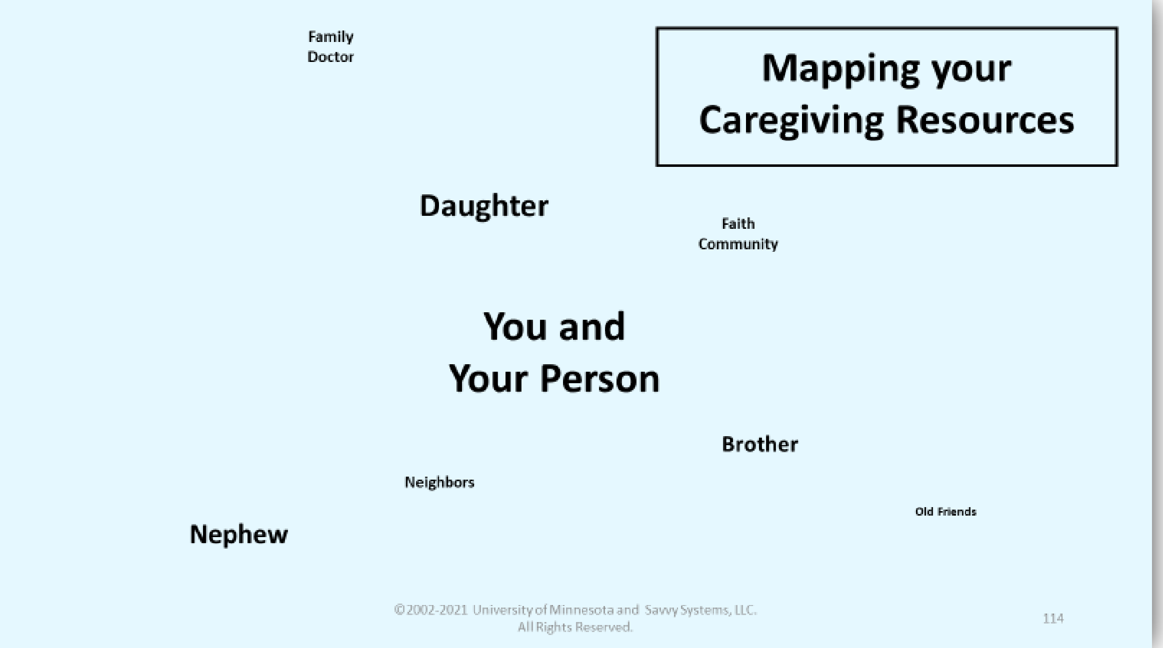
Conclude by making two points:

- The grid – and the process behind it – is useful not only for long-range decisions but also for the more day to day matters that caregivers face in managing their person's life.
- Once they have the questions and process clear, they may not have to go through the formal exercise of using the grid. Often the process of looking at the available options will make the decision clear. Nevertheless, the tool is there, and the participants should feel comfortable with how to use it. They can choose when to use the whole thing. The tool can also be used for decisions unrelated to caregiving.

Creating a Caregiving Resource Map

This is a brief instructional piece provided to guide participants in the home exercise in which you will ask them to engage. It is a simple application of a technique called "environmental scan" in which individuals are asked to take a careful and critical look at how things are in their lives and then to create a picture of how they would like those things to be. It's a three-step process:

As the slide below illustrates, in the first step, the caregiver uses a blank piece of paper on which the caregiver and care recipient are placed at the center. Then the key people and institutions or organizations in their lives are placed around them. How near or far they are placed indicates frequency of contact. How large or small they are written it describes the impact or weight of the contacts when they occur.



Mapping your Caregiving Resources

Family Doctor

Daughter

Faith Community

You and Your Person

Brother

Neighbors

Old Friends

Nephew

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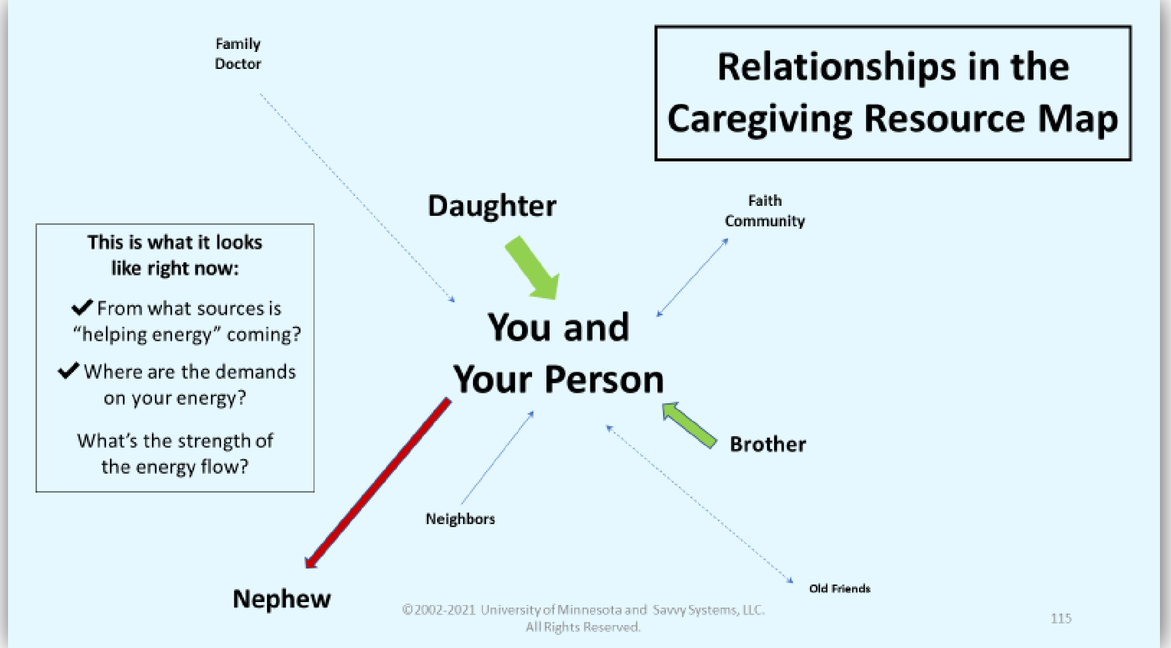
You can use this slide as an example of what a picture might look like after the first step is completed. In this example, the daughter, brother and the church are the people and organization the made up caregiver considers "close" to the caregiving situation. Neighbors are "sort of close" to the situation, and the family doctor, the nephew, and their old friends are relatively distant from the situation, although still in the picture.

The daughter and, to a somewhat lesser extent, the brother are the most important and the closest. The nephew is important, but is distant and, in terms of the exercise, is actually a drain on the caregiver's energies. The church and the neighbors are in the next circle out, in terms of closeness and importance, and the old friends and the family doctor are very distant.

Encourage people to make their own representations in whatever way they might want. It's easy to imagine people using different colors to represent the amount and importance of help – or to play around with how names are drawn in. This is meant to be their picture of the instrumental and emotional world in which they are carrying out their caregiving.

Note: Their picture doesn't have to look like the slide above.

The next step, as illustrated in the slide below, is to describe the nature of the relationship between the center dyad and each of the persons or entities identified in the original version of the map. Using arrows of various widths and even using dashes, indicate the strength of the energy that exists in the relationship. Using the arrow heads, indicate the direction in which energy is flowing (including in both directions); this step is meant to identify relationships that are providing help and support and those that are draining energy from the caregiver – or at least making demands on him/her.



Relationships in the Caregiving Resource Map

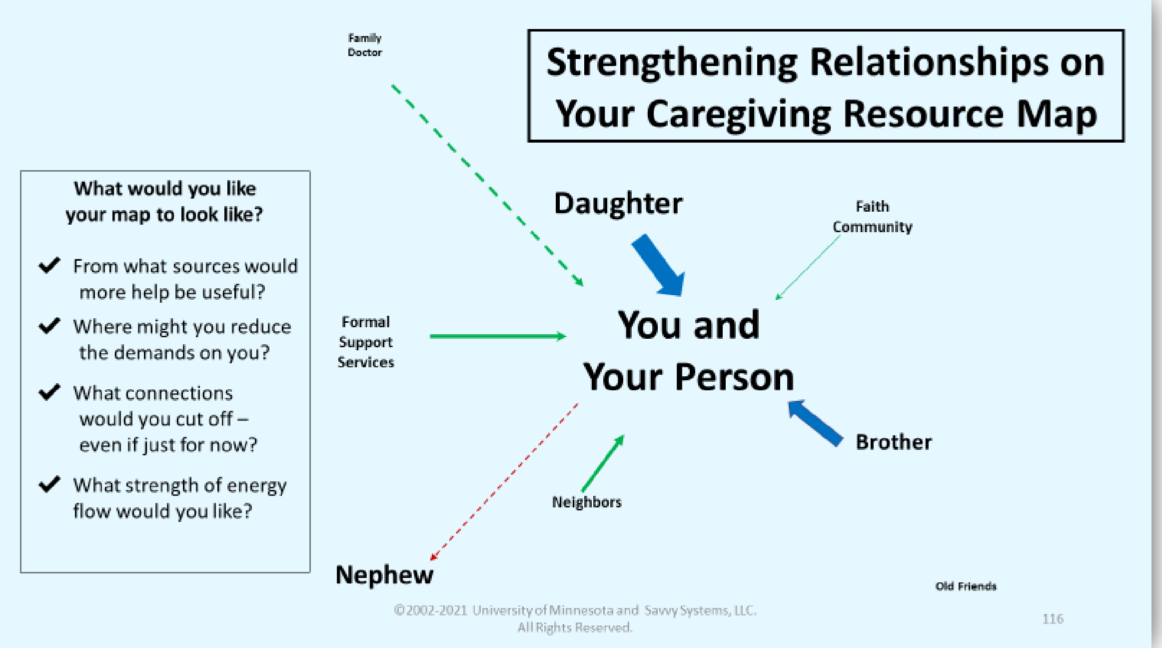
This is what it looks like right now:

✓ From what sources is "helping energy" coming?

✓ Where are the demands on your energy?

What's the strength of the energy flow?

The final step is to alter the map so that it represents a kind of "ideal" situation, one in which the relationships are strengthened – or terminated or initiated – so that the caregiving environment is providing as much support as possible under the circumstances. Thus, in this example, more support is coming from the family doctor and the faith community and neighbors, the link with the nephew has been loosened, the expectation that old friends will be helpful has been dropped, and there is now an expectation of support from formal services.



Strengthening Relationships on Your Caregiving Resource Map

What would you like your map to look like?

- ✓ From what sources would more help be useful?
- ✓ Where might you reduce the demands on you?
- ✓ What connections would you cut off – even if just for now?
- ✓ What strength of energy flow would you like?

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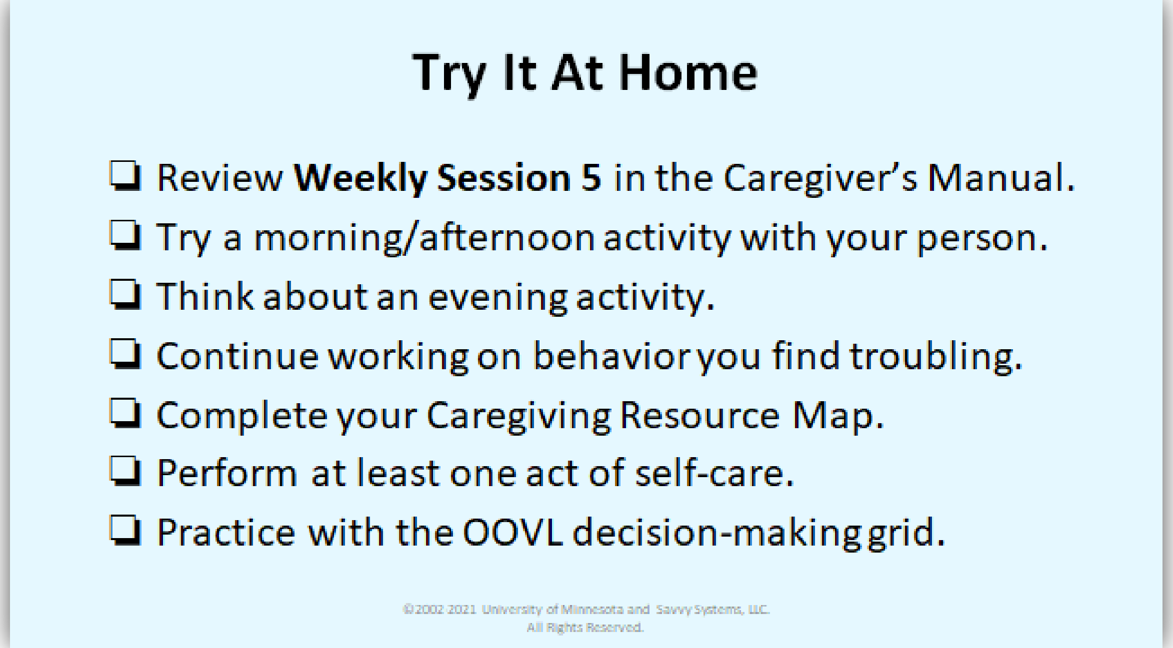
Home Assignments

Things to Try at Home.



Try It At Home

☐ Review **Weekly Session 5** in the Caregiver's Manual.
☐ Try a morning/afternoon activity with your person.
☐ Think about an evening activity.
☐ Continue working on behavior you find troubling.
☐ Complete your Caregiving Resource Map.
☐ Perform at least one act of self-care.
☐ Practice with the OOVL decision-making grid.

- Design and try a morning and afternoon activity (example: food prep or household chore).
- Think about the evening time and what they might do to involve the person after dinner and before bedtime. Use the Performance Level to design Structure and Support strategies.
- Continue to work on getting more control over a behavior you find troubling. Use Savvy Caregiver techniques (Thinking, Structure, and Support) to design a strategy for changing or settling (or living with) the troubling behavior.
- Conduct a Caregiver Resource Map (an environmental scan), as described.
- Perform at least one act of Self-Care. Check in with your feelings and, if they are too heavily in the lower left-hand quadrant, do something to change the balance. Or spring free and dip into your free-time list and do something for yourself.
- Practice with the decision-making grid. Perhaps you could use it as you design an engaging task or with work on a behavior.

Remind participants that next week is the final session. Invite them to bring any lingering questions from anything in the program, and to reflect on what they have learned and changed.

Weekly Session 5 Notes

Weekly Session 6

"Caregivers can get good at—and feel good about—mastering a basic set of caregiving skills."

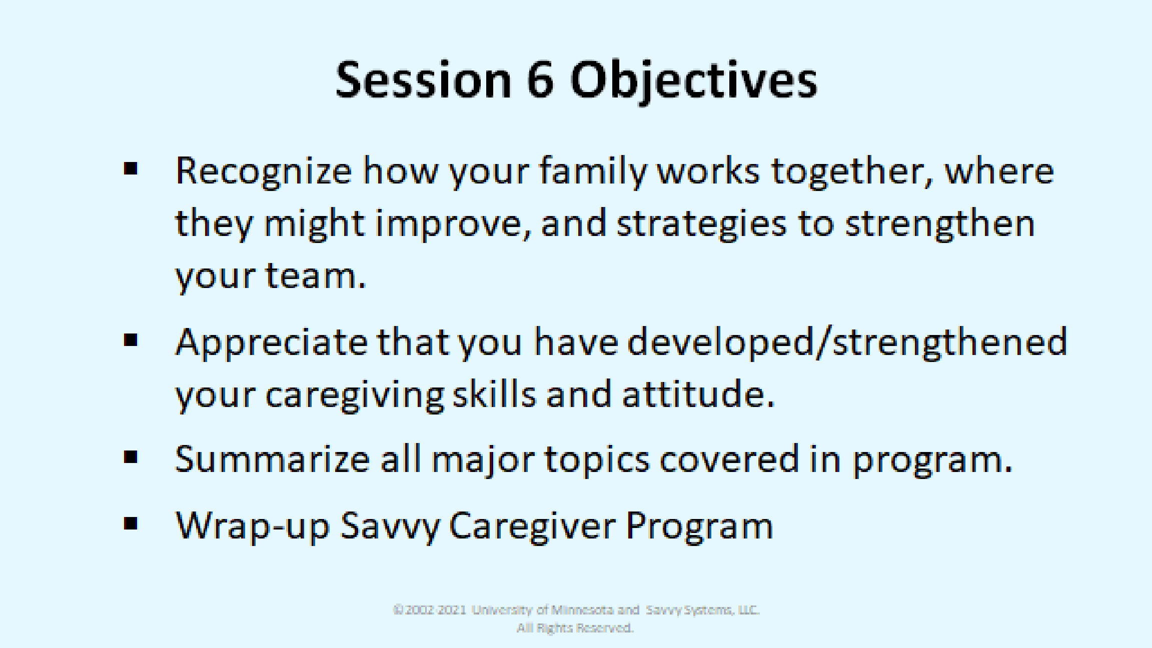
Session Agenda

Savvy Caregiver Program
Weekly Session 6 Agenda

Instructional and Topic Areas	Content Included In Area	Approximate Time
Coaching and Review	• Issues of Behavior and Daily Management • Network Mapping Exercise • Self-Care	45 Minutes
Teaching: Family Resources	• Strengthening Families as Resources of Care	45 Minutes
Teaching and Review: Savvy Caregiver Course	• Review Main Areas of Content	30 Minutes

Program Leader's Overview of Session 6

This is the last week of the program. You will present one piece of new material this session, but more than half of the time will be spent reviewing participants' efforts to apply what they've learned in the program to their own circumstances at home and in reviewing the content of the overall program. The main thrust of your facilitation efforts should be on pointing out participants' successes – at home and throughout the program.



Session 6 Objectives

- Recognize how your family works together, where they might improve, and strategies to strengthen your team.
- Appreciate that you have developed/strengthened your caregiving skills and attitude.
- Summarize all major topics covered in program.
- Wrap-up Savvy Caregiver Program

The only "classroom" content in this session will involve a segment on family issues in caregiving. You will likely have heard stories or examples about participants' family over the past sessions. The focus now is to examine how caregivers can identify their own family style of support (or lack of support) – and how to manage their own needs in light of this. If it important to note that participants define who is in "their family". This may include only nuclear family members – or a much broader, looser family of choice that includes long term friends, extended relatives, neighbors, etc. Trainers will need to accommodate the definition of "family" that each participant identifies. Finally, this session includes a review the material covered in the whole program. This review provides some closure and also a summary to remind participants about what they learned and were exposed to.

Review of Home Activities. As usual, the focus of the opening segment will be to have caregivers describe what their efforts at Savvy Caregiving have been like this week. There are a number of home assignments to review. Two of them involve the caregivers' efforts to put the Savvy Caregiver behavior management principles into practice. Reporting on these should form the majority of the segment. The third home assignment involved their attempting to improve family caregiving.

They were also expected to work on a self-care issue and on the decision grid. Check to see if there are any questions about the grid and to see what experiences participants had in using the grid.

> **Work on Issues of Behavior.** The main assignments were to continue to use the Savvy Caregiver strategies to try to work on issues of daily behavior. There were <u>two</u> assignments – work to change some behavior that was bothering them and try to design meal/household related and evening activities the person would enjoy.[20]

As usual, have the caregivers volunteer to describe what they did. Those who tried and met with success will usually want to step forward to talk about their experience. It may be useful to remind them of the home activities (work on a behavior that bothers you and work on finding a food-related task or activity that the person gets involved in and likes doing). Then try asking them one or two of the following questions to encourage participation:

- ✓ Did anybody work on trying to change some behavior of your person last week?
- ✓ Did you think about something that was bothering you and try to use what you know about the stages and performance levels and the ideas of Structure and Support to do something with the person about that?
- ✓ Did you try to design a meal/household task the person might enjoy?
- ✓ Did you try to design an evening activity the person might enjoy?
- ✓ Did anybody try things but find they didn't work?

Encourage all participants, even those who do not volunteer, to tell the group what they tried – or at least thought about trying. This is the last opportunity for members of the group who have not reported much. By now they should be comfortable with everyone. Some participants may feel that they have not accomplished much – or at least not as much as they feel others have achieved. According to your assessment of the group dynamics, encourage them to share what they have done or even considered doing. Every participant will have made at least some progress by this point. Ask questions that will highlight their own sense of learning and progress.

Throughout this session, make note of the ways in which caregivers speak about their person. In particular, how accurately do they seem to be taking the illness into account when describing the person? For example, caregivers are often concerned that if they do something – take over a job or part of a job – the person might resent or feel diminished by that. The Savvy Caregiver –

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[20] Try to get participants to report on both parts of this assignment.

one who has recognized the impact of the disease on the person – will recognize that, as the illness continues, the person's need to feel connected to the caregiver will likely grow. This will likely come to be a stronger feeling than one associated with a judgment or feeling that s/he is no longer able to do something or that something is being taken away. Similarly, those who recognize the implications of the declines in performance through the stages of the disease will use stages as a basis for adjusting the options they specify in a situation. For example, a caregiver for a person whose stage is estimated at Early-Middle stage will not list as an option an activity that involves the person taking independent action or engaging – without prompting or supervision – in a complicated sequence of actions. In other words, **this debriefing provides you with the opportunity both to check on caregivers' understanding of the decision grid and to hear again the manner in which they apply other Savvy Caregiving principles.**

Keep in mind the principles you used in the last session while debriefing participants about this part of the assignment:

- ➢ Some participants will have tried the assignment in a way that suggests they really understood a lot of the principles and ideas that the Savvy Caregiver program is teaching, and they will have met with success. That is, they will:

  - Describe what they did in terms that reflect the content of the program (applied, for example Structure and Support strategies appropriate to their person's stage and performance level)
  - Report that their person's behavior changed in ways they (the caregivers) both anticipated and appreciated,
  - Report that they tried some kind of meal/household and/or evening activity and that they were surprised about how well it worked (be sure to ask how they set the task up, what kind of support they provided and why), and
  - Demonstrate a sense of pride or accomplishment in what they did.

  Keep in mind that their expressions of feeling good about having taken what they have been learning, put it into practice in their caregiving, and met with success is Mastery. Mastery is a key goal of the Savvy program. A sense of mastery is evident when the caregiver feels more in control, more skilled, and more confident that his/her skills and knowledge make him/her more able to handle the caregiving they have undertaken. If/when you hear such expressions, reinforce them; point out that the person has gained a greater sense of mastery.

- ➢ It is equally important to allow for when other members of the group may have tried to apply the principles and ideas of the program, but they will seem not to have worked – again, ask what they did and why – have them (and the group) try to analyze the situation through the framework of the stages – was the task of an appropriate size? Was the mode of communication appropriate? Did the person seem to understand what was being asked of him/her? Might the estimate of the person's stage be too high or too low?

- A few will report that they did not try to do the assignments (change behavior or develop an activity). In such cases, encourage trying things, even after the program is over.

Think of each report – whether of success, failure, or not trying – as an opportunity to reiterate and reinforce the Savvy Caregiving model. As with Session 5, you will have a number of different kinds of opportunities as the caregivers report in:

- **Reinforcement.** Praise those who put the principles into play and met with success and give them an opportunity to talk about how they feel about the success they met with. Their success also provides you with an opportunity to review how they approached the task. Take this chance to review the steps the caregiver took – to go back over the ground s/he covered in putting together the stage estimate with Structure and Support steps to achieve the end s/he achieved. Help the group make the connection between what the caregiver describes and the course materials ("So, what I'm hearing is that you thought about what triggered his response, using the ABC model, and decided on a different response in the future.") Participants are generally pleased to realize that they are, in fact, correctly applying their new learning.

- **Clarification**. The Savvy Caregiver content is not always easy or easily understood. Listen carefully to how the caregivers talk about what they did and how they used the information from the program. Make sure that their understanding of the ideas and principles is correct. If it is off the mark in any way, take this opportunity to review the material and help them understand it more clearly. Remember, too, that even if the effort didn't yield the desired effects, the caregiver should be praised and encouraged for making the effort. The "experimental attitude" is especially important and should always be encouraged. Invite the group to help problem-solve and plan the next approach to try.

- **Encouragement**. This portion of the program should be used to encourage participants to continue to try to apply the ideas and principles of the program even after the sessions are over. This is also an opportunity to draw out those who generally did not volunteer to report back – to get them to talk about what they did do during the past week to put some of the Savvy Caregiver principles into effect. Encourage them to talk about what they did do. It may be they really did not try anything, but there is a good chance that they did make some attempts. Again, take this opportunity to reinforce them for their analysis and to encourage them for their efforts.

Decision-Making Exercise. Have group members review any decisions they made or worked on over the last week. Encourage caregivers to try using the decision-making grid.[21]

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[21] The OOVL will be reviewed in the later part of the session, so here you might just want to see if people used it and, if so, to what effect – and also if there are any questions about it.

Ask those who have tried using the grid what they liked or found helpful about it. In particular, ask them how easy or hard it was to identify the relative values of the outcomes they had specified and to estimate the likelihood of attaining the outcomes, given the various options available.

One of the best outcomes of the group regarding the decision-making exercises will be if caregivers find themselves a handy tool. For some, even the idea that they can think in terms of options or that their decisions may involve potentially competing values (especially when one value has to do with the wellbeing of their person and another value has to do with their own wellbeing) are important realizations. The phrase, “what can I do?” raises the question of what options do I have in a situation.

Ask caregivers whether, when they were working on the two behavior-related parts of their home activities, a phrase like “what can I do?” or the question “what options do I have?” ran through their mind. In other words, did they, when doing the behavior assignment, use all or part of the decision grid model to help themselves think through the issues facing them? Take this opportunity to remind participants that the grid can be very useful in thinking through day-to-day management questions as well as longer range decisions they may face, and that it can be applied to decisions not related to caregiving. Also, point out that making a plan and taking action moves them from Powerless to Powerful on the Feelings Quadrant.

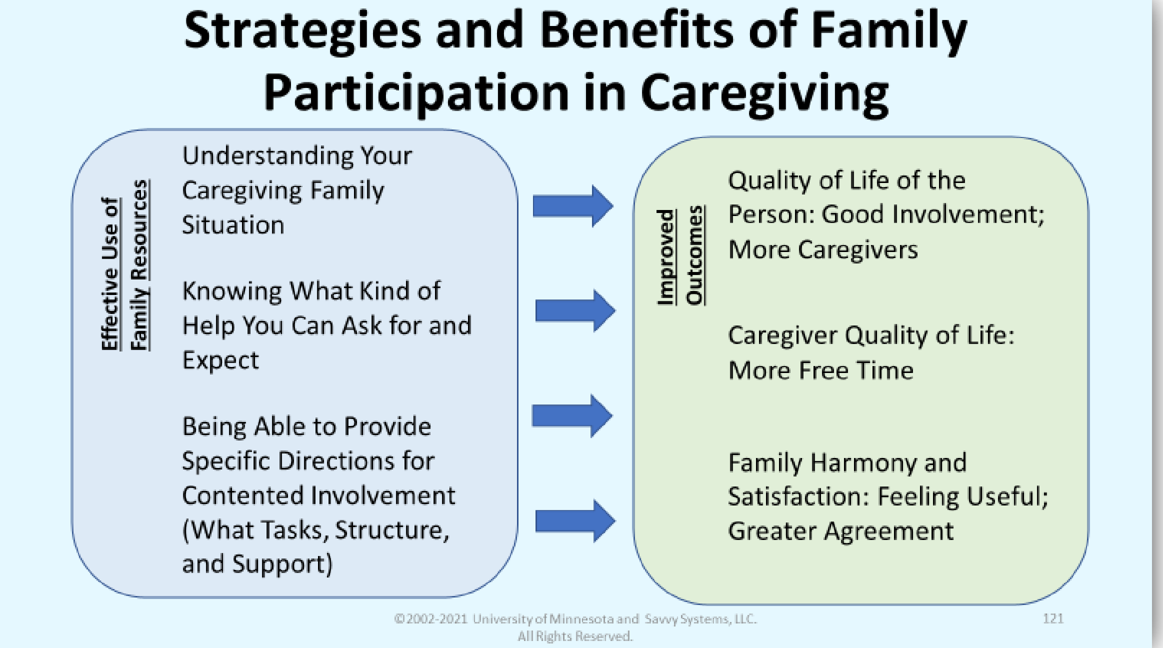
Debrief on Self-Care Activities

Ask the group to report back on their efforts to work with their feelings about caregiving and to allow themselves a self-time activity.

Finally, review participants’ efforts to complete the Caregiving Resource Map (an environmental scan). Make this a relatively brief exercise, but ask the group members to indicate if they had any insights about the way things are and the way they wish they would be in terms of the way they get help (or demands) from family, friends, and organizations? Use this brief discussion as a springboard to the new material you will cover next in the session.

Families as a Caregiving Resource

At this point we switch our focus to families and family issues that may arise in caregiving. We know that family and other close social relationships are critical in providing emotional and instrumental support for caregivers. The talk you'll provide is meant to shed light on the range of family styles, and how family support – or lack of support– can affect the nature of caregiving. In particular, it offers a way for caregivers to characterize the kind of family situation in which they find themselves. Ultimately, this exercise is related to the fourth basic task of the caregiver; the management of the family as a resource. The slide below may be useful in explaining why it is important to identify family style accurately and manage the family resource effectively.



Strategies and Benefits of Family Participation in Caregiving

Effective Use of Family Resources

- Understanding Your Caregiving Family Situation
- Knowing What Kind of Help You Can Ask for and Expect
- Being Able to Provide Specific Directions for Contented Involvement (What Tasks, Structure, and Support)

Improved Outcomes

- Quality of Life of the Person: Good Involvement; More Caregivers
- Caregiver Quality of Life: More Free Time
- Family Harmony and Satisfaction: Feeling Useful; Greater Agreement

Note that the term "family" is used in its broadest sense; it can include anyone in the caregiver's network. This can be especially important if there are caregivers in the group who do not have any biological family. The way to explain this slide is to point out that the improved use of the family as a resource can lead to a number of positive outcomes (as specified). The key to those outcomes is knowing what kind of help the caregiver can reasonably expect (hope) to get from his/her family and how to ask for that help. This, in turn, begins with having a basic understanding about the kind of family that is involved. And that is the point of the rest of this section of the program.

The objectives for this portion of the session are to:

1) Facilitate caregivers' explicit understanding of how their own family actually manages to work together.
2) Educate caregivers about different types of caregiving families.
3) Prompt caregivers to consider how their own family can realistically be more effectively involved in providing support, and how they might go about creating the necessary changes.
4) Help caregivers to link their understanding of what kind of family type they're in with what they have already learned about designing appropriate tasks or activities for their person to develop a strategy for asking for specific kinds of help from the family.
5) Remind caregivers to consider whether or not they are in complex family structures (divorce, remarriage), live near or far from family members, have little or no family, etc. Such factors will shape the potential for family involvement.

The talk that follows provides a way to describe a number of common patterns that families adopt in caregiving. These patterns typically reflect longstanding family dynamics and are adopted without much thought or discussion. When caregivers examine and recognize how they and their family members respond to a chronic stress such as caring for a relative or friend who is living with a dementia illness, it becomes easier for them to realize what they like about the response and what they would like to change. Once the caregiver realizes what about the family's response is helpful and what is problematic, s/he can then consider if they would like to generate any changes. It's usually up to the caregiver to undertake creating change in the family. Again, the talk that follows provides some hints about how to undertake creating change.

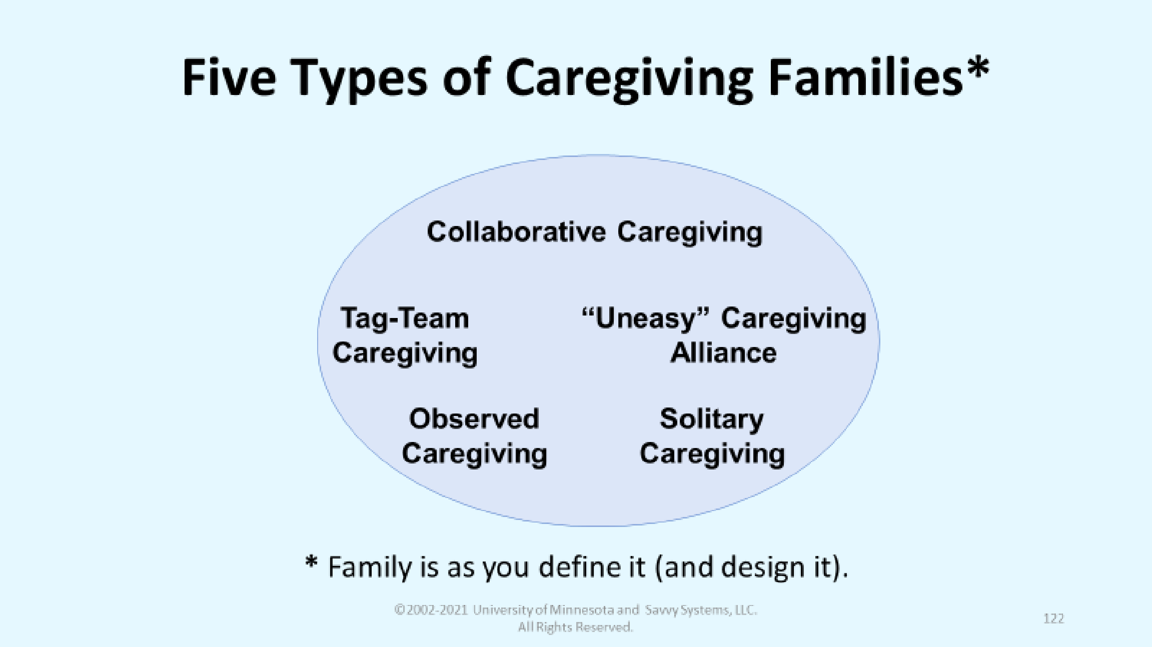
The network mapping exercise that caregivers were to have done at home should have put them in the mood to think about how their family works. This is a good moment to ask participants to share the results of that exercise. Ask them to share any conclusions they reached or surprises they encountered as they thought about their network, particularly about the family members who are (or are not) involved in it.

This is really a continuation of the debriefing portion of the session, so allow a few minutes for participants to report back on it.

Families and Caregiving. Now you want to give participants a framework that will help them to think about factors that help and hinder families working together and to characterize their family's style of working together (or not). This framework will be useful in the final exercise of this session (and in the home activities) – developing strategies for making better/fuller use of the help a family might provide in caregiving.

Five Types of Caregiving Families

The slide below identifies five common types of family caregiving arrangements. Families often find that, at any given time, they fit into more than one type of caregiving arrangement. It is important to stress that one type is not necessarily better than are the others. There are no “bad” types. In addition, families need the flexibility to change how they mobilize around caregiving as the illness progresses. Caregiving is always changing, and families may need to change from one type of caregiving family to another to adapt to the chronic illness.



Five Types of Caregiving Families*

Collaborative Caregiving

Tag-Team Caregiving

“Uneasy” Caregiving Alliance

Observed Caregiving

Solitary Caregiving

* Family is as you define it (and design it).

Solitary Caregiving. In solitary caregiver families, one person does all the work of caregiving. Other family members may live in the area, but the responsibility of care rests almost solely on the caregiver and little help is provided.

Example: Tina married Paul 6 years ago. About 4 years ago, Paul started showing signs of a dementia illness. Now Tina can no longer leave him alone. Her two daughters from her first marriage live in the area and have offered to come and watch Paul while Tina goes out. Tina does not take them up on their offers because she feels that Paul is not their father and, therefore, they should not have to deal with his illness or its symptoms. Paul’s two children live out of state and have strong feelings about the care Paul should be receiving. They usually visit once a year and call on occasion. Both of them also have jobs and families and busy lives. While they stay in touch, they do not offer to help.

Observed Caregiving. The observed caregiver, like the solitary caregiver, does all the work of caregiving. In the case of the observed caregiver, however, the family members are vocal about how they think care should be given.

Example: Ron is the husband of Agnes, who was diagnosed with a dementia illness two years ago. Ron has health problems of his own, and their daughter, Susan, is worried about them both. As a result, she keeps insisting that Ron and Agnes should move into assisted living. Ron does not want to move because the house is paid for and he knows the people in the neighborhood. What he would really like is for Susan to come and clean the house for him, but he does not feel right asking Susan to help him. Their son, John, is also concerned, but for a different reason. He knows that if the parents move to an assisted living facility, their assets will soon be used up and he and his sister will be expected to assume some financial responsibility. He is encouraging his father to "hang in there." and keep taking care of mom at home.

Tag Team. The tag team caregiving family shares the work of caregiving – sequentially. Rather than all members helping at once, tag team families have one family member at a time take care of the family member living with a dementia illness. The responsibility of caring for the person living with Alzheimer's or a similar illness rotates among family members.

Example: Randy, the father of three children, has a dementia illness. He can no longer take care of himself, and his wife died two years ago. Therefore, his children take turns caring for their father. They have arranged it so that Randy stays a month at each child's house. During that month, each child is responsible for getting Randy to daycare, and taking care of him at night, and the other two siblings are not expected to help, except in the case of an emergency.

Uneasy Caregiving Alliance. These families have more than one member at a time caregiving for their relative with memory problems. In uneasy alliance families, members share the work, but family members do not necessarily have the same goals, or similar styles of providing care.

Example: Sara and Martha are both caring for their mother, Midge, who lives in an assisted living facility. Sara believes that Midge should do as much for herself as possible. Sara has Midge help her make dinner and do small chores around the house when she brings her mother home to visit. Martha feels Midge is too frail to leave her apartment at the assisted living center. She is afraid that while she is helping Sara cook her mother will cut herself or burn herself on the stove. Martha has repeatedly asked Sara not to let their mother help cook. Sara believes that Midge enjoys helping and that she is not in danger when she helps.

Collaborative Caregiving. In this type of caregiving family, everyone in the family takes part in caring for the person living with a dementia illness. The family has a common goal for caregiving, and members perceive help as supportive. Everybody pitches in to help, but each person does not necessarily have to do the same amount of caregiving.

Example: Sharon cares for her husband, Ray, who has had a dementia illness for about 5 years.

Though Sharon lives with Ray, she gets a lot of help from her three children, Ray Jr., Paula, and Tim. Tim takes care of the outside work on the house.He mows the lawn and repairs things around the home. Paula does the shopping and helps her mother clean the house. Both Tim and Paula visit frequently. Ray Jr. lives 10 hours away and can't give the same consistency of help. One week each year, Ray Jr. comes and stays with Ray so Sharon can go to visit her sister in Nebraska. Ray Jr. also comes home during long holiday weekends and does what he can. All family members want to keep Ray at home as long as they are able.

> After this brief talk on the types of caregiving families, ask each caregiver into which type they would place their family. They will most likely say a combination of types. If so, ask them when –under what circumstances or during what kinds of situations or events – they see their family falling into the types they mentioned. After the caregivers have done that, ask them what type(s) they would like their families to be. Have them brainstorm about how they would know when their family was a certain caregiving type, for example "We would be a Tag Team family if my sister would take care of Mom every other week" or "We would be a Collaborative Team family if my brother took charge of mowing the lawn" or "We would be a Collaborative Team family if my sister, who lives in Florida, would call Dad every week to ask him how he is doing". This exercise will conclude after you give a brief talk on barriers and aides to successful family caregiving. So once the participants have identified where they would like their families to be among the caregiving categories, have them hold that thought.

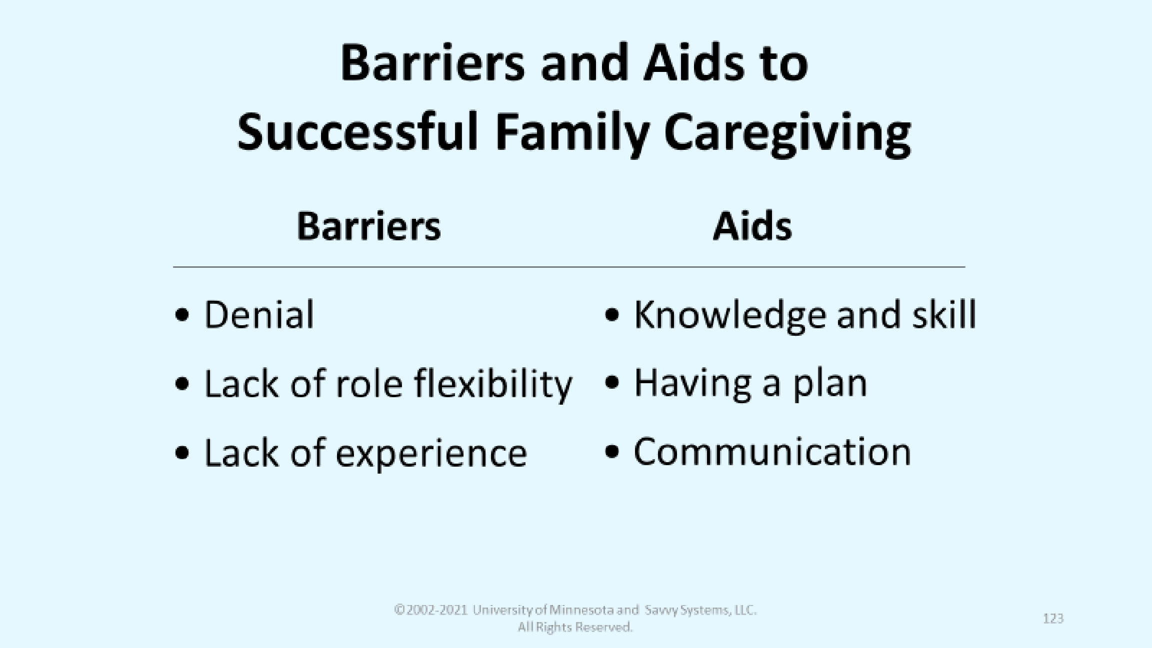
Sometimes, the reason one person is doing the caregiving is because the caregiver will not ask or let others help. This could be because the caregiver feels the members of his/her family are too busy, or that it is only the caregiver's responsibility. One reason parents don't ask their children to help is because they may feel it is not the children's job to take care of their parents, it is the spouse's job. One way to get caregivers to consider asking/letting others help is to ask them what they would do if they fell and broke their hip, or something else that incapacitates them for a while. Point out that it is better to have plans in place than to have to figure them out in an emergency.

Sometimes a caregiver will say his/her family is a collaborative family because they think that is the "right" thing to say. You, as the instructor, need to be able to question the caregiver if the examples you heard do not fit the collaborative description. You can say things such as "Gee, from what I've heard you say (give an example), it sounds more like a tag team family."

It is especially important to emphasize that there is no "bad" kind of family. What is important is that the family type is working for the family, especially the family member living with a dementia illness and the primary caregiver.

Barriers and Aids to Successful Family Caregiving

The slide below lists common barriers and aides to successful caregiving. These barriers and aides are helpful to keep in mind when talking with the caregivers about the types of caregiving families. You will find that caregivers often mention the barriers listed below when discussing the reasons they feel unable to take time for themselves. It is especially helpful to point out how caregivers can use the aides to help overcome the barriers they are experiencing. One example, frequently on a caregiver's mind but not said out loud, is that caregivers fear other family members will not do as good a job at caregiving as they do. Giving family members information about dementia illnesses, and details on how best to interact with the person with memory problems (communication) helps family members to overcome any reluctance to be alone with the relative with memory problems others face (lack of experience). Not knowing what to do if their family member gets agitated, or asks the person who they are, keeps many people from volunteering their help.



Barriers and Aids to Successful Family Caregiving

Barriers	Aids
• Denial	• Knowledge and skill
• Lack of role flexibility	• Having a plan
• Lack of experience	• Communication

You will now give a brief talk on the barriers and aids to successful family caregiving. The participants have all of this material in their manual, so you can refer them to that and just hit the highpoints. This talk is a set-up for the final part of the exercise about improving the family as a resource for caregiving, so, as you give the talk, encourage participants to share anytime they feel you have spoken about something that describes their family situation. As you proceed through the talk, ask participants at the end of each small section if there is anything familiar about what you've just talked about – anything that reminds them of their family or of some family member in it.

Barriers: There are three main barriers that get in the way of a family successfully coping with having a family member living with a dementia illness: denial, lack of role flexibility, and lack of experience.

Denial. Denial is the result of the inability or unwillingness to deal with the losses associated with dementia illnesses. The losses include losses that the person is experiencing as well as the losses that family members feel (or don't want to feel) in seeing the person experience these losses. Denial that a family member has a disease like Alzheimer's is common, especially around the time that some members of the family are seeking or considering a diagnostic work-up. Both the person living with a dementia illness and his/her family members can be in denial. Some people are not ready to confront the reality of how the disease will affect the lives in the family. Fear that they may get Alzheimer's when they get older, or the inability to face the loss of their relative as they once were, are both important issues that get in the way of coping. Unfortunately, families cannot mobilize to cope successfully with the disease if members cannot admit there is a problem. Denial is frequently the cause of friction within families. Family members in denial are likely to resist the primary caregiver's efforts to seek their help or to use outside help, such as moving the person to assisted living or using a day program. Denial by other family members also puts additional pressure on the primary caregiver. S/he cannot turn to those who are denying the reality of the situation for any comfort for his/her own situation of loss and increased workload.

If others realize that denial is a result of fear, rather than laziness or an inability to care, it might be easier for them to deal with the person in denial. Rather than getting frustrated and angry because the person "refuses" to see the illness at work, members could talk about the underlying fear the person in denial feels that keeps him/her from accepting the truth. Providing information about the disease and having the person spend significant time with the person who has the disease are both powerful tools for getting someone to face his/her denial

Lack of Role Flexibility. A second barrier for families coping with a dementia illness is the inability to adjust and change roles. This is often necessary when a family member has a disease like Alzheimer's. When a family member gets a dementia illness, s/he gradually loses the ability to perform tasks for which s/he was previously responsible (like driving, paying the bills, cooking, and making major decisions, like whether to buy a car). In addition, the caregiver often finds that doing all the things s/he accomplished before the onset of the disease is more difficult.

Lack of flexibility can lead to a disorganization within the family. If members of a family are flexible regarding who can perform certain roles, the family's transition into caregiving will be smoother and the family will continue to be a resource in caregiving. Take the example of a mother of a large family who used to prepare elaborate holiday dinners for everyone in the extended family, but is no longer able to because of her memory problems. If roles are flexible within the family someone else can take over the role of hosting holiday dinners or the other members can share the role. In families that have a lack of role flexibility, the family may stop having holiday dinners together because that was always Mom's job, and nobody else is able or willing to take it on. If a family's roles are not flexible, other persons do not take over the tasks the disabled person used to be responsible for – or assist the caregiver in some of his/her roles in order to lighten his/her load.

In many instances, it is the caregiver who fosters or supports role inflexibility within the family if they cannot or will not ask others in the family for help. Many caregivers feel their relatives, especially their children, are too busy to help. This is an example of lack of role flexibility. Parents frequently see their role as a provider of assistance rather than as someone in need of help. They may believe their children are too busy with their own lives to assist in caregiving. This is not to say that children do not have busy lives with work and children of their own. However, the fact remains that the caregiver will need help at some point, especially if s/he can no longer be the primary caregiver. In this instance, it is the caregiver who has to recognize his/her own need for help and who has to bend in the situation and ask the family to reorganize itself around the reality of the situation brought on by the dementia disease.

Lack of Experience and of a Caregiving Repertoire. Lack of experience is just that: members in the family do not know what to do regarding caring for a person living with a dementia illness. They may have never been in this situation before and have no models for how to deal with it. Lack of experience may show itself in various ways. First, a person may not want to spend any time with the person living with a dementia illness because they don't know what to expect. The disease is a mystery to him/her. The behavior of a person living with a dementia illness is beyond his/her experience. S/he might feel fear about what the person living with a dementia illness might do and how s/he (the family member) might handle anything that came up. Second, family members may not know how much work is involved in caregiving or how to do the work of caregiving. To the extent that the disease remains a mystery – and a frightening one at that – or that they feel inadequate about how well they could provide care or in the dark about what to do if they were to be "in charge" of the person, they are less likely to offer help and understanding.

A third important barrier to getting help from family – and friends – is their not knowing what to do with the person. Someone who doesn't spend a lot of time with a person who is living with dementia may be very unsure about how to fill the time, how to help the person with things, how to keep the person calm and in control.

Aids. Below are five ways to break through the barriers to successful coping. These are tools that can help families cope with having a member with a dementia illness. The tools help in everyday life, but are more crucial when an illness invades a family.

Share Knowledge and Skills. As the Savvy Caregiver program has emphasized, it is important to know about dementia illnesses, and what to expect as the illness progresses. However, it is even more important to know what to do – how to manage things – as the condition progresses. It is also important to know about the resources that exist to help ease the work and stress of caregiving. This knowledge and skill can help prepare a caregiver for the task of ongoing caregiving. Sharing this knowledge and skill can also help families to organize successfully to aid in the care of a person living with a dementia illness. If individual members have information about the illness, know the types of losses the person living with a dementia illness may face, and know how best to interact with their family member to give him/her the best quality of life possible, both the caregiving family and the person living with a dementia illness will benefit. Many organizations exist to help family members dealing with dementia illnesses. Knowing of the available resources can offer caregivers help in a variety of ways. For example, volunteer respite programs and professional day programs can give caregivers a break from caregiving and time to do other things. **Again, when the family understands the disease and the community resources for it, the family is more likely to promote and support the use of such resources.**

Have a Plan. Successful caregiving requires a plan. A plan can include who assists in caregiving for certain activities, or at certain times; how to handle a certain problematic behavior; or how to keep the person living with a dementia illness meaningfully occupied. Plans can also include decisions about caregiving in the future. For example, will the family decide to place their member in a nursing home? If so, how will they know when it is time? Family members have a better chance to organize and work together effectively if a common goal exists. If family members are each doing what they feel is important, but the members are working toward different goals, then help will not feel supportive. (See the “Uneasy Caregiving Alliance” type of caregiving family for an example.)

Provide a Menu. Have a list of answers ready for when someone in the family or among friends says, “Let me know if I can help in any way.” Be ready to give the person a number of specific options from which s/he can choose. A list might include: specific times (and durations) when a person could come to the house to stay with the person; times when transportation is needed; help with specific chores around the house that the caregiver can’t get to; help with other household affairs; bringing over meals. Have caregivers generate their own lists. Encourage them to keep these lists handy for times when someone says, ”Oh, I wish I could do something to help.” At such times, the caregiver can check his or her list and, in the same way that we match the abilities of the person with the task, match the task with the helper. An accountant might take over billpaying, for instance, of someone who loves to cook might bring meals.

Provide “Recipes.” Helpers need some tips from the caregiver’s strategies. If the help that is provided involves direct care, then caregivers should provide a list of things that the helper could do with the person living with a dementia illness. A description of the schedule of activities that is typically done at that time of day would alert the helper to the routine. Provide descriptions of what the helper can expect of the person in those activities, what kinds of set-up the helper is likely to need to provide, good distracters, things that help the person focus, and things the person especially likes to do.

Communicate. Communication helps to break down the barriers to successful coping. Communication is also a necessary component of the two other aides—Knowledge and Having a Plan. Talking about the disease, and how it affects all members of the family, including the person living with a dementia illness, can help family members let go of denial. Communicating about day to day caregiving to family members and friends enables them to comprehend the effect of dementia illnesses on the person and the caregivers. Communication about what works for the caregiver in his/her interactions with the person with memory problems helps others feel more comfortable around the person living with a dementia illness. If caregivers are able and willing to let family members know what they need, and what works in day to day caregiving, other people will be more able to assist with, or take over, the tasks that need to be accomplished. Families cannot create a plan for successful caregiving without exchanging information on what individual members need and what goals each individual has regarding caregiving and the future of the member living with a dementia illness. Communicating emotions, which certainly are plentiful, can also foster feelings of support and understanding. The bottom line is that talking with one's family helps get over barriers most families face when struggling with a long-term progressive disease such as Alzheimer's. When family members truly understand, they are more likely to pitch in and offer support.

Exercise. A final exercise is meant to bring to the surface concrete steps that caregivers could take to improve the family resource for caregiving – that is, to get more help from his/her family and to get them more – or more effectively – involved in caregiving. Point out how this exercise ties into the idea of Savvy Caregiving. Emphasize the positive. Taking part in this exercise shouldn't imply that participants' families aren't helping. [Remind them that "family" is whatever they define it to be.] Rather it means that even the most helpful and collaborative of families could be even better at what they are doing. And in those cases where the help is less than optimal, strategies can be developed to improve the situation. Help them recall the possible improvements they identified in the network mapping exercise.

In this part of the exercise, ask caregivers to refer to the Barriers and Aides handout (see next page) to think about their family situation. Ask them to consider what might be preventing their family from more effective family caregiving. Have them take a minute just to think about the situation and to consider whether and, if so, how each of the barriers is at work in their family situation. Then have each report briefly on what they have come up with. When all have reported, ask participants whether what others said stimulated any other thoughts.

Next have the participants spend a minute on the Aids section. Then ask them to indicate what kinds of knowledge and skill they wish other members of the family would have. Ask how they might convey this to their family members. Finally, ask them to describe what they would say to help another family member take care of the person living with a dementia illness. As above, have individuals report back and then have the group consider whether these reports prompted additional thoughts. Since caregivers will be encouraged to apply this information to their own situation at home in the coming week, tell caregivers that they should just provide an outline of what they would do.

Exercise: Barriers and Aids to Successful Family Caregiving

Denial. Is there anyone in the family who does not believe that the person has a dementia illness? Or that the problem isn't as serious as you see it to be?

Lack of Role Flexibility. Are you willing to ask your family for help? Are there reasons why they cannot help? Are there reasons why you haven't asked for help? Or, are there family members who want to uphold family traditions or ways of interacting but are not willing or able to make adjustments that are needed given your person's illness?

Lack of Experience. Are there members of your family who don't understand what dementia illnesses look like or what your person is like? Do you think any family members are frightened by your person's dementia (or too sad to be around him/her)?

Knowledge and Skill. What kinds of information about the disease or how to care for the person would help family members to be more a part of the situation and more able to help?

Having a Plan. Can you think of two or three caregiving tasks that you could delegate to other family members? Given the family situation and the person's condition, what are a couple of ways in which you could ask for specific help?

A Menu of Activities. Can you think of 2 to 4 tasks or activities that you could tell a helping friend or family member to do with the person over a 2- to 3-hour span of time?

Recipes for Helpers. Take one of the activities from the menu and describe how you set it up for the person, how you get him/her involved with it, what kind of help you expect to give, and how you give that help.

Communicating with Goals in Mind. Think about one of the tasks you feel you could ask for help with. Now develop a specific plan for communicating this to that family member. Tell him/her: what you want him/her to do with the person, what kind of Structure and Support to provide (and how to do that), what to expect and look for. Give the person specific advice on what to do if the person becomes distracted or distressed. Set helpers up for success!

Since this is the last session of the program, you will not be providing participants with home assignments, but you can tell them that, if you were providing assignments, this would be the assignment related to strengthening the family resource for caregiving:

- **Design a change strategy to improve family caregiving.** This should be based on what you see to be the barriers at work in the family. You might choose to assign a task to a family member (in which case, provide a detailed plan) or to provide information (e.g., your manual.) to someone to help him/her better to understand the situation.

Friends as Support and Help to Caregivers

One Final Word. The emphasis in the section above was on engaging family members in care and on understanding family dynamics as a way of seeing different kinds of helping and conflict that occur in families. What is not covered in the section is friends.

Friends can provide great support and help to a caregiver, and the techniques described above apply to friends as well as relatives. But caregivers often report that, as the disease progresses, friends – even long-time friends – seem to fall away and disappear. Caregivers report that when friends “go away” it is painful, and it also makes them feel angry or disappointed.

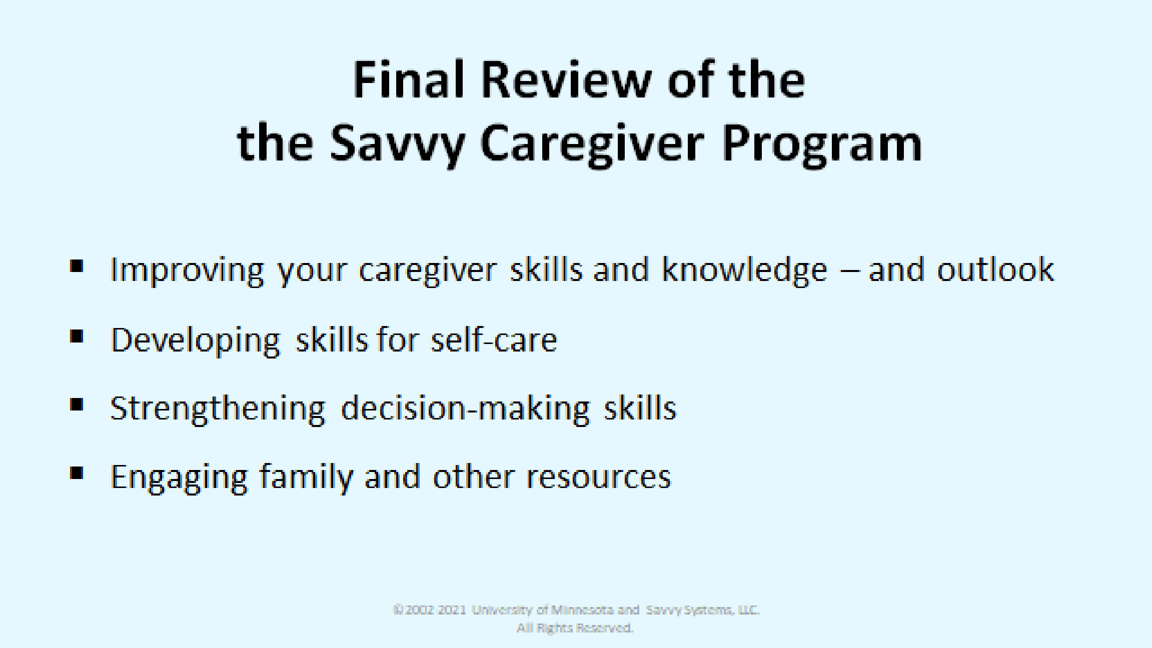
For some people, the onset and progression of a disease like Alzheimer’s in a friend signals the end of the friendship. The connection is lost, and the friends go away. It’s likely there’s not much that can be done with or about these kinds of friends. They have pulled away, and the best thing for the caregiver is to let go of them.

Others may feel that the disease signals a time when family circles closely and friends have to stand back and let the family take over. Some encouragement to friends to stay close might be helpful to such people – and may be all that’s needed for them to stay connected.

Still others may be just like many family members: they may want to do something but not know what or how. In this kind of situation and the one above, being specific about possible ways to help and providing detailed descriptions of activities and ways to help the person through them may be very helpful.

Final Review of the Entire Savvy Caregiver Program

The Finale. This is the last part of the Savvy Caregiver program. This part of the session should be spent reviewing the content of the program. The slide below can serve as an overall summary of the six-week curriculum. The program centers on developing caregivers' mastery in guiding the person through days that are as safe, calm, and pleasant as possible and that promote the person's Contented Involvement in the tasks and activities of the day.



Final Review of the
the Savvy Caregiver Program

- Improving your caregiver skills and knowledge – and outlook
- Developing skills for self-care
- Strengthening decision-making skills
- Engaging family and other resources

Note: Review slides in the PowerPoint are not displayed here.

Plan to spend 1-2 minutes per slide to reinforce the take-home messages of these important concepts. Point out ways that participants have integrated the Savvy materials into their caregiving, and recognize the enormous commitment they have made on their person's behalf.

The program has sought to develop or enhance caregivers' skills knowledge and outlook through a variety of instructional sessions, exercises, readings, coaching, and an emphasis on practice at home. The program also emphasized developing skills for self-care. We have tried to make it clear that caregiving is more than the day-to-day dealing with the person. Taking care of oneself, being able to draw on other resources in the family, and feeling equipped to manage the longer-term realities of being the household leader are all integral to the role.

The training program has also been built on the idea that caregivers will not only learn the information we are teaching and be able to put the skills into practice, they will come away from the program with a different sense about themselves, a sense we have termed "mastery." This sense combines an appreciation both that they know and are able to do more things but, more fundamentally, that they feel more confident about their ability to carry out the role they have undertaken.

Use this as an opportunity to draw caregivers into the discussion. The review should be a "bragging session" for them. It should give them a chance to show off – as individuals and as a group what they have gained and what they have become as a result of the program.

As you begin to review the material, keep the following points in mind:

- ✓ You've found ways to use knowledge, skills, and outlook in your caregiving.
- ✓ You've found some strategies that work for you.
- ✓ You've incorporated self-care into your caregiving routine.

Briefly remind caregivers of the main points of the program.

- **Caregiving requires savvy**. Over time, dementia illnesses change everything. As the person changes, everything about the relationship between the person and the caregiver – and the rest of the family – changes as well. The expectations of normal life can no longer be assumed, and it falls on the caregiver to make changes and adjustments in his/her manner of relating to the person living with the illness. The caregiver gradually assumes more and more responsibility for communication, decision making, structuring daily life, and thinking through the moment to moment actuality of the day. Understanding cognitive losses and the impact of confusion are important starting points for the caregiver to make this shift to greater responsibility and to begin to adopt a more deliberative and analytical – a more savvy – approach to how s/he deals with the person living with a dementia illness.

- **Caregiving should have a reasonable goal**. The person cannot be cured by caregiving, no matter how good and selfless. Nor should the person's every need and want trump all other concerns, including the caregiver's own wellbeing. Nor does a dementia illness take away the person's ability to zero in on things and take pleasure in them. So, helping the person to become and remain reasonably enjoyably involved in things is a reasonable target for caregivers' activities. And caregivers are allowed to be enjoyably involved too – either along with the person or on their own.

- **Caregivers can get good at – and feel good about mastering – a basic set of caregiving skills**:

- ***Understanding the Stages and the effect of the disease on performance***. The participants have learned that the global losses can be described in a staging system that they have learned. They have seen that the stages link to important elements of performance (Purpose, Order, and Use) and to the key elements of tasks (size/complexity, geography, etc.). Finally, they have used the Personal Task Worksheet to estimate their person's stage and performance level.

- ***Linking to Structure and Support strategies***. The main part of the program has been spent teaching a simple model of developing strategies for maintaining a person in a condition of Contented Involvement, represented below.

Recall for participants the various handouts linking structure and support to stages.

- **Linking confusion to troubling behavior**. Many of the behaviors caregivers report as most troubling – like repetitive questioning and shadowing – relate to the fear the person feels from the confusion that is characteristic of the disease. Recall the section of the readings on dealing with troubling behaviors. Remind participants that they have worked on this at home and that the principles of Structure and Support can be applied to these situations.

  - ***Developing a caregiving routine***. The program has tried to emphasize the value of a regular routine for the person living with a dementia illness. Although s/he may not remember what will happen, repetition will develop a sense of familiarity, and familiarity provides comfort. Having a routine – for the day and for what to do (how to respond) in difficult or bothersome situations – will also help the caregiver. It will save the energy of having always to create each day anew.

  - ***Improving communication.*** Several parts of the program dealt with communication between the caregiver and their person. The section on cognitive losses should have helped to clarify for the caregiver what s/he could expect in an exchange with the person. The section on Thinking and Support dealt directly with the kinds of communication that are most appropriate for persons at various levels of the disease. Beyond this, there is a section in the readings on communication techniques.

Remind participants of the main content related to the second major theme of the program, taking care of their own wellbeing.

Use the slide to remind them of the two main topics covered:

- **Caregiving can produce great emotional stress**. Early in the program caregivers learned a technique for sorting their feelings into quadrants and for working on moving to a more positive feeling state. Their home activities should have helped them to check in more regularly with their feelings and to work on moving them to a more positive state.

- **Caregivers can – and should – have satisfying and rich lives**. The program worked on helping caregivers specify or recall interests they might like to pursue if they had the time. They developed a list of things they would like to do. In later exercises – particularly those related to the family as a resource – they tried to create time to pursue some of these activities. The notion of a daily routine also works in the direction of caregivers pursuing some of their own interests.

Review the main points of a third theme of the program – the caregiver as key decision-maker.

The key points to make here:

- Caregivers have been given a simple and flexible tool to help them with decisions. They can ask and come up with answers to six basic questions to help themselves arrive at a level of comfort with most decisions. In many cases, just thinking about a portion of the model (for example, what options are there or what's really important here) will be enough to clarify a caregiver's decision.

- These decisions may be large and long-range (selling the house, getting rid of the car, etc.) or they may be more day-to-day, relating to how to take care of the person or manage other situations.

- A dementia-related illness plays a part in thinking through decisions. Many of the person-centered outcomes that caregivers worry about (his/her feelings will be hurt or self-esteem damaged) need to be considered in light of the disease. A dementia illness dulls many feelings in the person, and issues like these, while still important, are increasingly less pronounced as the disease progresses.

Families as a Caregiving Resource

Remind participants about the program's final theme, covered today, that families are (or can be) important resources for caregiving.

- **Families have different styles.** Point out that participants have identified the type of caregiving family they have, and how they might like to enhance it, using the Resource Mapping home exercise and the Barriers and Aids

- **There are barriers and strengths in every family**. Remind participants of the major barriers to stronger family caregiving (Denial, Lack of Role Flexibility, and Lack of Experience). Remind them of the class exercise and home application in which they worked to design a strategy for improving the family resource for caregiving. The two particular strategies they were to work on were: develop agreement within the family about others' doing specific tasks at specific times, and provide to family members a detailed plan for how they can provide care to the person during the agreed upon times. Successfully implementing this plan depends on other family members' appreciating and acknowledging that the care-receiver has a disease (a dementia illness) that seriously affects daily life. It also depends on strengthening communication within the family.

One of the central goals of the Savvy Caregiver program is that participants acquire a sense of mastery about their caregiving. Before this session, think about the gains and progress you have seen in each of the participants, especially as they relate to material covered in the sessions. Point out the successes you've seen – the progress you have seen them make toward becoming or improving themselves as Savvy Caregivers. This will reinforce their sense that they have become more knowledgeable, more skilled, and more able as caregivers.

Below are some things you might consider as you compile a list of successes you want to comment on among the caregivers:

- **They have changed something of the way they deal with their person, based on what they learned in the program.**
  - ✓ Accepting and dealing more realistically with the losses
  - ✓ Handling difficult behaviors better
  - ✓ Finding new things for the person to do
  - ✓ Changing the way they relate to the person – different language and speech patterns; more control; more directive; etc.
  - ✓ Creating more routine and structure
  - ✓ Using external resources – day program, etc.

- **They have reported that they are thinking and/or doing more to take care of themselves.**
  - ✓ Using the quadrant tool to manage their feelings
  - ✓ Taking some time for themselves – and feeling okay about that

- **They are involving their family network in caregiving in various ways.**
  - ✓ Asking for more help
  - ✓ Helping the family to get involved

They have used the decision grid or can think about decision making in a new way.

Final Wrap Up

At the end of this last session, caregivers appreciate it if you can make their completing this training as much of a celebration as possible. It is a kind of "graduation." Some group leaders/trainers have given out "diplomas" that they make on a computer. Encourage participants to keep in touch – and if they are in a support group, encourage them to share what they have learned. Remind them that they are leaving with new skills and have acquired new knowledge and a more masterful outlook on their own work. In addition, they have materials they can keep referring to as their caregiving continues – the Caregiver's Manual and each other.

SAVVY
CAREGIVER™
KNOWLEDGE. SKILLS. MASTERY.

Thank you for all that you are doing!!!!!

You have now learned the knowledge, skills, and mastery to be a Savvy Caregiver!

Weekly Session 6 Notes

Conclusion

The Savvy Caregiver

Knowledge, Skills, and Mastery

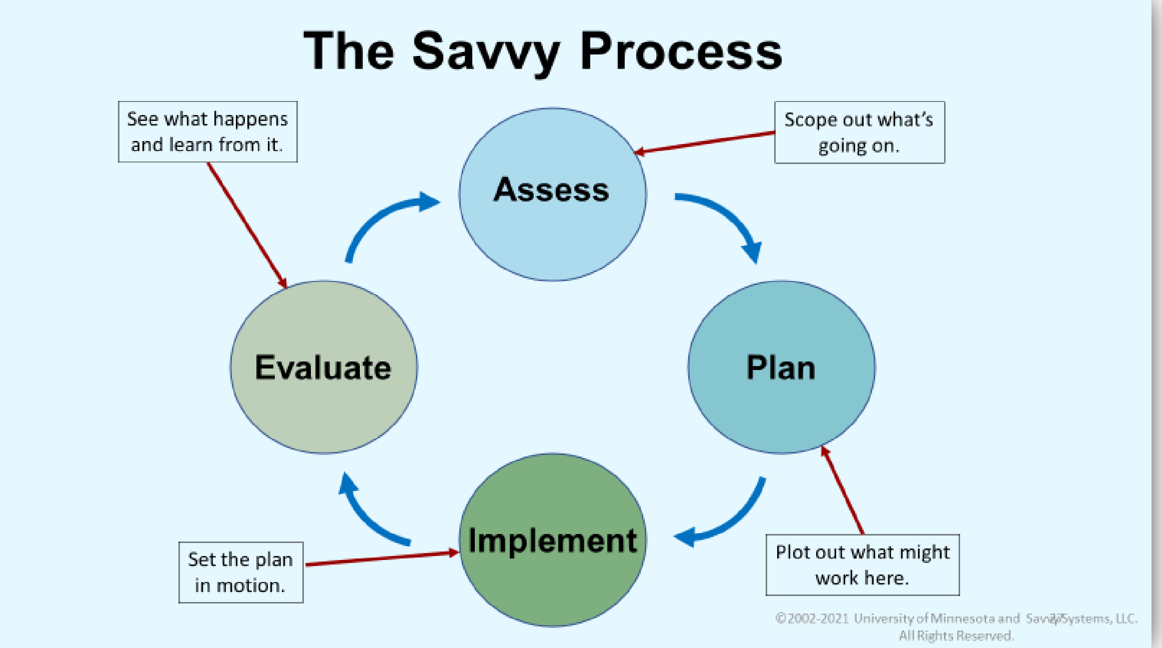
Final Review

The following information is provided in the Caregiver's Manual. Review this with participants to set them up for success as they complete the course.

Even as you finish the Savvy Caregiver program, the illness with which your person is living is continuing to progress. The illness will continue to erode the person's ability to operate effectively in the world. What you are able to see and understand about those abilities today will change. The timing and rate of change are uncertain. But it *is* certain that **your caregiving road forward will be a path in which change will be a major factor**.

We hope Savvy will have provided you with information and tools that will help you to be successful and effective in managing the changing demands on you as a caregiver.

The Savvy process that you learned will be key, going forward.



The Savvy Process

Assess

Scope out what's going on.

Plan

Plot out what might work here.

Implement

Set the plan in motion.

Evaluate

See what happens and learn from it.

Assess. An important skill you have acquired is to use your knowledge of the effects of the disease and your knowledge of the person to figure out your "next step" in caregiving. Whether the question you're facing is "What am I seeing?" or "How can I guide him/her to do something?" **the key first step is to assess, or take stock.** Remember the Savvy mantra: "Don't just do something; stand there."

Plan. The guidance you provide to the person should be intentional. We hope that the program has helped you to see the powerful role you play in your person's behavior. This is not only a matter of the silent messages you are sending – whether of reassurance or of frustration – but of how you set things up and provide cues. We hope the program has reminded you of **how good you are at fitting tasks and activities to the ability of the person**. You understand the importance of fitting the dimensions of any activity or task – number of steps; complexity; geography – to what the person's strengths can make best use of. You understand how the environment can support the person's contented involvement in an activity, or distract from it. And you understand that the method you use to cue up and reinforce an activity also has to fit the person's ability to make use of the information you're trying to convey.

Implement. Do it. You've made the best plan you can come up with, based on all your skills and knowledge. So, put it into effect.

Evaluate. See what happens and learn from it. When a plan works, that's information. It means that your reading of the person's skills and interests was on the mark and that you structured and supported the task in an effective manner. This might be something to add to your toolbox and repeat. And when a plan doesn't work, that's information, too, but you will have to work at figuring out just what the information is. This creates another opportunity to assess and plan.

Remember that all behavior has meaning, so if a plan doesn't work and your person does something you hadn't expected, that behavior is conveying information. It may be that something is bothering the person – like pain, hunger, fatigue, just an "off" day – but he or she can't tell you about it. Or it may be that the illness has progressed and your estimation of the person's abilities may need to be revisited.

Keep Checking your Resource Map. You can always benefit from help, and the need for help is likely to increase as the illness progresses. From time to time, go back and look at the map of your network that you developed. See if there are resources and people on the map from whom you can seek more help. And, if so, reach out to them.

The Decisions Keep Coming. We have made the point that dementia illnesses are progressive and terminal. It is also the case that, since most who are affected with these illnesses are older persons, other chronic conditions are also part of the caregiving task. As a caregiver, therefore, you will be called on to face decisions about advance care planning and end of life care as well, quite likely, as about placing the person in a setting where more skilled and round-the-clock care can be provided. Issues of financial planning may also come into play.

Always: Take Care of You. You've undertaken a large role that certainly benefits the person for whom you are providing care. It's a role that takes its toll on caregivers. So: Take Care of You.

Conclusion Notes