SAVVY CAREGIVER™

KNOWLEDGE. SKILLS. MASTERY.

Caregiver's Manual

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Additional Information About Savvy Caregiver

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Introduction

Living in an Extra-Ordinary Situation

Stop to consider the situation you find yourself in. This is probably different from any other situation you have experienced. Looking at that difference is a key first step in appreciating the work you have undertaken as a caregiver.

Consider the ordinary events and processes of life. Take, for example, how you have arrived at reading this manual and taking part in the **Savvy Caregiver™** program. Here, likely, are some of the things that brought you to this moment:

- You are caring for a family member or someone living with Alzheimer's disease or a similar dementia illness. Somewhere along the way, you saw that you are engaged in something challenging.

- Probably you feel these challenges are difficult. They weigh on you enough to want to take action.

- You realize it would be a good idea to get some help or advice.

- Maybe you discussed the idea of getting help with someone. Perhaps it was with a family member, friend, or a healthcare provider.

- Somewhere, you heard about the Savvy Caregiver program. Perhaps you asked others about it. For whatever reason, you wondered about it, asked about it, and decided to try it out.

- You took steps to connect with the program and get more information. You asked about what it would involve and how much time it would take.

- You pondered. You decided.

- And here you are.

Joining a program like this involves a lot of steps. Taking these steps depends on brain-based processes like self-awareness, reflection, deliberation, investigation, planning, and decision-making – just to name a few. But you probably didn't say to yourself: "Now I must reflect;" "Now I should gather more facts;" "Now I will consider my options."

Getting to this point uses cognitive – or thinking – processes and powers that are quite sophisticated. Probably, though, you did not stop along the way to think about the steps you were taking. You got here. And you feel relatively comfortable. You have some expectations and probably some doubts. But very likely you never paused to examine the thought processes that brought you here.

That is "ordinary" living. We rely on our powerful brain processes as we move through the world. But we take them for granted. We seldom stop to admire or recognize the complex skills we use in managing daily life.

Consider something else. Think back on a recent time when you were with friends and family in a comfortable, pleasurable conversation. Play the scene back in your mind:

- How much of the interaction depends just on the words you said to each other?

- How much were you relying on the special vocabulary and shared history that had developed among you over time? What words and stories had meanings only really understood by these friends or family members?

- How much of the communication among you was conveyed by gesture? The raised eyebrow? The emphatic hand movement? A shrug? A leaning in or a leaning away?

- What about touch? How much of your meaning did you express by the physical contact you make with each other?

Communication like this involves a lot of elements. But it is likely that using these elements is not something we do deliberately. We don't proceed intentionally. These elements are woven into "ordinary" communication. We take them for granted. Like the processes involved in making the decision to join this program, we rely on non-verbal elements to enrich and enable our communication.

The two examples above of “ordinary” decision making and communication illustrate how we take very complex and sophisticated processes for granted. We do not think about the brain processes of how we have arrived at an important point in our lives or how we communicate subtle and important information. If we had to stop to think through all of these “ordinary” activities, events, and transactions, it would be exhausting. And it would greatly change the pace and rhythm of our daily lives.

Here’s the point: you are now living in a situation that is *not* ordinary. It is extra-ordinary, out-of-the-ordinary. You are caring for a family member or friend living with an illness that is gradually but progressively diminishing his or her ability to interact with you and with the world in ways we would consider “ordinary.”

Quite understandably, we focus on how these illnesses affect those living with them. We recognize that it is increasingly difficult for them to manage in the world. We understand that as these ordinary capacities fade, it must be confusing and frightening.

While the **Savvy Caregiver** program will benefit the person living with an illness like Alzheimer’s, **this program is really about *you*.** And the program starts with a simple observation: Because you now live in an extra-ordinary situation, you are regularly and constantly facing what can be an exhausting task.

In practically every interaction with your person, who you now care for, you have to “read” the situation. You have to ask yourself: “How much of my person’s ability can I rely on in this interaction, and how much of our interaction do I have to supply?

The Savvy Caregiver program is meant to help you develop, strengthen, and master the skills that will help you in this ongoing balancing act that defines your caregiving work.

Core Savvy Principles

After you complete this training program, we want you to feel surer about your ability to carry out the work in which you find yourself. Let's start by reviewing some core principles – or key ideas – on which the Savvy Caregiver Program is based.

- **Personhood Persists**. At the core of this program, there is a central idea: Your person, who is living with a dementia illness like Alzheimer's disease, is always there, never erased. These illnesses will progressively erode your person's thinking capacities, behavioral and emotional control, and ability to do everyday things. It will progressively be harder for your person to be in touch with him- or herself and to make connections with you and with others. Nevertheless, your person's life story is still there. Their lifelong interests and accomplishments are still there. Their habits of speech and gesture are still there. Their likes and dislikes – still there. Peculiarities and mannerisms – still there. They are there, but it's harder for the person to find and connect with their personhood. And it's harder for you to see and tap into it.

- **Engagement is Possible**. Your person's capacity to become engaged in tasks and activities in ways that are satisfying and pleasant for him or her also persists. 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 the person to design tasks and activities that fit for the person. The Savvy Caregiver learns to promote contented involvement throughout the day.

- **Caregiving Mastery is the Objective**. The Savvy program sees caregiving as a role, a work responsibility you have taken on. In many cases, individuals become caregivers in the context of a long, established, and positive relationship with their person. But make no mistake: this is a *work role*. And, as with all work roles, it is possible to become particularly good at it with training. It is possible to develop mastery in the role.

  In the Savvy program, you'll learn how to work past the effects of dementia illnesses like Alzheimer's to help guide your person in daily life. You will learn how to develop strategies for working effectively in providing care for the person. This kind of caring and guidance is almost certainly a more deliberate way of interacting with your person than you are used to. At first, it may feel more controlling than is comfortable. If it feels uncomfortable, perhaps even disrespectful, keep in mind that you are using the skills and knowledge from Savvy to reach through the effects of a dementia illness to touch the person for whom you are providing care. That kind of guidance is a form of caring and kindness.

- **Self-Care is Essential**. As a caregiver, you are instrumental in maintaining your person's wellbeing. The Savvy program thinks of you as a kind of clinician – like a nurse or a social worker. We train clinicians that their work is demanding and that ensuring their own wellbeing is critical for effective performance in their role. This is true for caregivers, as well. So, this program is going to insist that you take care of yourself.

A Word on Terms

Throughout the program, we will use the term **"dementia illnesses"** to describe the brain *diseases* that affect individuals living with them. We also use the term **"dementia"** to describe the *symptoms* produced by these neurocognitive illnesses. We use the term **"dementia condition"** to refer to the *processes* these illnesses produce that result in progressive losses in cognitive and other brain-related capacities (neurocognitive capacities). Similarly, we refer to those affected as **"persons living with a dementia illness."**

Stigma still persists regarding these illnesses and for those living with them, and we have chosen these terms carefully to avoid feeding into this uninformed set of beliefs. Savvy training is intended to help you provide person-centered caregiving. We emphasize the importance of building caregiving strategies around the remaining strengths of the person even as these dementia illnesses progress.

The Savvy Caregiver Program

The Savvy Caregiver Program is **a training program for caregivers.**

Caregivers are persons like you who care for family* members who are living with a dementia illness. Savvy seeks to train caregivers about ways to work with your person's remaining strengths and to use the acknowledgement of "personhood" – and person-centered care – as a central principle in designing and using caregiving strategies.

Why Do You Need a Training Program?

You probably never expected to become a caregiver. And, you never trained for the role.

There are three important ideas in those last sentences:

- **Caregiving is a role**. Being a caregiver is different from being a spouse or child. Those terms describe relationships. Caregiving describes something a spouse or child or another relative or friend does to assist and guide someone who is living with a chronic illness. It is work.
- **The caregiving role has a "job description."** You couldn't hire other people to care for the person the way you do. But think about this. You could, *if you had the means*, hire people to do many of the things you do for that person. All those tasks put together – the helping, the cleaning up, the watching, the worrying, everything – make up the caregiver's job description.
- **The work of caregiving requires training**. Taking care of a person living with a neurocognitive illness like Alzheimer's is specialized work. To do this successfully, caregivers need special knowledge and skills. They also need an outlook or attitude that helps them to look after themselves.

The Savvy Caregiver Program provides that training.

*****We use the word "family" broadly, to include whoever you see as part of your caregiving network, whether or not they are related to you or your person.

Why “Savvy” Caregiver?

Our program’s name – Savvy Caregiver – is unusual and deliberate.

Savvy means “knowing.” **Someone who is savvy is knowledgeable.** The word also suggests being clever, even shrewd. The savvy person is smart and capable and is also able to stand just a little bit back from the situation. The savvy person uses this ability to look at what is going on and to develop the best possible response to a situation in order to increase the chances for long-term success.

We use the word “strategy” a lot in the program. **A strategy is a deliberate action taken to achieve a specific aim.** Good strategies are based on a good understanding of a situation. Caregivers need to develop strategies to accomplish the goals of their work. In the course of the Savvy program, you will learn about strategies that experts have developed in their work with persons living with dementia illnesses. The most important thing, though, will be for you to **work out strategies that work in your own caregiving situation**.

Why Become a Savvy Caregiver?

Those who take on the caregiving role are often under a lot of stress – usually for a long time. For family members caring for persons living with neurocognitive illnesses, the risks of the situation are clear. Compared with other non-dementia caregivers, dementia caregivers are:

- Twice as likely to have physical and emotional health problems
- Two-and-a-half times as likely to be taking medicine for their depression and anxiety
- Slower to heal and less resistant to illness (Their immune systems are weakened by the stresses of caregiving.)
- Half as likely to seek medical help for their problems
- More likely to feel cut off from their family and friends
- More likely to be stressed financially

Being savvy about caregiving won’t stop the course of the illness your person and you are dealing with or make it go away. Savvy caregiving won’t reduce all of the stress in the day-to-day or the long-term situation with which you are dealing.

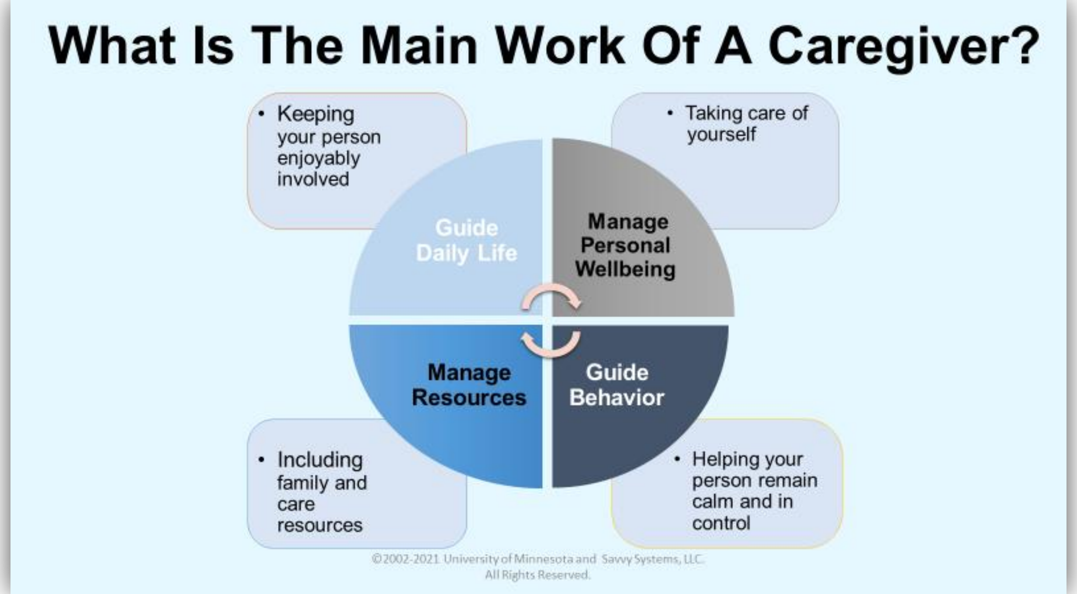
But, **Savvy Caregiving can enable you to develop a sense of control or mastery**. It will help you to find ways to reduce the effects of caregiving stress and to increase your sense of satisfaction and accomplishment.

The Five Goals of the Savvy Caregiver Program

The Savvy Caregiver program is built on the notion that the successful caregiver has five main goals:

1. Manage daily life with the person.
2. Guide behavior of the person throughout the day.
3. Find and manage resources to help with caregiving tasks.
4. Manage your well-being and take care of yourself.
5. Learn and use new decision-making skills.

The program is designed to increase your knowledge, skills, and outlook to help you succeed in your caregiving tasks. It will help you develop strategies to help your person engage more successfully and comfortably with daily tasks and activities. The program will help you see that the changing nature of your person's illness means that your strategies need to be refined as the illness progresses. The program will help you understand how these illnesses progress and how to amend successful strategies to keep pace with the changes.



What Is The Main Work Of A Caregiver?

- Keeping your person enjoyably involved

- Taking care of yourself

Guide Daily Life

Manage Personal Wellbeing

Manage Resources

Guide Behavior

- Including family and care resources

- Helping your person remain calm and in control

All of this work is carried out using new decision-making skills that you will learn in the Savvy Caregiver training program.

What is the Main Work of a Caregiver?

1. **Manage daily life with the person.** The program recognizes that caregivers assume increasing responsibility for the life of a person living with dementia illnesses. This responsibility extends to all aspects of your person. It means paying the rent or mortgage, managing finances, and making decisions. It means arranging and keeping appointments. It means keeping the home in working order. In other words, the family caregiver is increasingly in charge of maintaining the person in the world.

   On a more day-to-day basis, the caregiver's responsibility means getting through each day, every day. As your person's illness progresses, you as the caregiver become the "keeper of the day." Caregivers schedule and structure the tasks and activities in which the person engages. This happens day in and day out.

   The Savvy program will encourage you to establish some kind of regular order for your days and to set up routines for the various tasks and activities that make up the day. Caregiving typically goes on for a long time, so the more that is routine and regular about your days, the easier it will likely be for you.

2. **Guide the person's behavior throughout the day.** "Behavior" is a term you will hear a lot in this program. It is important to recognize that behavior is just what people do, how they act. It is not meant as "good behavior" or "bad behavior." Behavior only means action – like walking, talking, or sitting.

   Behavior is at the center of caregiving for a person living with a dementia illness. This program suggests a modest goal for caregiving: **To help guide the person through days that are as calm, safe, and pleasant as possible.**

   The behavior of a person living with a dementia illness can be puzzling. As the illness progresses, the person will be less able to direct his or her own behavior. He or she will become more confused and have less reliable powers of thought and communication. **Confusion** is a central problem in dementia illnesses. Confusion is the upsetting feeling of being mixed up and overwhelmed by all that is going on. It is the root of many of the problems that caregivers face, particularly problems related to behavior.

As the disease goes on, those living with it will experience more confusion and will be less in control or planful of what they do or how they behave. They won't necessarily know why they are behaving in a certain way. They will often not be able to tell you why they are doing things. In fact, behavior will not be intentional. They will not be able to respond to attempts to use reasoning to change behavior.

A cornerstone of the program is that all behaviors have meaning. The behavior of your person is not random or meaningless. Behaviors are typically reactions or responses to needs, emotions, wishes or impulses. The challenge is that persons living with a dementia illness will increasingly be unable to express what their behaviors mean or why they are doing them.

Guiding behavior means working to encourage and enable the person to engage in a positive activity or to move the person away from acting in a manner that seems uncomfortable. The Savvy Caregiver program aims to help you develop strategies that promote **"Contented Involvement."** The idea of Contented Involvement is that everyone, including even persons living in a late stage of a dementia illness, can become engaged in doing things and experience delight or satisfaction in doing them. **Savvy identifies contented involvement as a sign of successful behavior guidance.**

Savvy caregiving involves figuring out what the person's behaviors mean and how to deal with those behaviors. The illness with which your person is living makes this harder to do. Caregivers need to appreciate and accept that daily life and their connectedness with the person is steadily changing. Things that worked before will stop working. New strategies will have to be designed, perhaps drawing on what had worked before. The person will become less of an ally in developing and implementing effective strategies. Eventually, as the caregiver, you are even more responsible for the situation.

3. **Find and use resources and can help with caregiving tasks.** The third kind of caregiving work is that of **resource management**. This work can take two forms:

    - **Strengthening family and friends as resources for caregiving assistance.** All caregivers are involved with relationships. There is, of course, the relationship with the person living with the dementia illness. But there are often other relationships as well:

  - The **spouse or partner caregiver** often has children or stepchildren. Sometimes there are siblings and other extended family.
  - The **adult child caregiver** often interacts daily with her/his own spouse or partner and children. Sometimes s/he also is involved with siblings and other relatives.
  - The **caregiver and person living with dementia** typically had circles of friends, neighbors, and other social relationships before the disease process began. These people can still somehow be in the picture.

The Savvy Caregiver program also offers information and training to help you solve two frequent problems that caregivers experience:

  - ✓ **Disagreements.** Sometimes family members and friends disagree with the caregiver about what's going on. The program seeks to help all gain a better understanding of the situation and join together to help the person living with Alzheimer's or a similar illness.
  - ✓ **Help and Support.** Sometimes, family members and friends don't know that help is needed. Often, they don't know what help to give or how to give it. Savvy Caregivers are better able to decide which parts others might play in providing care to the person and to instruct others in how to perform those tasks.

- **Finding and organizing formal help** (like doctors, home health agencies, state and local aging services, and the Alzheimer's Association). There are also many kinds of formal help for caregivers. You have to be able to find and use such resources to lighten the load of caregiving and increase the person's quality of life.
  - ✓ The Alzheimer's Association has state and regional chapters all over the country. Call their national toll-free 24/7 Helpline for assistance at any time: **1-800-272-3900**. Valuable information is also on their website at www.alz.org.
  - ✓ The U.S. Administration on Aging Eldercare Locator can help you find local help. Visit www.eldercare.acl.gov/Public/Index.aspx or call toll free **1-800-677-1116** (Monday – Friday, 9:00 a.m. – 8:00 p.m. Eastern Time).

- ✓ In most parts of the country, these and other senior agencies offer help that can come into the home. The Internet offers access to information and help. Adult day programs or volunteer visitors may be available for your person. Home healthcare agencies and senior centers can be sources of help.

4. **Take Care of Yourself.** Caregiving is a generous and loving act. It can be rewarding, but it is also taxing. Burden and burnout are real problems. This program emphasizes the need for caregivers *to attend to their own needs*. It offers a number of strategies and home practice options that caregivers can use to recognize and deal with their own feelings and to better care for themselves while they care for their person.

5. **Learn and Use New Decision-Making Skills.** The Savvy program works on strengthening decision-making skills. Over time, you, as the caregiver, become the decision-maker for the household. This is true if you are the spouse, child, or other relative. For some caregivers, being the one who has to make the decisions may be a new experience. Even for caregivers who are used to taking the lead in household decision-making, there is now something missing – a partner, a sounding board, someone to appreciate the work.

   A portion of the Savvy program is devoted to presenting a structured way for approaching and making both day-to-day and long-term decisions. Someone has to decide about all the little and big things that need to get done. How will assets be sheltered and spent? What kind of housing best suits your new situation? Should the person go to a day program? Should you take a trip as usual? Should you consider nursing home placement and, if so, when? All the day-to-day activities of caregiving itself can also be thought of in terms of decision-making.

What Will It Mean to Be a Savvy Caregiver?

Savvy Caregivers are problem solvers and action takers. And, they learn from the results of their actions. They are able to stand back and look at the scene calmly. They recognize they have to take charge and manage the care situation. They know they will increasingly have to figure out what's best for their person in any given circumstance. They see that their person may have less and less to contribute to problem solving.

Ordinarily, when we interact with another person to solve problems, we can rely on that person for critical information. All of our usual methods and patterns of communication help convey important information. We can expect the person to:

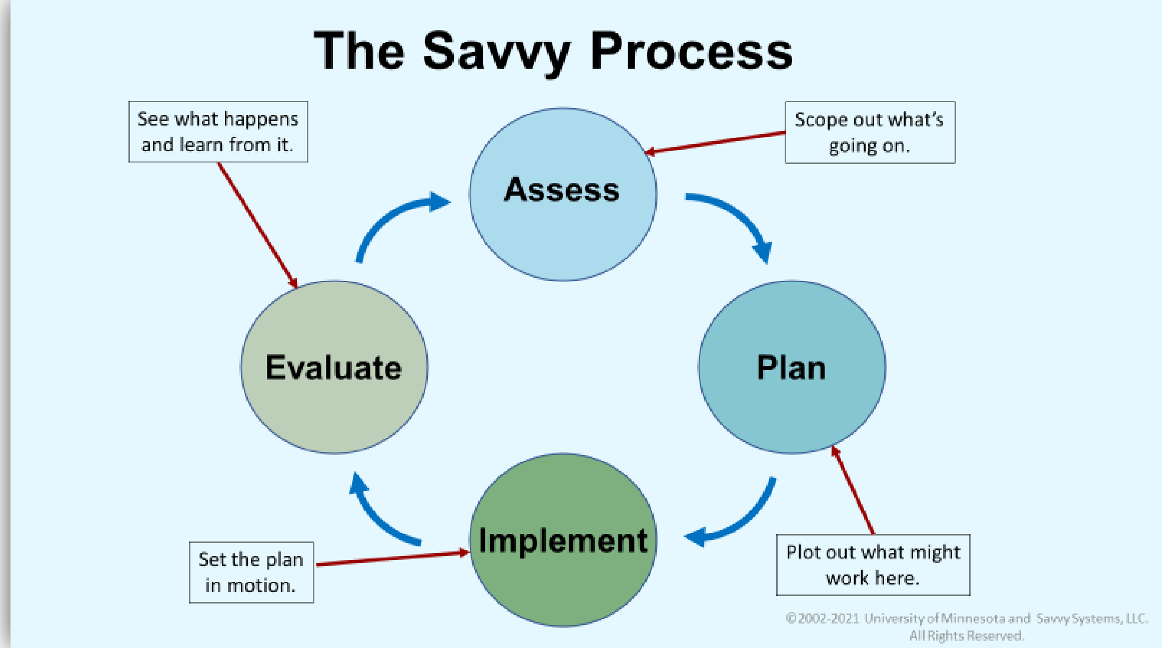
- Describe the problem.
- Tell what happened and why it's a problem.
- Describe how the problem is affecting him/her.
- Tell us what it feels like, how disturbing it is, and what a crisis it is.
- Give us some idea about what kind of solution s/he wants.
- Cooperate with us in solving the problem.

Savvy Caregiving, however, is not business as usual. When dementia illnesses enter the picture, caregivers are faced with having only parts of the ordinary means of sharing information. That is a challenge. Letting go of former expectations of how things used to be – and piecing together meaning from a new and often unclear and incomplete set of cues – is really hard work.

Still, your person's behaviors may give clues about what is happening. Familiarity with your person and new understanding about dementia will help to form hunches about what may be going on and what might help. These hunches will lead to trying things out in an attempt to solve the problem. Some solutions may work; others won't. This is to be expected. The key is that if the first solution works or doesn't work, you will learn from it. You may have to devise another solution and try it out. Eventually, you *will* solve the problem.

The Savvy Process

In the Savvy Caregiver program, we urge using **the Savvy Process** to deal with most caregiving situations. This process is one that nurses use in almost all their work with patients. Actually, it is a process that is common to almost all of the clinical professions. The first step is to **Assess** the situation: What's going on? What am I seeing? The next step is to create a **Plan**: What can be done that fits your person and the situation that will result in a desired end? The next step is to **Implement the Plan**. Try it: Put the plan into action. And then **Evaluate**: What happened? Did the plan work as hoped? What did you learn? The outcome of putting the plan into effect gives you the next situation that you need to Assess (and then create a new Plan that you will Implement and Evaluate – and so on).



Through this process, you will learn more about how the disease affects your person and what strategies work – and when they work. Savvy Caregivers store up information and classify it as "things that don't work and things that do work sometimes." The process also helps caregivers understand that, since the disease is progressive, things that worked one time may or may not work the next. Over time, the condition will change, and new strategies will be needed.

Caregivers also learn more about themselves as they work with their person. They learn in what ways they are most comfortable and effective. They learn what skills they want to improve. They see where they are confused or discouraged and need help, advice, or information.

What Kinds of Information Will I Learn To Become a Savvy Caregiver?

We have already covered some of this information in the five main goals of this program – managing daily life with the person, guiding your person's behavior, finding and using help with caregiving tasks, taking care of yourself, and learning and using new decision-making skills. We will spend a bit more time on finding and using help with caregiving tasks as it can assist in meeting the other goals. This can also be called resource management.

Beyond resource management, there is other information that is essential to your understanding of what your person's life is like and how you can help them to lead the best life they can. See the following for a glimpse of what other information you will be learning in this program.

- **There Is an Illness at Work.** The first part of this manual is a guide to dementia illnesses. It provides general background information about the illnesses with which caregivers deal – and with which the persons they care for live.

- **Thinking Through and Feeling What the Illness Means.** These sections have multiple purposes. First, they focus on how dementia illnesses affect key powers of thought – like memory, reasoning, and judgment – and then you will begin to learn about caregiving strategies. Looking at changes for each element of thought, you will find out how caregivers have to think and work strategically when providing care.

  It's one thing to think about how dementia illnesses work on the person. It's another thing to appreciate how it must feel to experience having this condition. These sections also help you understand and feel how **the experience of Confusion plays a powerful role in the daily reality of your person** – and what that Confusion can mean for you.

- **Understanding Behavior.** Caregivers are often in the business of trying to get their person to do something or to stop doing something. This program provides four models for understanding behavior – including causes of behaviors, and that caregiver reactions to behaviors can be the cause of the next behavior.

- **Everything Working Together = Performance**. All of the separate pieces – thinking, behaving, moving through a confusing world – come together in doing things in everyday life. The program calls this "Performance." Everyday actions like dressing, washing up, and helping with chores are all examples of performance. The program will help you see that, **in these illnesses, the capacity for performance declines in a certain predictable fashion**.

- **Stages of Your Person's Changing Abilities and Providing Practical Help.** Because dementia illnesses are progressive, your person's abilities decline over time. These changes progress through broad **stages**. In these sections of the program, the Savvy Caregiver learns **a practical way to describe how abilities fade**.

  These sections also focus on how to help your person become and remain involved and content in daily tasks and activities. We call this "**Contented Involvement**." It draws on everyone's natural sense of satisfaction in being engaged and in your abilities for matching activities to abilities. People living with a dementia condition *can* have good quality of life. In fact, the Savvy program proposes that **a goal for caregiving is to guide the person through days that are as safe, calm, and pleasant as possible**.

- **Taking Control, and Dealing with Daily Care and Complicated Behaviors.** The caregiver comes to recognize that s/he's in control, in charge of daily life. Control is not a word we use comfortably when dealing with another adult; we believe in the freedom of the person to make choices. Dementia illnesses threaten and, eventually, destroy the person's ability to make wise, safe, and informed choices. **Taking control can reduce confusion and provide calm and security.** But caregivers have to understand and accept this new part of their role. If it's more comfortable for you, think of this as providing guidance to the person.

  These sections also provide information and suggestions about how to look at and better address and **guide behaviors that are challenging**. It also provides information about how to help with other care tasks.

- **Communication and Dealing with the Emotional Truth of Situations**. This section covers interacting with and responding to your person in a way that promotes reaching the goal of having a safe, comfortable, and engaging day. Different approaches for responding to negative verbal and physical behaviors are considered, with this program choosing to focus on finding the "emotional truth" of situations as the best option. This approach considers the underlying emotions of such behaviors and responding to the emotions, rather than trying to respond directly to the words or actions. Other approaches you may have heard about – like "Reality Orientation" and "Therapeutic Lies" – are also presented.

The Savvy Caregiver Program Sessions

How is the Savvy Caregiver In-Person Training Structured?

The program unfolds over a series of weekly sessions (usually six, but this may vary).

What Materials Will Be Used in Class?

- **Caregiver's Manual.** This manual explains and expands on the talks given during the weekly Savvy group sessions. You can read and use the manual at any time.
- **Slides and Handouts.** The leader may use some visual materials to help emphasize ideas presented in the program. Some of these will illustrate key points. Others will help you take part in experiences during the sessions. You will receive copies of all the materials to help you follow along.

What Should I Expect *During* Training? **Participation and Practice!**

This training is not passive learning. We expect you to participate in and prepare for the sessions:

- **Participation**. You already have a great deal of experience and expertise in caring for your person. As such, you are one of the experts in the class. We encourage you to contribute to everyone else's learning.
- **Practice**. We will ask you to "try things at home." We will ask you to read sections of the manual to prepare for the next session. Most importantly, we'll ask you to apply the information and ideas at home. We want you to think about things you learn, try them out at home, and share your experiences.

What Should I Expect *From* the Training? **Mastery!**

We expect the program will expand your knowledge and skills for caregiving. The most important outcome, though, is for you to feel more able to carry out the caregiving role you have taken on. We describe this feeling as **Mastery**.

We want you to have a strong sense of confidence in your caregiving abilities. While we will be teaching you a lot of things, most of the program's activities are designed to let you try out and gain confidence in the new skills at home. We already know that you are the most skillful care provider for your person. We want *you* to appreciate how skillful you are in this very important role.

Introduction Notes

Weekly Session 1

Welcome to the Savvy Caregiver Program

Introduction to Dementia Illnesses

This section includes information that will orient you to the illnesses affecting the person for whom you are providing care. This is an overview, and not a comprehensive and detailed description of such illnesses or of the risk factors that might contribute to their development. At the end of this section, we provide links to a number of websites where you can find more detailed information about the particular illness with which you are dealing. Here we want to provide a general orientation to the world of illnesses with which you are dealing.

In this section, you will find:

- Dementia illnesses → **not** a part of normal aging!
- A definition of dementia illness
- A description of the main illnesses that produce dementia symptoms
- Information about depression, an illness that can produce dementia-like symptoms
- A description of the course of dementia illnesses
- A discussion of medical evaluation and care
- Information about treatment possibilities for dementia illnesses

Not Normal Aging!

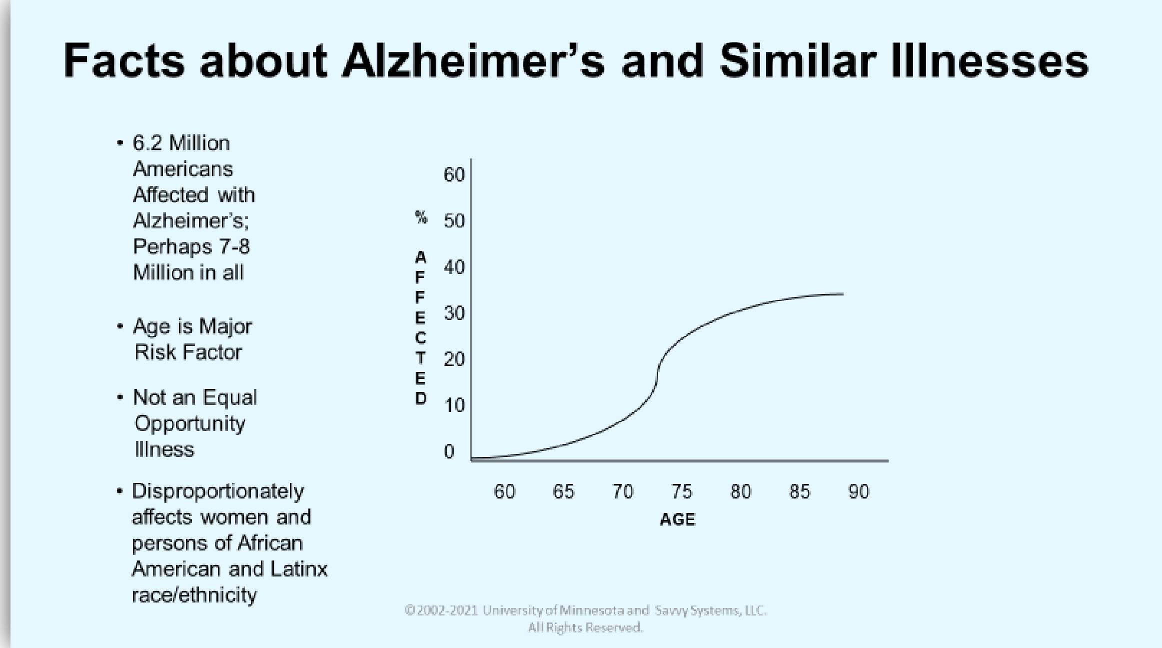
Aging is the main risk factor for developing most dementia illnesses (somewhat less so for Frontotemporal Dementia and Lewy Body Disease), but getting older does not mean one will develop the condition. Only about one out of nine persons over the age of 65 will develop a dementia illness. The risk of becoming affected with a dementia is, in general, not very great at any point in time. For a given individual who is 65 years of age, the *risk* is approximately 1 to 2 in 100. *Risk* does increase as people age, but it is never all that great. Thus, for a person who is 85 years of age who is not yet affected, the immediate *risk* is approximately 2 to 3 in 100.

Dementias are typically long-term illnesses. It is generally said that the average course of a disease like Alzheimer's is 8 to 12 years. However, there is a lot of variability between individuals. For some, life with the disease lasts only a few years. For others, it can extend for 20 or more years.

As more adults live longer, we see as many as 35-40% of those over the age of 85 are living with these dementia illnesses. It is not that a lot of people suddenly acquire the illness when they turn 85. It is that it developed 5, 10, or 15 years ago, and they have remained alive with the disease. In other words, many of those with the disease survive into old age while others of their age group have died of other causes.

The diagram below shows that the percentage of the population affected by a dementia illness increases with age. Only about 1% of all persons age 65 have a dementia illness. About 10% of persons who are 75 have such an illness. Some estimate that nearly half of all persons 85 years or older have a dementia illness.

Percentage of the Elderly Population Affected by Alzheimer's and Similar Illnesses at Various Age Points



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

Just about everything we do slows down as we age. Our body becomes slower and weaker. It takes longer to do things, and we tire faster. The same is true for mental ability. Even in healthy adults, there is a small but measurable slowing in thinking as we age. We process information more slowly than when we were young. It takes longer to recall information and to learn new things. Mental exercise can help healthy older persons increase their thinking speed and capacity. However, older people don't gain as much compared to younger people doing the same exercise.

Most people notice these physical and mental changes as they age. Both can be troubling, but the mental slowing seems to be more disturbing. We are surrounded by information and misinformation about Alzheimer's and similar diseases that affect the brain. Most of us see these as terrifying diseases, and we worry about developing them. When natural mistakes occur, we sometimes experience them as "signs" of these diseases.

The truth is: Young people forget where they left their keys. Young people have difficulties remembering names. Young people can't come up with words. They just don't worry much about these things. Eventually they find their keys, remember the name (or Google it), and come up with the word or a good substitute. When these things occur in older people, however, they can be a source of anxiety… "It's happening; I've got it."

Over time, people recognize certain kinds of typical and regular problems with memory, and they develop "tricks" to avoid them. To prevent loss of keys or glasses, for example, people have fixed places where they always leave them. They remember these "tricks." People may also realize that they have always been bad about remembering people's names. They stop worrying and may even make a joke about it. When the search for a word fails, people let it go. Hours or days later, the word comes to mind. There is an acceptance that the brain is working normally, but it's just working more slowly. This is normal aging. These losses are not the result of diseases attacking the brain.

Dementia Illnesses

"Dementia" is a description, not a disease. There is no disease called "dementia." The word dementia refers to a condition that can be caused by many illnesses. It describes the signs and symptoms that result from having an illness. Alzheimer's is the most common of the illnesses that cause a person to be identified as having dementia symptoms. The main difference between "dementia" and Alzheimer's is that one (dementia) describes what is happening, while the other (Alzheimer's) provides the name of a disease that is causing it.

But your person is living with an illness. It is an important step in caregiving to acknowledge that a family member is living with an illness. A disease process is at work. The person cannot help it. It is not depression (though depression can co-exist with it and make it worse). It's not laziness or giving up. The person cannot control the problem, nor will it to go away.

As noted above, Alzheimer's disease and related dementia illnesses are not normal in aging. These are diseases that are attacking the brain. In 2020, about 6.2 million Americans were thought to be living with Alzheimer's. The number is likely closer to 8 million when other dementia illnesses are included. If no cure is found before then, about 15 million Americans will be affected by 2050.

Dementia illnesses are global in nature. They typically affect memory, but they also affect thinking, behavior, and the other cognitive skills needed to care for oneself and to function safely and independently in the world. In almost all cases, these diseases are global, progressive, and irreversible. Let's examine these characteristics.

> **Global.** The disease affects a person's entire range of thinking abilities. Often, dementia illnesses are thought of as diseases of memory or of one particular cognitive skill. That's only partly right. Memory loss, a hallmark of many of these illnesses, may seem dominant, but it is important to realize that all other areas of thought are also involved.
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> **Impair and erode ability to function safely and independently in the world.** This goes beyond forgetting other people's names. Gradually, but eventually, the person loses the living skills we take for granted. The world becomes foreign. The person doesn't recognize or know how to get around in it. The person may gradually lose the ability to behave in "ordinary" fashion with others. Gradually, the person can't be relied upon to keep himself from harm in what used to be ordinary situations – like driving, handling firearms, or using power tools.
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> **Typically, progressive and irreversible.** The person's condition changes and gets worse over time, and it cannot be stopped. An ability that the person has today will begin to fade, and over time it will be lost. For a caregiver, this means that things that work in caregiving today may work for a while. Over time, strategies for guiding the daily activities of affected family members will almost certainly have to be changed as the person loses more ability because of the disease. It is important to understand that these are terminal illnesses.

What Are the Main Dementia Illnesses?

All such illnesses are brain diseases. At least 70 different diseases can cause a dementia condition. The four most common of these illnesses are Alzheimer's disease, Lewy body dementia (LBD), vascular dementia (also called multi-infarct dementia), and frontotemporal dementia (FTD). These diseases act in different ways to cause the brain to lose its ability to absorb, recall, or make use of information. They can also co-occur. It is not uncommon to see someone with both Alzheimer's and vascular dementia.

Alzheimer's disease is the most common form of dementia illness. It results from abnormally large accumulations of types of protein normally found in the brain (amyloid and tau). These proteins destroy brain cells. They do this either by clumping the cells into abnormal groups (called "plaques") or by causing cell structures to disintegrate (resulting in "tangles"). It also alters the chemical balance in the brain. Together, these interfere with the brain's ability to communicate with itself, and that is the ability that enables us to function effectively in the world. As cell loss and chemical imbalance continue, the brain's abilities decline. With that, functioning declines. By the late stage of the disease, few important abilities remain, and people are unable to function on their own. They seem entirely cut off from the world around them.

Historically, the changes produced by Alzheimer's – the plaques and tangles – could only be seen through an examination of a brain at autopsy. Now, new kinds of imaging techniques and new ways to examine fluid from the spine are becoming better at detecting a person's brain changes due to Alzheimer's. As these techniques get better, it may be possible to make earlier diagnoses and to begin potential treatments earlier as well.

Current thinking is that the Alzheimer's process in the brain begins many years before the first signs and symptoms occur. For this reason, more research is now focused on early detection and on seeking treatments for those with the illness but who show no signs of it.

Lewy Body Disease. "Lewy bodies" are another form of protein accumulation not normally found in the brain. When they enter the brain in great quantities – and we don't know how or why this happens – they produce a progressive illness similar to Alzheimer's disease. This disease accounts for perhaps 10% of all cases of dementia.

It can start at an earlier age than Alzheimer's. Many of the symptoms are the same as those in Alzheimer's, but there is typically a slowing of gait (walking movement) that is similar to Parkinson's disease. Persons living with this illness also have progressive losses in powers of thought (memory, reasoning, judgment, etc.). Lewy Body disease can produce greater changes in mood and feeling. So, big mood swings and sudden bursts of temper are sometimes seen. Hallucinations may also be more common and vivid. As many as 80% of those who survive to late stage Parkinson's disease develop a Lewy Body condition. Lewy Body disease is the second most common of the dementia illnesses.

Vascular dementia results from brain cell death caused by a series of small or large strokes. Strokes are produced either by a blockage of a blood vessel in the brain or by a leakage in a blood vessel. Strokes are associated with earlier cardiometabolic disorders including high blood pressure, diabetes, high levels of cholesterol, and obesity. Small and often unnoticed strokes are called transient ischemic attacks: "TIAs." Vascular dementia is also called "multi-infarct dementia." [An infarct is an area – for instance in the heart or brain – that has died from lack of oxygen or blood flow.]

When a stroke occurs, the area of the brain that is affected is killed and cannot regenerate. If a single small area of the brain were destroyed, the brain might be able to work out ways around the damage. With vascular dementia, there are repeated small strokes and TIAs. Damage is occurring somewhat regularly. This means that the brain cannot compensate. It also means that larger and larger areas of the brain are being affected by damage that is irreversible. As this damage occurs, there is increased damage to the powers of thought, behavior, emotional control, physical ability, and other areas of day-to-day performance. Continued strokes lead to greater and greater loss. These strokes eventually affect life-sustaining functions and can be the direct cause of death.

Frontotemporal Dementia. Similar to Alzheimer's disease and Lewy body dementia, Frontotemporal Dementia (FTD) is produced by deposits of unusual proteins in the brain. As the name suggests, this illness affects the front part of the brain, the frontal cortex. This part of the brain controls our judgment, behavior, and language. There are three variant forms of FTD, and these affect behavior, motor control, and language. The behavioral variant is often associated with very erratic behavior; those with this variant can be impulsive in a variety of ways. They may engage in odd and highly varied food cravings. Their inhibitions in the use of language may be loosened, and they may show profane or vulgar behavior and may become sexually disinhibited.

Those with the language variant (Primary Progressive Aphasia) experience, very early on, severe difficulties using or comprehending spoken communication.

FTD often occurs in relatively younger persons (in their 40s or 50s). In these cases, families with young or teenaged children may be involved. Thus, FTD caregiving can involve added challenges. Marriages can be disrupted. Children watch a parent change dramatically. The financial stability of a working family can be greatly disrupted. The course of FTD is usually shorter than that of Alzheimer's, but it still extends across several years.

Other diseases that cause dementia symptoms. Many other illnesses produce dementia symptoms. Among these are Creutzfeldt-Jakob disease, and Wernicke-Korsakoff syndrome. A variety of conditions can produce a dementia conditions in their later stages. Brain injuries, especially those associated with repeated injuries, and a variety of illnesses that compromise the autoimmune system can produce dementia-like conditions.

Co-existing dementia conditions. It is not uncommon for two illnesses, particularly Alzheimer's and Vascular Dementia, to be present together in an individual.

Reversible dementia conditions. A very few dementia illnesses are reversible. These are disorders that can produce a condition that mimics (looks and acts like) dementia symptoms. In some cases, the disorders have a permanent effect on the brain, but by treating them the damage can be stopped or slowed. These conditions include the effects of prolonged alcohol abuse, nutritional disorders (like Vitamin B 12 deficiency), urinary tract infections, and brain infections (like meningitis).

In other cases, a disorder is producing dementia-like symptoms, but if the disorder is treated, these symptoms may disappear. These include depression (see below), fluid pressure on the brain (normal pressure hydrocephalus), disorders in the way the body uses nutrients (e.g., hypothyroidism), and other brain infections. In these cases, proper treatment can result in improved function.

Depression. Depression, a condition more common among older adults, is relevant to dementia illnesses in two ways. First, depression is the most common disorder that mimics dementia symptoms. Depression when untreated affects thought processing, social interaction, and a person's ability to perform tasks they are normally able to do.

There are several common signs of depressive disorders:

- Sad or depressed behavior
- Loss of interest in things (apathy)
- Change in eating habits
- Change in sleeping habits
- Changes in personality

It is worth noting that these are the same signs that are commonly seen in persons living with dementia illnesses. So, it is easy to see why depression could be confused with one of these illnesses.

Depression is a frequently missed diagnosis inolder adults. Doctors often don't pick it up on a routine visit. If you have any reason to suspect your person might be depressed, make a point to tell this to the doctor. Ask the doctor explicitly to assess the person for depression.

There is a second way depression fits into the picture. It is also commonly found along with illnesses that produce dementia symptoms – especially in their early stages. The two can co-exist. When they do, the depression can make the symptoms of dementia illness worse and add to the person's and the caregiver's burden.

Depression is a treatable disease. This is an important point to remember. Suspected depression should be evaluated. Diagnosed depression should be treated. Treating a depression that is mimicking a dementia illness can be good for the person. It may also help clear up whether there is such an illness present. Treating a depression that coexists with a dementia illness may help lighten some of the signs and symptoms of the dementia illness.

What Causes Dementia Illnesses?

We still do not know what it is that activates these illnesses. A number of genes have been identified that appear to be associated with Alzheimer's and a few other such illnesses. But not everyone who has these genes develops the illnesses. Environmental factors, toxins, and previous head trauma have all been linked to Alzheimer's disease onset, but not conclusively.

Heredity and Dementia Illnesses. Only a very small percentage of cases (1 to 2%) of Alzheimer's can be thought of as being strongly hereditary. In these cases, more than half the members of the family for several generations have been documented as being affected by a dementia illness. Also, in these cases, the disease often begins very early in life (as early as the 20s or 30s).

Outside these unique families, people whose parents had Alzheimer's do appear to be at increased risk for the disease. Those with one parent who had the disease have a three times greater risk of the disease than those with no first degree relative with it. Those with two first-degree relatives with the disease have a seven-to-ten-fold increased risk. Tthe risk for the disease is not ever very great, so even the increased risk of an hereditary association is not determinative; it is not a sure thing

Should family be tested for genes associated with Alzheimer's? Nearly all experts say no to this question. At this point in time, knowing whether one has one of these genes does not provide conclusive information. At most, such information provides only rough odds of the likelihood of developing the disease. So, it is not information on which to base any certain actions or plans. Plus, we do not currently have any intervention or treatment that might delay or prevent the onset of the illness. A person might make certain life choices based on such information, but the burden of uncertainty and anxiety might well outweigh the sense of being prepared.

Does Everyone Have the Same Risk for Dementia Illnesses?

There is evidence that Alzheimer's disease and other dementia illnesses are more likely to develop among women than among men. This greater risk among women is not just because women typically live longer than men and so have a longer time to acquire the illness. The reasons for this greater risk are not yet understood. Dementia illnesses are also more likely to develop among African Americans than among whites, and more likely to develop earlier in persons of Hispanic/Latino descent compared to other groups.

Some risk factors for developing a dementia illness cannot be altered. A person can't change his or her age or who his/her parents were. Experts and common sense point to the fact that the brain does not exist in isolation. The cardiovascular system is vital to brain health – to function, the brain needs 20% of the oxygenated blood the heart pumps with each beat. The systems that enable the body to respond to stress (the inflammatory system) and to fight infection (the immune system) are integrally linked to the brain. And the brain is an organ that can and does benefit from active use. So what happens to the heart, what happens in life that produces stress, what illnesses challenge the immune system, and the ways in which the brain develops and continues to grow all have bearing on the development or avoidance of dementia.

Some other early life factors are unchangeable and may contribute to or reduce overall risk. The social and economic circumstances of one's early life, circumstances that may have produced ease and nurtured development or sustained stress (which can produce chronic inflammation), may reduce or contribute to the risk of developing a dementia illness. The quality and extent of one's education may play a role as may the kinds of work in which one has engaged. Sustained economic or social stressors, including persistent discrimination or living in conditions that make it difficult to live a healthy life style or access proper preventive healthcare, appear to enter the risk factor picture. The presence of cardiometabolic conditions – particularly high blood pressure, diabetes, and obesity – pose risks for dementia. As noted above, other conditions – repeated brain injuries, autoimmune conditions, and possibly the exposure to toxic environments – are also risk factors for dementia.

Preventive activities. Taking these risk factors into account and recognizing that some are not subject to change, experts suggest five broad categories of actions that individuals at all risk profiles can take that might be preventive in nature:

- Manage co-morbid conditions. Keeping one's blood pressure or diabetes under control and managing one's weight appear to be very important, especially in preventing stroke-like events that contribute to vascular dementia.
- Eat well. Attention to diet is an important way to both manage other conditions and to stay healthy in general.
- Engage in physical activity. Moderate amounts of regular physical activity improve overall condition and can reduce stress and the demands on the inflammatory system
- Engage in social activity. Regular interaction with family, friends, social, religious or community groups engages the brain and is protective against depression.
- Engage in intellectual activity. Exercise the brain – take classes, learn a new skill, read, discuss; these kinds of activities can build "cognitive reserve," a capacity that can compensate for losses even ifa dementia illness should begin to develop.

How Are Diagnoses of Alzheimer’s or Similar Illnesses Made?

One of the most difficult things about dementia illnesses is how slowly and silently they come on. Persons often go for years before someone will decide that all is not right and that they should see a doctor. On average, it is 2 to 3 years between the time someone in the family notices that something is wrong and the time a doctor makes a diagnosis.

Evaluation for dementia illnesses. Anyone faced with the possibility of living with dementia deserves a complete and careful evaluation of the condition. There are three reasons to get a good evaluation:

- It is important to become sure about and to name the problem
- It is important to rule out treatable causes of dementia symptoms
- It is important to know the extent and stage of the problem.

It is not an easy evaluation. For example, there is no single test for Alzheimer’s. However, recently developed guidelines (See, for example, the Agency for Health Care Policy and Research *Guidelines for the Diagnosis and Treatment of Dementing Disorders*) recommend tests and procedures for evaluating possible or probable Alzheimer’s. Your clinician or healthcare provider (physician or nurse practitioner) should be aware of these. You have every right to expect two things:

- Before giving the diagnosis, they should test the person in a number of ways to rule out treatable causes.

- You should get a clear answer. Do not be satisfied with a vague answer or one that suggests that what is happening is just due to aging. “Senility” is definitely not an acceptable diagnosis. In fact, it is not a diagnosis at all. Even a statement that it is “a dementia” is not acceptable. You should learn what kind of illness you are likely dealing with.

What are the key diagnostic signs? Probably the main “signal” that a good diagnostic workup is needed is repeated evidence that a person is having substantial difficulty performing a complex task that he or she had usually and regularly been able to manage with success.

Certain conditions must be present to make a diagnosis of an illness that produces dementia symptoms:

- Noticeable problem(s) with memory, especially recent or short-term memory (memory of recent events or information).

- Loss of thinking abilities that is bad enough to interfere with normal social functioning. This usually involves at least one of the following:

    - impairment of abstract thinking – such as numbers or time
    - impaired judgment
    - disturbances of other powers of thought – such as attention or organization
    - changes in personality

In addition, the person must be alert and awake. A person who is unconscious or in a daze (delirious) cannot be judged to be affected by a dementia illness.

What goes into the evaluation? A definitive determination is generally made over a period of time. There are several key elements in the diagnostic work-up:

- **History.** Usually the most telling piece of information is the history of the person's condition. Often the healthcare provider/ clinician will rely on family members to provide the history or to fill in parts that the person can't supply. The clinician is looking for patterns of change in ways of dealing with the world, memory, personality, and behavior over a long period of time (~ 1-2 years). The clinician will also ask about the pattern of loss and decline. Was it smooth and steady? Was it more like a series of drops in ability followed by no change for a period of time? Such questions can help determine whether the process is caused by a gradual accumulation of specific protein substances in the brain or whether it might be caused by stroke, a blow to the head, or even nutritional deficiency.

- **Tests.** The clinician may order a number of blood and spinal fluid tests to rule out possible causes of decline in thinking ability. These will include tests of thyroid function and nutritional status, and the spinal fluid test will enable assessment of the presence of amyloid protein in the brain. Other tests for chemical imbalance and the presence of infection will likely be ordered. S/he may also perform a short exam to test the person's thinking processes. Some new diagnostic tests are emerging. The lumbar puncture procedure for drawing cerebrospinal fluid is, when performed by an experienced person, a relatively safe procedure.

- **Imaging studies.** Brain imaging allows the clinician to see whether there are any signs of slowing in parts of the brain or of brain injury such as that caused by stroke or head injury. These can also detect brain shrinkage (atrophy) that occurs in Alzheimer's. Imaging techniques include magnetic resonance imaging (MRI), positron emission tomography (PET) and computer assisted tomography (CAT). These tests are costly. Families may have to judge if there is enough clear evidence to enable the clinician to make a confident diagnosis. If so, a scan may not provide added value.

- **Psychological tests.** At a minimum, the person should be assessed for depression. Some centers also administer neuropsychological tests. These can help locate where losses have occurred in the brain. Some diseases produce characteristic results on these tests. This can help the clinician pinpoint the diagnosis.

The clinician may put all this information together to arrive at a diagnosis. Or, there might be a referral to other diagnostic specialists. Neurologists, psychiatrists, neuropsychologists, and occupational therapists can all be called on to contribute input to a diagnosis. Geriatricians – internal medicine physicians or family physicians with special training in the care of older persons – can also be useful experts in the diagnosis of dementia illness.

What is Life Like for My Person, and What Can I Expect as a Caregiver?

Dementia illnesses are generally progressive and have a long course. The person – the essential person – remains. However, the changes brought about by the illnesses make the person less and less present to him- or herself and to others. One caregiver author called this process "a slow disappearance."[1] In almost all of these illnesses, the condition of the person will slowly change and worsen. "Worsen" is a hard word. Here it means two things:

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[1] See: Stolen Mind: The Slow Disappearance of Ray Doernberg by Myra Doernberg, Algonquin Books, 1989.

- Much of who you consider your person to be will fade. As you will learn in later chapters, connections or abilities we consider essential gradually weaken and go away almost entirely. Sometimes, personality itself changes and becomes quite different. Changes in personality are more frequent in certain of the dementia illnesses. This is often the case in Frontotemporal Dementia where the parts of the brain that control impulsive behavior are affected early on.

- The person's control over his or her life and actions will slowly fade. This can lead to difficult moments. Guiding your person's actions to keep things calm is a big part of what this program is about. You will learn a lot more about this in later chapters.

As the family caregiver – and there is usually just one primary caregiver – you will likely be faced with these changes. As the illness progresses, the work of caregiving generally increases. Caregivers are increasingly in control of what their person does and how the person acts. Care choices also become more difficult. Choices and decisions the person might once have made now fall on the caregiver to make, such as whether to call in extra help; whether to pursue aggressive treatment if other illnesses develop; or whether care needs can only be met in a 24-hour setting like a nursing home. In most cases, these are choices the caregiver has to make.

What is a Reasonable Caregiving Goal?

Think about what people normally hope to work towards when they take care of someone who is ill. Think about whether these goals fit when caring for a person living with dementia.

See the person through the illness and back to health. This is probably the most common goal of caregiving. Most people's experience of giving care to someone looks like this. People are used to a person "coming down with something."

- There is a period when you think something is wrong. This is when you find yourself looking for little signs.

- There is the period when the illness is in full bloom and the person is miserable. This is a very busy time for caregiving.

- Then the illness starts getting better. There are still caregiving chores, but the worst is over. The person seems him/herself again.

It does not work this way with dementia illnesses. "Nursing the person back to health" is not a reasonable goal in dementia caregiving. It is important to recognize that caregiving cannot bring the person back to how they were before onset of the illness. There can be no expectation that the person will get better. There are no tricks and no treatments that can jolt the brain back to health once a dementia illness starts. No amount of caregiving can help the person return to where s/he was before the disease began.

Stop or slow the progress of the disease. This goal is common in many chronic illnesses. Efforts to stop or slow the progress of the disease can be effective even when irreversible damage is being done. Some ability may be lost permanently, and other losses will follow. Care and treatment can limit or slow the losses.

This is not a reasonable goal in dementia caregiving. Caregiving activities cannot help to preserve the person's abilities, and no current treatments accomplish this either. There is nothing we can do to prevent the condition from worsening in diseases like Alzheimer's. The person's powers will fade.

Attend to the person's quality of life. This goal is common in the care of people with incurable diseases. Quality of life efforts focus on controlling pain and making the person as happy and comfortable as possible. This kind of care goal seeks to provide the person with enjoyable moments. Family, friends, and spiritual concerns are important.

This is the quality of life goal we propose for Savvy Caregiving:
Guide the person through days
that are as calm, safe, and pleasant as possible.

What is the Medical Care of a Person Living with These Illnesses?

Research has made good progress in understanding dementia illnesses. This knowledge has led to some medications that are used to **treat the *symptoms but not the underlying causes*** of these illnesses. There are medications that seem to slow the progression of the disease. Once such medications are begun – and assuming the person can tolerate them – the condition seems to slow down, even improve slightly. It is as if the person returns to the state s/he was in 6 to 12 months before. So the person seems better. However, the disease is still present. It continues to progress. It may be that these medications help slow the progress somewhat, but the disease is not stopped.

It is important to realize that dementia illnesses make it more difficult to identify, treat, and manage other medical conditions. In the middle and later stages of these illnesses, the person may lack the ability to recognize or clearly express that something is wrong. Or s/he might lack the ability to tell you or a doctor just what is wrong. For example, pain might not “register” or be understood as pain in your person living with a dementia illness. All you might see, as a caregiver, is some change in mood or behavior. This same set of difficulties also makes it harder to know whether the treatments a physician prescribes are working or not. So, this is another part of the caregiver’s role. You must observe and interpret your person’s physical signs and symptoms.

It is worth repeating that depression is an illness that frequently accompanies dementia illnesses. Monitoring for depression is important. Being sure that depression is treated is especially important.

In addition, prescribed and over-the-counter medications often affect the brain. Therefore, it is especially important to rely on expert advice on any possible effect of medications on your person. If your person is taking medications for any other medical conditions, it is crucial to find out how those medications affect the dementia symptoms. Likewise, if there are medications being prescribed to deal with problems associated with the dementia illness, find out about their side effects. Here’s where a good healthcare partner is important.

Agitation and emotional upset are frequently reported in persons living with dementia illnesses. So much is confusing for them and out of their control. It is easy to understand that they may react to things in ways that are self-protecting. Reactions can, for some people, take the form of aggression and striking out or yelling. These kinds of behaviors are as uncomfortable for the person as they are for you.

It is important to realize that, while the disease makes the person susceptible to these behaviors, they are not a necessary part of the disease. Much of the Savvy program is focused on teaching you strategies for helping your person stay calm and involved through-out the day. These strategies can help reduce or avoid difficult reactions and behaviors.

The importance of proper health care. You are investing a lot of time and energy to take care of your person. You have a right to have a good health partner in your person's care. You need a clinician partner who will work with you to help manage your person's care over a long period of time. This means you will need a physician, physician assistant, or nurse practitioner who will:

- Really listen to what you are saying and asking for
- Treat you as a full and valued member of the healthcare team; share information; ask for your input; and teach you ways to manage the situation
- Help you manage day-to-day life with your family member, including any other illnesses that need to be managed
- Help you with tough issues, such as getting your family member to stop driving, recognizing when you need more help, and/or help you with tough choices regarding nursing home placement and advance directives
- Ask how you're doing and be direct with you when you need help with care or need to take a break
- Know, over time, what it is you're going through and tell you (and your family) what a good job you're doing

Caregivers need to question whether or not the clinician is really helping manage the course of the person's care. Sometimes this means having to be very direct. Tell the medical provider just what you need. If help is not forthcoming, consider looking for another health partner.

Not all physicians, physician assistants, or nurse practitioners are as knowledgeable or skilled as others are in evaluating persons with dementia disorders or in managing their care, long term. You should be aware of the skills various kinds of clinicians bring to the situation.

- **Internal medicine and family physicians, physician assistants, and nurse practitioners** usually know the person's history. These clinicians should be able to detect key changes that signal the need for a complete work-up. However, the care of older persons is still not emphasized in most medical and clinical training. Medical providers will vary in their knowledge and abilities with regard to recognizing and managing dementia illnesses. Some clinicians are uncomfortable delivering "bad news" in a situation they think of as being untreatable. They feel, perhaps, that, since there is no cure or treatment, it might be better not to name or "medicalize" what is happening. Choose a provider who shares information readily with you.

- **Geriatricians** are family physicians or internal medicine physicians who have additional training in caring for older persons. Adult/gerontological nurse practitioners are certified to care for older adults. The assessment and management of dementia disorders are typically an integral part of their added training.
- **Neurologists** specialize in conditions of the central nervous system, including the brain. **Psychiatrists** are specialists focused on the brain. Many, but not all, neurologists and psychiatrists have extensive experience with the diagnosis of dementia disorders.

There are centers around the country that specialize in diagnosing dementia illnesses. Your local Alzheimer's Association chapter can refer you to them. These services may be expensive and may not be fully covered by insurance. Consider using such diagnostic centers if you feel your person's clinician hasn't paid enough attention or if s/he recommends getting a second opinion. But if you feel that your clinical partner has been careful and has arrived at an appropriate diagnosis, accept it and begin to deal with it.

The Internet *might* be your friend. We know that caregivers search the Internet for information and advice. Information from reliable sources, like those at the end of this section, can be beneficial. However, not all of the information on the web is accurate or trustworthy. Be aware of "cures" and "tests" you might read about on the Internet, or even in popular magazines, even when it seems that a medical person is associated with it. Drugs and tests that are currently recommended by reputable healthcare providers go through a careful process of testing. Many of the cures and treatments on the web have not been thoroughly tested.

Dementia family caregivers are always – and quite naturally – searching for hope. Claims about cures and treatments feed into this search. There are people who are sincere and passionate believers in the claims they make, and they want others to believe as well. Most mean well, but their claims do not help. For example, Gingko Biloba was all the rage as a memory drug, but after very careful study, it was found not to be effective. Nevertheless, it is still available in pharmacies and health food stores. It also has to be pointed out that there are people who use the Internet to scam people living with a dementia illness and their caregivers. Be aware of false or unproven promises and advice.

The takeaway messages: Talk with a good and reliable health partner. Discuss anything you hear on the web or TV about dementia illness treatments with that person.

What Is on the Horizon?

Scientists around the world are working on how to treat and prevent these dementia illnesses. Research is taking place in laboratories, and clinical trials with selected patients are in a variety of stages. Some are small scale, testing the broad safety of new treatments. Others are in larger trials meant to determine how effective new treatments are, including treatments that might actually slow the progression of Alzheimer’s disease. Important work is also being done to establish good ways to identify the presence of a dementia illness earlier, long before symptoms characteristic of a dementia illness show. This work is essential to the testing of early intervention strategies.

Taking Part in Research Studies. The advances in treatment so far have relied on people to volunteer for studies. Joining a study yourself or allowing your person to be in a study can be a good thing, but keep a few things in mind:

- **Know the risks**. Read the informed consent form carefully. If there is no such form, don’t take part. You should be able to ask – and get answers to – any questions you have about a study. You should be given information about whom to contact if more questions arise. You should be able to see that an Institutional Review Board (IRB) has approved the study and will monitor its progress. You should also be given the name and phone number of a person at that IRB whom you can call for additional information.

- **Be realistic**. Many research studies are randomized trials. Participants are assigned to various study groups by a process much like the roll of dice or flip of a coin. Most studies have a “Control Group.” In a Control Group, participants receive some care or instruction, but do not receive the treatment that is being tested. So, be aware that your person may not receive the treatment being studied.

Be realistic, too, about the possible benefits. Drugs and treatments are being tested because it is not certain that they work. The scientists testing these treatments have good reasons for thinking they might. The treatments have been tested in trials with research animals and in small trials with people – just to prove they are safe and to figure out what dose to try. But it is still important to keep in mind that, even if your person does receive the study drug or treatment, it may not help. Or there may be unexpected side effects that make the treatment not useful.

Information Resources. Information about issues of treatment, prevention, and new research changes rapidly, and a lot of it can be found on the web:

- The Alzheimer's Association website at www.alz.org is a good source of current information. In addition, the Alzheimer's Association produces an annual report – *Alzheimer's Disease Facts and Figures* – that provides up-to-date information on dementia illnesses. The most recent volume (2020) can be viewed at www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf. The document provides comprehensive information about factors contributing to the development of Alzheimer's, including discussions of theories about why the development of the disease is not even across genders or racial/ethnic groups. The report has an extensive reference list that points readers to additional reliable informational resources.

- The National Institute on Aging sponsors the Alzheimer's and related Dementias Education and Referral (ADEAR) Center. The ADEAR Center website at www.nia.nih.gov/health/about-adear-center is another excellent source of current information about dementia diseases and treatment. The ADEAR Center toll-free weekday phone number is 1-800-438-4380.

- The Lewy Body Dementia Association website at www.lbda.org/ and the Association for Frontotemporal Degeneration website at www.theaftd.org/ provide reliable information on those conditions.

- The National Stroke Association at www.stroke.org as well as the Alzheimer's Association provide reliable information on Vascular Dementia.

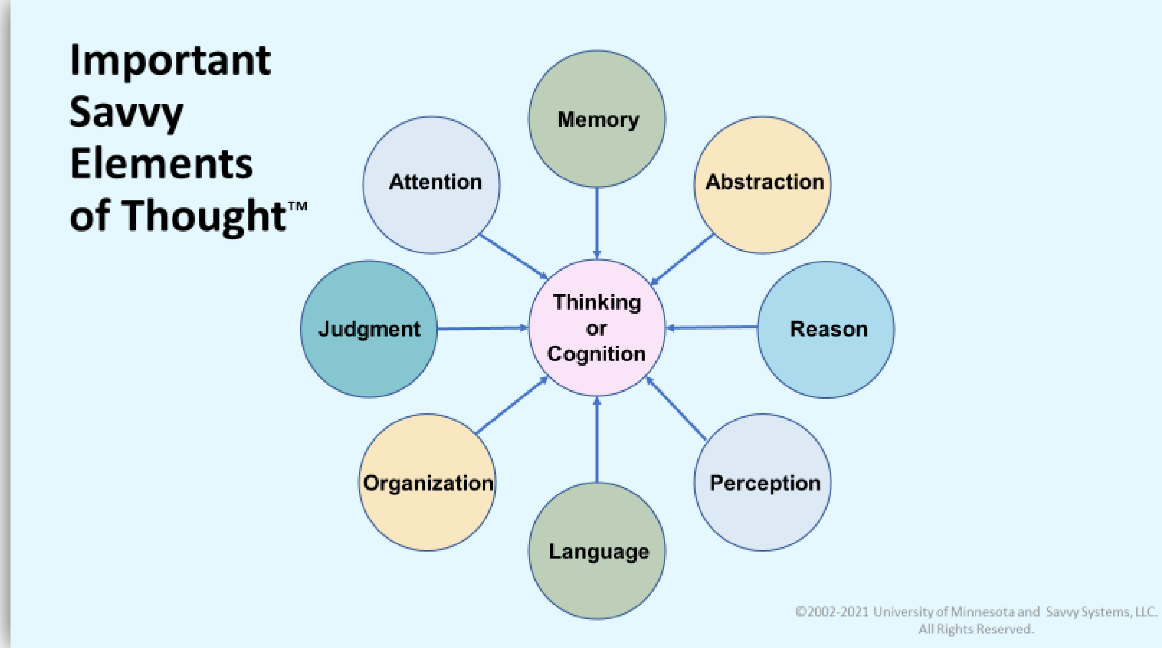
The Elements of Thought™

The Effect of Dementia on Thinking

This portion of the manual is about:

- What happens to thinking processes when dementia illnesses set in
- How these losses affect persons living with these illnesses
- Caregiving strategies to deal with these losses

The brain is central to our lives. It links us with the world around us. It takes in information and makes sense of it. The brain allows us to act on that information in ways that are useful – even essential – to function in our lives. The diagram below identifies some key functions the brain performs.



What Happens to These Powers When a Dementia Illness Is Present?

Each of the eight areas that follow is structured in the same way. In each, we:

- Describe the thinking function and the losses that occur.
- Discuss the effects of these losses in everyday life – on the person and on you, as a caregiver.

- Point out how the illnesses will cause ordinary ways of interacting with a person to be less effective.
- Suggest Savvy Caregiver strategies for dealing with these losses.

Over time, dementia illnesses can affect each of these functions. We describe each loss separately, but the losses are taking place together. That is, the illness is affecting all these powers. However, **the losses take place in different ways and at different rates in each individual.** Dementia illnesses have a general pattern, but each individual experiences this pattern individually.

These losses will change what your person can do and how s/he acts. Things your person could do will gradually be lost. How s/he experiences and reacts to these losses will vary from person to person. Some will have a sense or awareness of losing powers. Others will not. Some will keep their same temperament, while others will change, even dramatically. Some will become timid and fearful. Others might become aggressive or defensive. Some may deal with the changes by becoming more agreeable or compliant. For others, caregivers may have to work through resistance before obtaining cooperation. And, the range of reactions and behaviors may change as the disease progresses.

The eight areas of thinking, what happens in those areas as the dementia illness progresses, how this changes your person’s behavior, and what strategies you can use to be a Savvy Caregiver are presented in the following chart. We hope this proves to be a valuable resource during your caregiving journey.

8 Important Elements of Thinking or Cognition Affected by a Dementia Illness
What’s Being Lost? What Are the Effects on Daily Life?
How Do You Deal with Problems?

#1: MEMORY

What’s Being Lost?	What Are the Effects on Daily Life?	How Do You Deal With Problems?
Memory is the glue that attaches a person to life’s continuity. Memory provides the web or network for our family and social relationships. It keeps us in touch with who’s who in our lives and with how we fit into our social world. It keeps us plugged into the work and play of our lives – what we do and how to do it. Memory also stores the key habits, beliefs, and values that make us unique and vital. It also stores our learned social behaviors. When memory begins to fail, our ties to life as we know it begin to unravel. **In these illnesses, memory almost always fades in reverse.** Many families begin to recognize that a problem with a dementia illness exists when short-term memory begins to fade. These first memory problems usually occur with recent – sometimes very recent – events. The person has difficulty recalling what occurred last month, last week, yesterday, or even earlier in the day. Even though the person can understand what you say at the time and can respond appropriately, a short time later s/he will not recall the interaction. **Long-term memories seem to last the longest.** For some people, they remain	As memory begins to fail, there are at least four main effects to watch for: • **The world doesn’t “hang together.”** Life is a series of events strung together over time. Memory helps to keep these events ordered. It helps relate one event to another. It allows us to have a past and a future as well as a present. A person with a failing memory may not, for example, be able to keep in mind that getting dressed and going in a car are leading to dinner with friends. Events come to exist on their own – they lose a larger context. This experience of the world can be lonely, confusing, even frightening. It might make a person withdraw. Or it might make the person defensive – even hostile. • **New learning will not occur.** Memory, especially short-term memory, is important for learning. Persons with memory problems are less able to learn. One must have memory to learn new skills, facts, or ideas. People living with dementia illnesses might be able to follow steps, if instructed. But they won’t remember these steps for any length of time. **This does not mean these persons should not be asked to do new things.** Like anyone else, people living with a dementia illness will enjoy doing things. And they will be able to do even new things – with help. The important thing is not to expect people to be able to do that same thing tomorrow. They may	KEEP IN MIND WHAT’S HAPPENING. • **The person feels lost**. The remembered world is disappearing. The person may feel anger, fear, or confusion as a result. A lot of your work is to provide comfort and security. • **Memory cannot be jogged back into action**. Nothing you do can “jump start” the brain back into remembering. ADJUST YOUR EXPECTATIONS. • **Don’t be hurt**. Be prepared for the person not to remember family members – and eventually you. Be prepared for her/him to remember others from the past and not you. This can be especially hard when second, remarried spouses remember their first spouse but not their caregiving spouse. • **Don’t be frustrated**. Learn to expect memory to fail. Don’t expect the person to acquire new behaviors you try to teach. • **Don’t be shocked**. There is a link between memory loss and behaviors that might be very uncharacteristic of the person. Good manners and a learned sense of being considerate of others may be forgotten.

very far into the disease. Your person may be able to remember people, events, and facts from their early life or distant past well into the dementia illness. However, long-term memories may often become "fuzzier" – that is, the exact details of events or experiences may shift or become altered. This is not lying – it is the effect of memory loss. **"Over-learned behaviors" are also kept for a long period of time.** This phrase refers to actions a person learned long ago and that have been repeated so often that they are done without thought. Many daily activities, like dressing and eating, are over-learned. Other acquired skills, like playing a musical instrument, knitting, even driving a car, count as over-learned behaviors for some people. **There is a general pattern to the memory loss.** The names of the grandchildren are forgotten; then the names of the children; then the name of the spouse or partner.[2] Eventually, almost all is forgotten. In the late stages of the disease, recognition of even the most familiar people fades.	not remember. They won't have learned it. But they may well enjoy it again – if they are helped to do it. • **People living with dementia illnesses may feel awkward.** Especially in the early stages, people may realize they are having memory problems. This can be hard. They can feel embarrassed by not being able to remember. Self-esteem can suffer. People living with a dementia condition vary in their reaction to memory loss as they do with all losses. Some feel a sense of failure. Others appear to grieve. For some, it can be a source of depression, while for others it is a source of humor. Still others do not even seem to recognize they have a problem, or may deny the problem, even intensely. • **Social skills fade.** Many social skills rely on memory. Manners and other social behaviors are learned early in life. We learn and remember how to behave in public, how to behave at the table, and how to interact politely. As these learned behaviors are forgotten, social graces may fall away. Even the politest of persons might be affected. They might eat with their hands, use language they would have thought offensive or impolite, or dress (or undress) in ways that would have shocked them.	DEVELOP CAREGIVING STRATEGIES. • **Be ready to supply information** that's forgotten without drawing attention to the memory loss. • **Try to avoid language that relies on memory** ("Remember when we… ?" or "Don't you remember… ?"). • **Don't point out the memory loss.** This can make the person feel like a failure and can be embarrassing. • Familiarity can substitute for memory. **Create or strengthen routines; familiarity can promote feelings of comfort and security**. Use familiar objects – pictures, mementos, etc. – to give the person ways to connect with a familiar world. • **Long-term memories provide the basis for reminiscence and shared activities.** Looking at old photos and talking about them can be pleasurable. The person may remember people or events from the past. You can use these as cues for recollection. **Over-learned and well-remembered skills should be part of your toolbox as a caregiver.** These can be useful diversions when you find yourself in a bind with the person.

#2: **LANGUAGE**

What's Being Lost?	What Are the Effects on Daily Life?	How Do You Deal With Problems?
The ability to communicate allows us to connect with others in the world. We rely on communication to express our needs and feelings. It's the ability we use to get and give information of all sorts. Language is the most obvious form of communication, but we also rely on gestures, body language, and facial expression to communicate. The ability to communicate is gradually lost in dementia illnesses. **The first problem that appears is usually with word-finding.** People struggle to find the right word for the situation. There might be difficulty in finding the right word in a conversation. They may forget names of people that have been known. Later, they may have difficulty expressing ideas or sharing how they are feeling. They may know what they want to say, but be unable to find the words. All of this can lead to embarrassment and frustration, and may prompt people to withdraw. It could produce an emotional outburst. Sometimes people might blame caregivers for the problem. Over time, people's thoughts become less complex and more concrete in expression. Sentences will become shorter and simpler, with words left out. Eventually, efforts to communicate may be through single words or gestures.	• **The person may feel these losses.** Early in their illness, persons sometimes know they are having word-finding problems. They often express or show discomfort about this. Sometimes they can work around the problem. For example, when they can't come up with the word "watch," they might say "…. that thing you tell time with." Other times, they seem to draw a blank. • **Words and looks can fool you.** People have habits. Some of these are verbal habits that are over-learned. Some people, even when they are far into the disease, still use remembered phrases. They appear to have good verbal skills. Such skills can mask just how much the dementia disorder has affected them. This can be doubly hard for the caregiver. The person looks so good, looks and talks like his/her former self. But the caregiver knows how great the distance is between looks and reality. • **Words and looks can fool others**. Many interactions are patterned. Brief social exchanges follow predictable routes (what a nice day; what a lovely outfit). Exchanges in phone calls can follow similar patterns. In those exchanges, the person may perform well because s/he is just following a long-practiced pattern. Such exchanges may be pleasant for the person, but they may also lead others to underestimate the extent to which the person is affected by the dementia illness. Such underestimates can produce or reinforce disagreements in families about what is happening to the person. Differences like this can be very hard on caregivers.	KEEP IN MIND WHAT'S HAPPENING. • **Language as a way to connect is breaking down.** All communication is becoming more difficult and less reliable. ADJUST YOUR EXPECTATIONS. • **Don't expect communication to be two-way or equal.** You will gradually be doing most of the work. • **Be delighted with retained verbal skills.** However, don't let yourself think that your person is getting better or that decline of the disease is stopped. DEVELOP CAREGIVING STRATEGIES. • **Help the person.** Give the person a missing word if you can figure it out. Don't try to force the person to come up with the word. This won't "cure" the problem. And when the person uses a phrase to express a word, be positive. • **Fill in missing words when you can.** • **If it's funny to the person, laugh along.** It's not a funny disease, but there is still the possibility of joy. Seize any opportunity you get for it. • **Judge what's getting through.**

The ability to understand also declines. Words become less effective as a way to communicate with the person. More concrete methods are needed. **Eventually, caregivers have to rely on visual cues and touch.**	• **Making the connection is tricky.** Patterns of communication are often habitual, especially among family members. We take for granted that the person understands us. We're not used to having to adjust how we communicate or to check to see if we're getting through. Think about conversations you've recently had. Think how much you rely on non-verbal cues from other persons. Their nods, for instance, assure you they are following you. Those non-verbal cues – like remembered phrases – are over-learned. It's often hard to know whether a person living with Alzheimer's or a similar illness is using them on purpose or just because they somehow fit the situation, or it's just muscle memory at work.	• **Don't worry about correcting the person** or trying to get him/her to be more effective. • **Match your communication strategy to the person's strengths and abilities.** For example, use shorter sentences or emphasize just one or two key words. **As the disease progresses, too many words will be confusing.** • **Bring the person back on track when s/he gets off track in speech.** Do this casually without drawing attention to the problem. • **Visual (sight) and tactile (touch) communication techniques will become more necessary, and comforting, as the disease progresses.** For example, showing someone what you want them to do by doing it with them, and/or using guiding touch to direct them through a task will support effective communication with your person.

#3: REASONING

What's Being Lost?	What Are the Effects on Daily Life?	How Do You Deal With Problems?
Reason is perhaps the ability that most makes us who we are. It is an ability that gives us some kind of control over our lives. It's the ability to "think things through." We use reason to: • Negotiate our relationships with each other. • See patterns and relationships in everyday life. • Make careful choices. • Solve problems. • Create plans. • See other points of view. **As dementia illnesses progress and reason declines, people are less able to make sense of the world.** Their illness gradually lessens their ability to control their lives. **With reasoning reduced, people live in the present moment.** As their world gets smaller, they also become very self-centered. Listen for phrases that assume the ability to reason ("Don't you understand that…" "Can't you see that…"). Hearing yourself using phrases like these may suggest that you haven't thought all the way through the losses that are occurring.	Effect of Reasoning Changes on Daily Life • People **living with a dementia illness lose the ability to be reasonable.** Most of us expect others to be reasonable. We assume this when we interact with them. We regularly appeal to a shared understanding of what is reasonable. We use reason, logic, and persuasion in many situations. We expect others to use logic and persuasion in return. Most of all, we expect that these forms of interaction will guide choices and behavior. Dementia illnesses turn these expectations upside down. Increasingly, usual forms of interaction – like persuasion – won't work. Reason will not make sense. Logic will fail and may backfire. Asking the person to think ahead through a series of steps will likely cause confusion, withdrawal, or impetuous behavior. With the loss of reasoning power, the caregiver needs to provide more guidance for and take greater charge of the person's routine, choices, and decisions. • **The relative importance of things becomes unclear.** Reason helps us to understand what things are more important than others and allows us to set priorities, weigh our choices, and plan things out with intention. Dementia illnesses cause people to lose this ability. So sometimes things we consider unimportant become especially important	KEEP IN MIND WHAT'S HAPPENING. • **Using familiar methods of interaction with the person may not work.** The thinking power that supports this kind of relationship is failing. ADJUST YOUR EXPECTATIONS. • **Think about what brings pleasure to the person.** Those living with a dementia illness can still enjoy being fully involved in things. As the illness progresses, recognize that being involved in the moment is satisfying for the person. You can plan what to do next today or tomorrow, but don't expect the person to be able to be involved in this kind of thinking things through. DEVELOP CAREGIVING STRATEGIES. • **Become more directive.** Asking the person to make choices about things to do, what to have for dinner, or what to wear may end up in frustration. **As reason declines, offer fewer choices** ("would you like the blue shirt or the white one?"). **As the disease gets worse, make choices for the person.** Don't present these as choices. Present them as things that happen next ("Put on this shirt you like," "Here's your lunch," "It's time for your shower").

You may think more reasoning is present in your person than is actually there. Such phrases may also convey your frustration or irritation with the person. While the person may not be able to respond, it’s possible s/he will feel your emotion, and that might trigger a similar reaction in the person.	to the person. Talking and trying “to be reasonable” often doesn’t work and conflict might occur. • **Decision making is impaired.** What would you like to do? What would you like to wear? Where would you like to go? What would you like to eat? Which show would you like to watch? Should we take a drive? Ordinary life and ordinary relationships are full of such exchanges. They move important information back and forth. They nourish relationships. They show respect. And they rely on the power of reason. As the illness progresses, this natural impulse to think through and negotiate decisions – an impulse that springs from respect and affection – can produce real discomfort. The person living with the disease may feel more confusion. The caregiver who repeatedly provides choices may become frustrated.	**Minimize resistance.** When given a choice on an activity, some people with dementia may default to “no” and may dig in their heels without being able to reason. Offer an option without a choice (“Let’s go for a walk.”) • **Figure out how to get the person to do what needs to be done.** Typically, people do things because they see some form of self-benefit. As the illness progresses, people are less able to see why doing something might be good for them. ○ You may find that the person will do things just because you tell him/her to do so, or because they will be doing it with you. ○ Or s/he may respond positively when you ask for help with something (“It would help me if you’d put this shirt on”).

#4: ABSTRACTION

What's Being Lost?	What Are the Effects on Daily Life?	How Do You Deal With Problems?
We rely on abstract thought to deal with everything in our lives that is not touchable or concrete. A lot of things we take for granted are abstract. For example, our understanding of "**time**" is abstract. **Money** is abstract. A green piece of paper equals $1.00 because we say it does – we can use abstract thinking. Even our understanding of **the past and the future** rely on the power of abstraction. Possibilities are abstract. Being able to think about the **"What ifs"** in our lives relies on abstraction. **Numbers and directions** are abstract. Being able to know "where" and "how much" is part of abstraction. Relationships – **the connections among family members and friends, as we label and discuss them** – are abstract. Along with the other powers of thought, abstraction declines with the progress of the dementia illness. **This ability is lost fairly early in the disease.** This means that many concepts we rely on to live in this world no longer have meaning for the person.	As memory begins to fail, there are at least four main effects to watch for: • **Life is lived in the present. Time and order are lost.** Early in the disease, notions like tomorrow, next week, yesterday, or this evening begin to become less clear. Without a sense for time, it is difficult to order and prioritize activities. At a certain stage of the disease, persons living with a dementia condition cannot make, follow, or appreciate plans. They live in the here and now and may be confused by ideas of past and future. • **Connections are lost.** Words may remain, but their deeper meaning will fade. Their exact use will deteriorate. Persons living with a dementia illness might call an adult son "son" one day and "father" the next. They feel a connection, but may not recall or understand what it is. The name or term they use may incorrectly represent the actual connection. • **Space is confusing.** All of us have a "map" in our heads. We know, in general, where we are in our neighborhood, our city, our state – even in the world. We generally know where "here" is in relation to some other "there." As abstract thought declines, people living with a dementia illness are less able to put "here" and "there" together. They are where they are, and have a hard time finding a way to somewhere else. **Feeling unsure and confused about where they are is common. Getting and feeling lost is more likely.**	KEEP IN MIND WHAT'S HAPPENING. • **The person is living more and more in the here-and-now:** a very concrete present and a very immediate space. ADJUST YOUR EXPECTATIONS. • **You can't rely on the person to understand or relate to anything abstract (such as time, money) or outside of what's happening right now.** • **Be prepared for growing confusion about who you, other family members, or friends are.** DEVELOP CAREGIVING STRATEGIES. • **You have to think about the future and about plans for both of you.** • **Limit your use of directions that rely on abstract concepts like time, value, or relationships.** Instructions like, "We've got to get you ready by 10:30" or encouragement like "Don't you want to look good for your daughter's visit this afternoon?" will be confusing and not motivate them. They may not understand what you mean by "this afternoon" or "next week." As a result, they may ask repeatedly about when the event is to happen.

#5: **ATTENTION**

What's Being Lost?	What Are the Effects on Daily Life?	How Do You Deal With Problems?
Attention is the ability to become and remain focused. Attention includes the ability to start, maintain, and stop a task. We rely on attention to get things done. Attention lets us stay on track with a task or activity even when we are faced with distractions. Normally, even when a lot is going on around us: • We are able to stay focused and not be diverted from what we are doing. • We can stick to a task or get back to it if we are taken away for a time. • Often, as distractions arise, we create or reprioritize a list of things we will do once the task is complete. All of these abilities erode as dementia progresses. **One of the main losses in these conditions is that the person can be diverted or distracted increasingly easily.**	**The main effect of losing the power of attention is that** people cannot focus on a task. They have a harder time staying on task. They are easily distracted. Their attention can quickly shift from one thing to another. . This can be a problem for a caregiver because things need to get done in the course of a normal day. People need to bathe, dress, and eat. It's good if they can do things that are pleasant and occupy them. Losing the ability to stay focused can make these everyday things more difficult and time-consuming.	KEEP IN MIND WHAT'S HAPPENING. • **Increasingly, the person will need your help to stay focused on a task.** • There is a relationship between attention and ability. **Tasks that fit the person's ability are more likely to engage and hold attention** than tasks that are too complex or too simple. ADJUST YOUR EXPECTATIONS. • **You will become the person's guide for staying involved** in tasks. • **Helping the person to get and stay happily doing things is a big part of success for the Savvy Caregiver.** • **Quality and the finished product is less important. Doing things is the important goal.** DEVELOP CAREGIVING STRATEGIES. • **Keep in mind the kinds of things that used to hold the person's attention and try them out.** • **Structure: Support attention through the way tasks and activities are chosen and set up.** The caregiver has to figure out the kind of activities the person can successfully perform and for how long s/he might perform them. This will mean that someone gets the supplies, defines and sets up the task, and helps him or her get started. Problems with attention in tasks and activities typically relate to matters of fit and distraction.

		• **If there is too much going on around the person, s/he can be easily diverted.** • If a difficult task is presented in a busy environment, the person can be distracted even more easily. • **Keep in mind that it is okay if the person gets involved with an activity but doesn't complete it.** Quality of performance is overrated in dementia caregiving. Being engaged is more important. • **Support: Providing cues and direction will help.** Persons living with a dementia illness will need more and more help starting and staying with activities. Many persons appear unable to begin a task, but when someone gets them started, they're fine. They may also need reminders and cues during the task. Eventually, they may need reminders at each step. **This need for support will increase as the disease progresses.** Over time, the person may only be able to do very repetitive activities with one or two steps, such as sweeping, dusting, wiping, folding, or stacking. Later, the person may repeat the same motion over and over, until reminded and directed to move to another spot.

#6: JUDGMENT

What's Being Lost?	What Are the Effects on Daily Life?	How Do You Deal With Problems?
Judgment is the ability we use when we ask the question "What if?" Asking ourselves this question allows us to weigh the options and determine, or judge, the safety or benefit of a situation. The ability to imagine the possible outcomes of a situation is critical for safety. A person may be drawn to a fire by its warmth and loveliness. However, judgment allows us to assess the risk of and avoid getting too close to the fire and the likelihood of getting burned. Likewise, judgment keeps us from wandering across busy streets or getting into other harmful situations. **Judgment enters into all of the more complex areas of life.** Among the more complex choices that involve judgment are: • Where to live • What to do about life-sustaining treatment • How to spend our money **The capacity of judgment is weakened relatively early in most dementias.** Because of distorted thinking, judgment may be poor or	• **Safety first.** Safety is a major issue when judgment becomes impaired. As the disease progresses, caregivers have to take more control. The use of kitchen appliances has to be supervised and controlled. Firearms and power tools have to be secured. Driving ability and safety has to be assessed and, at some point, driving has to be stopped. Even going outside unaccompanied can be dangerous. The person can wander and become lost. Monitoring and limiting going outside are important caregiving tasks. Identification items (bracelets, name tags on chains, GPS devices, cards in purses or wallets) are particularly useful to keep your person safe. • **Caregivers must take control.** Some individuals with dementia become hesitant, use more caution, and begin to rely more on others. They may willingly give up tasks that become stressful or frustrating and may, for example, allow the spouse to take over the finances or driving. They may be quite inactive, not initiating activities that might be dangerous. Many persons shy away more from crowds and social gatherings, even family gatherings. This may be due to confusion and an impulse to shield oneself from too much stimulation. Others may lose inhibitions and the sense of caution. They may become impulsive, acting without considering the consequences.	KEEP IN MIND WHAT'S HAPPENING. • **Judgment problems have to be considered seriously when thinking about activities like driving, using power tools (saws, sewing machines), firearms, and even kitchen tools or other objects that pose a safety hazard.** The person may have been able to use such objects or machines under ordinary conditions. As a dementia illness progresses, the person won't have the judgment to respond effectively when anything unusual occurs. You have to determine whether your person has the ability to handle any sudden changes safely for themself or others. ADJUST YOUR EXPECTATIONS. • **It's not personal or deliberate.** Often, persons living with dementia illnesses say things without concern for others' feelings. They may say hurtful things. Sometimes individuals living with a dementia illness will not recognize their spouse or partner. They may identify that person as a stranger. They may accuse their spouse of infidelity or family members of stealing. If they are still driving, they may be unable to adjust if there is a detour or they take the wrong turn, so they might become lost. Such behaviors are not uncommon when the disease advances. • **The person cannot watch out for his/her own safety. Expect to be watchful all the time.** Simple, familiar tasks now pose safety concerns. **Persons living with a dementia illness might use words or behave in ways that are crude or offensive that they didn't use in the past. These behaviors are not personal.**

faulty and quite different from the person’s previous decision-making and behaviors. The person’s own insight into his/her limitations varies greatly from person to person and changes as the disease advances. All of this makes it hard to know whether and how much you realistically can involve the person in critical life choices.	People may resist attempts at rational discussion and be a danger to themselves. They may want to continue activities that are too complicated and that rely heavily on quick, sound judgement,such as those mentioned above. The person may become vulnerable to sales pitches or “get rich quick” schemes in the mail or on TV. They lose the ability to determine reality from fiction, or make-believe. **If the person still has access to their checking account or credit card, be careful to look for any new or unusual spending patterns**. • **Behavior may change.** The gradual loss of judgment can contribute **to insensitivity towards others**. This is somewhat common in individuals living with a dementia condition. The ability to imagine how their behaviors affect others is gradually lost. Sensitivity to others’ feelings is a learned social behavior. We learn to respect other people and that words can be hurtful. We learn that being self-centered is not acceptable. But these learned manners can be forgotten as the disease progresses. f we see someone wearing a hat that we think is ugly, we typically don’t say anything. Usually, we go through an “If, . . . then” process in our minds. (If I say, “that’s an ugly hat,” she may be hurt). We’ve learned it is impolite. With a loss of judgment and memory, a person living with dementia blurts out something that could be unintentionally hurtful or offensive.	If these things are said or done, they are a result of the disease and not the person. DEVELOP CAREGIVING STRATEGIES. • **Get clear about values. The person’s safety is at stake.** A dementia illness has taken away a lot of the person’s ability to make judgments. **An individual’s right to choose has to be balanced against their own safety and that of others** with whom they may come in contact. • **Be prepared to take control of safety.** Remember that reasoning won’t work. You have to decide when is the time to stop driving; when is the time to stop using the stove. • **Be prepared to explain to others what is happening to the person.** As long as you can, and as long as the person remains engaged, keep doing things and going places. But be ready to explain the person’s condition and to ask for help and cooperation from others in those places. For example, if you have a favorite restaurant, keep going, but let the staff know that they should direct their questions to you. • **Do what it takes. Enlist others’ help.** Ask your doctor to help (perhaps write a prescription that the person can no longer drive). Call the motor vehicle bureau and have them retest the person. Sell the car. Be prepared to be strategic: Disable the car; put a hidden control switch on the stove. Put guns in a locked safe; remove ammunition, and/or ask an expert to disable them.

#7: PERCEPTION

What's Being Lost?	What Are the Effects on Daily Life?	How Do You Deal With Problems?
Normal perception involves two things. First, our senses allow us to take in the world around us. Sight and hearing are primary, but touch, smell, and taste also allow us to take note of things outside of ourselves. **Then, our brain makes sense out of what we perceive, or take in.** Perception plays an important role in social living. **We rely on perception to:** • **Identify and recognize sources of pleasure and delight.** These may be people we know, sights we enjoy, tastes we like. • **Warn us of discomforts and threats.** These may be things that are harmful or unpleasant. They may be people, or odors, or scenes we find uncomfortable. **Perception is a key ability that lets us size up and prepare for things as they happen**. It helps us to not be surprised or startled by the world. It also lets us make more informed choices. We eat things we know are good and that we like. We avoid entering situations that "feel" wrong or threatening.	• **Mistakes are made. As the illness progresses, those living with a dementia illness make mistakes in sensing and interpreting things.** For example, they may interpret images on television as being real. They may start talking back to the television. Reflections, including a person's own reflection in a mirror or window, can be mistaken as real people who suddenly appear and disappear. Patterns in floor tile or carpets can be mistaken for holes that need to be stepped over or avoided. They may even be seen as barriers that cannot be crossed. It is especially important to test and correct hearing and visual problems. However, the person may see and hear clearly but still be unable to interpret things accurately. • **Overload and confusion are common.** As the disease progresses, the person living with it is less able to take in and make sense of the world. This can lead to overload. The person might become confused and upset if someone approaches him/her from behind or from the side, makes sudden or unexpected physical contact, and asks questions all at the same time. Crowded and noisy places (like shopping malls) might be overwhelming. • **Suspicion and paranoia can occur.** Problems with memory, reasoning, and /or misperception can lead to suspiciousness and paranoid thoughts. People may believe someone is about to harm them. For example, if a caregiver takes clothes to a laundry, or the person living with a dementia illness can't find their purse or wallet, they may notice they are missing and think they have been stolen. Some caregivers report that due to loss of accurate perception, their	KEEP IN MIND WHAT'S HAPPENING. • **Because of the illness, the person is losing the ability to make sense of what his/her senses take in.** This can be frightening and confusing. It can produce reactions ranging from terror to self-protective combative behavior. ADJUST YOUR EXPECTATIONS. • **Don't assume you and the person are operating from the same base of perception and interpretation.** Increasingly, you and the person do not share experiences of the world in a similar way. What you and s/he understand about what you both see may be quite different. DEVELOP CAREGIVING STRATEGIES. • **Reassure your person rather than reason with them.** This is true whether you're dealing with a visual or a conceptual misperception. People may imagine that there's someone outside the window. They may accuse you of stealing the checkbook that they can't locate. Don't try to correct their mistake. Rather, **offer reassurance.** Offer to check outside and to stay with the person. Offer to help find the

	persons accuse them of terrible things (like cheating, infidelity, stealing, or abandonment).	checkbook. • **Periodically check and monitor the environment.** Look around the home or other settings to remove or manage things that are likely to confuse the person. Remember that the likelihood of confusion will increase over time. If you can figure out what's causing the problem, you may be able to remove it from the environment. For example, it can help to turn the radio or television off if it confuses or upsets your person. • **With dementia illnesses, problems of perception can go along with problems of judgment.** Perceptual problems further contribute to the danger of a person continuing to drive, use power tools, or handle guns. • **Choose outings carefully.** Even if the person used to enjoy public places, watch carefully to see if this is still the case. If you notice signs of discomfort, maybe quieter places would be better. Or, go at times when you know there will be fewer people or less activity.

#8: ORGANIZATION

What's Being Lost?	What Are the Effects on Daily Life?	How Do You Deal With Problems?
The mind controls all of our actions: • It identifies a purpose or goal for an action. • It establishes the sequence of activities that leads to accomplishing the goal. • It coordinates and monitors action and oversees the use of any objects required in carrying out the activity. This ability also allows us to understand the plans that others have made for us and to cooperate with them.	• **Purpose may be lost, but patterns can remain.** Even early in the disease, people may not remember the purpose of or the reason behind actions. Or they may get distracted and forget the purpose. When purpose is lost, people usually do not complete a task on their own. They may start it or get part way through, but then lose track. For example, you might ask your family member to do a load of laundry. S/he may head off to get the laundry basket but become diverted by something s/he sees on the way. Or, s/he may remove the clothes from the washing machine but not put them in the dryer. Mistakes like these are very likely to occur. The person may not be able to complete a whole task on his/her own but can be guided through it. The person may still be able to do smaller parts of tasks. **Over-learned skills and routines are good.** Persons living with a dementia illness do well with over-learned skills, things they know so well they can do without thought or reflection. Encourage their involvement in these kinds of activities. Routine can produce a kind of over-learning. Thus, it is helpful to establish (or reinforce) routines. Do things the same way each time, so patterns will be formed or strengthened, and familiar habits can continue as thinking declines.	KEEP IN MIND WHAT'S HAPPENING. • **Organization,** the executive ability that supports setting goals and following through with an activity, **begins to break down early in the disease.** ADJUST YOUR EXPECTATIONS. • **Relax your standards.** The organization of a household is usually very complex. You may feel things are increasingly disorganized as the disease progresses. This is common. There is extra work to keep the person well and content. Something has to give, or you will become overwhelmed. You may have to let go of how well and thoroughly things are done around the house. You may have to accept a certain amount of sloppiness (or help) in exchange for a relief of pressures. DEVELOP CAREGIVING STRATEGIES. • **Encourage the person to do whatever s/he can still do.** S/he may not be able to create and manage the plan for an activity. But if s/he can do parts, encourage this. • **Simplify.** Figure out how personal care and daily activities can be streamlined or involve fewer or smaller steps. • **Substitute.** Fill in whatever it is that s/he cannot do. Supply a goal, if it is missing. Help with the sequence of steps when s/he needs it. • **Be prepared to organize and direct activities**. Setting up an activity or task is a basic aid to organization. Find the materials. Arrange the items needed for the activity. Put them in sequence; if needed, direct the person in their use.

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

Caregiver Self-Care Skills & Feelings

Caregiving can bring great rewards as well as demands and challenges. Being available and responsive to any other person requires patient acceptance and being willing to adapt. This is even more so with a person who is living with increasing needs and decreasing abilities.

Caregivers who take the time to take good care of themselves physically, emotionally, socially, and spiritually are often better able to face the challenges, avoid negative effects, and experience the greatest rewards.

It can be extremely hard for caregivers to take time for themselves. They often feel that "finding time" is almost impossible. Many caregivers feel guilty or sad if they take time for themselves. Others feel stuck in their situation and have a hard time admitting to feeling trapped, cornered, or resentful. Sometimes their person cannot safely be left alone. Too often, caregivers feel they do not have any help to rely on in the home. Other caregivers have their own physical or medical challenges. Not all caregivers have assumed the role willingly or gladly; they were the only option for the job, and it wasn't one they had hoped for.

Whatever the circumstances, getting enough sleep, finding time to exercise, eating right, and having positive social support are essential to managing the long-term demands of caregiving.

This section of the manual highlights the importance of self-care for caregivers. It offers ideas and strategies for recognizing and attending to the emotional challenges of caregiving. Every caregiver has different physical and emotional needs. But, all caregivers deserve and need to find ways to feel energetic, refreshed, and well cared for in the midst of their caregiving.

You can use the information in this manual to help take care of yourself; the information covers issues related to:

- Identifying and dealing with feelings
- Taking time for yourself
- Involving the rest of your family in caregiving
- Making decisions

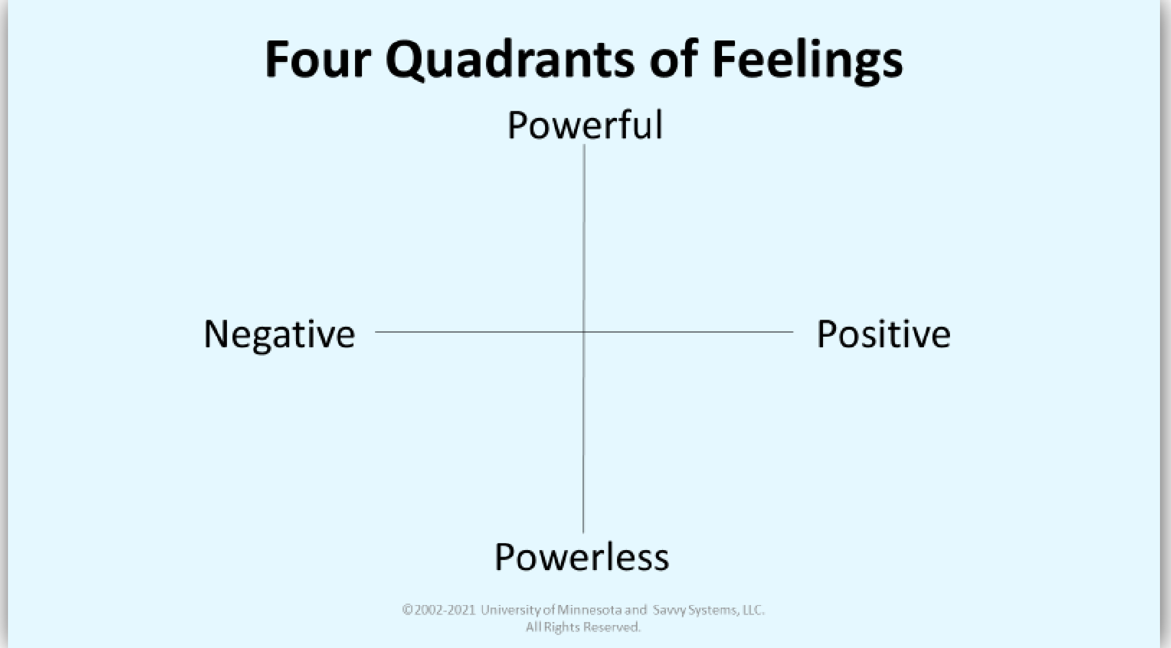
Identifying and Dealing with Feelings

Spend some time reflecting on your experience as a caregiver. Think about the feelings that have been and are a part of caregiving. Let yourself experience those feelings.

Think about your feelings when:

- You first suspected something was wrong with your person.
- You first heard the diagnosis.
- You reach the end of a very hard day.
- You think about the future.
- Your person smiles and says thank you.

The Savvy Caregiver program uses a diagram we call the "**Four Quadrants of Feelings**" to understand and label feelings caregivers are having regarding their roles. The diagram will help you to organize how you are feeling. And, it offers a way to move to more positive or pleasant feeling states. This diagram was adapted from the work of a university psychologist who found that people's feelings could be categorized using two simple dimensions. One dimension was whether a person's mood was positive or negative (good or bad). The second dimension had to do with how much in control the person felt. Did s/he feel in charge (powerful) or controlled by something larger than or outside of him/herself (powerless)?



Four Quadrants of Feelings

Powerful

Negative

Positive

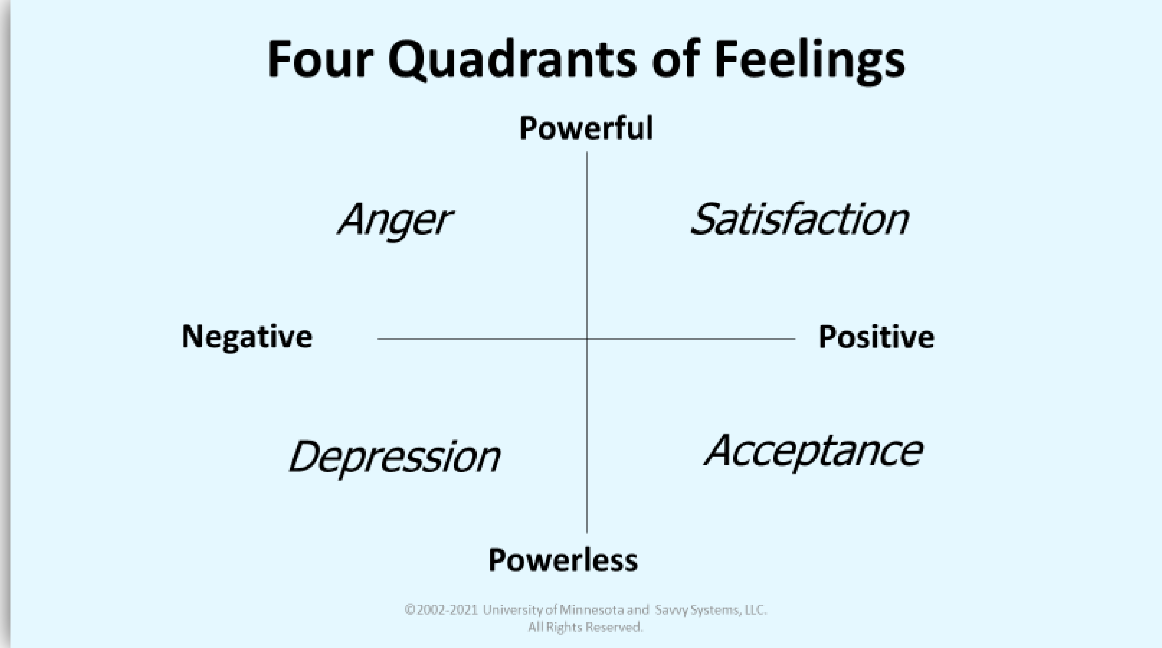
Powerless

The breakthrough of this work was to see that any emotion could be fit into one of the resulting four quadrants if the two dimensions were arranged perpendicular to each other.

Suppose, for example, four college students reported four different feelings:

- Depression – The student had not studied and had failed a test.
- Anger – A student was mad at her former boyfriend because he had broken up with her.
- Satisfaction – Another student had just finished a long project and felt good about it.
- Acceptance – The student had worked hard studying the material and felt ready for the test, but s/he knew it would be a hard test.

The quadrants of feelings grid and how it can be used to analyze these four feelings is shown in the next figure. Each one can be assigned to one of the four quadrants. Each can be described in terms of the name that can be given to the quadrant. Depression is a negative powerless feeling. Satisfaction is a positive powerful feeling.



Four Quadrants of Feelings

Powerful

Anger

Satisfaction

Negative

Positive

Depression

Acceptance

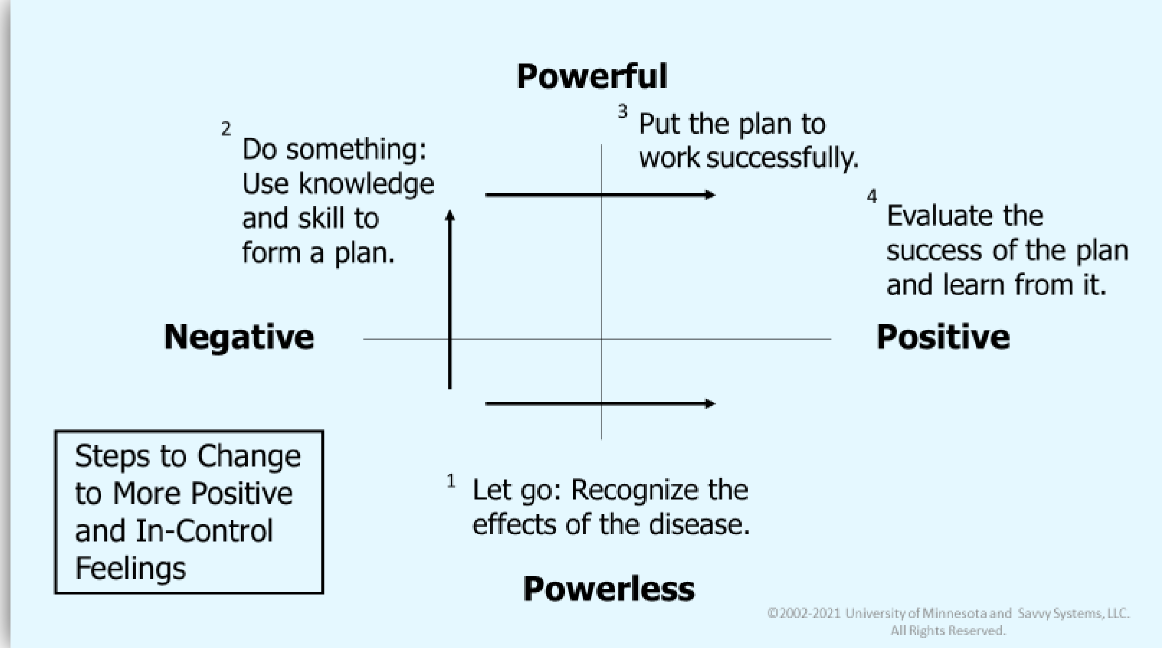
Powerless

Consider your feelings as a caregiver. Caregivers typically identify many feelings like sadness; devastation; loss; grief; acceptance; being pleased that they can give something to the person "in return"; frustration; exhaustion; and rage at the disease, the person, and the system just to name a few. Think about assigning those feelings to the quadrants. On this list sadness, devastation, loss, grief, frustration, and exhaustion are all negative and powerless feelings; they go in the lower left quadrant. Rage is negative and powerful; it falls into the upper left. Satisfaction and being pleased are positive and powerful; put them in the upper right. Acceptance is positive but outside of your control; it is in the lower right.

Negative powerless feelings are common in caregiving. This is the quadrant where you'll find many of the feelings that caregivers express. You may well find that you place many of your feelings in that lower left quadrant, too. It is likely that very few will be on the positive side of the figure. Consider three things in this regard:

- **Your feelings are common and expected among caregivers. Do not feel guilty** about these perfectly normal feelings.
- **Caregiving is a taxing role.** This is reinforced by every feeling you place in the negative and powerless section of the diagram. Consistently experiencing mostly negative and powerless feelings can be punishing.
- **You need to find ways to get out of this negative state and to move toward more positive feelings.**

Strategies for Changing Quadrants. You will begin to make the determination that you would much rather be in another quadrant once you become familiar with this way of categorizing your feelings. You may feel overwhelmed. Those feelings are in the lower left quadrant. You may want to feel a sense of satisfaction or reward instead. You cannot simply jump diagonally in a single move to accomplish this. You may have to make a series of moves to get to where you 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

1. **Let go.** Accept the situation as it is. Accept that the disease is progressing and irreversible. Know that it is futile and counterproductive to deny this. This action is built on recognizing the effects of the disease – accepting that the effects are real. Then build a response based on that acceptance. The material in the first three sessions of the Savvy Caregiver program can help you to better understand the disease and its effects on the person.

   Another important kind of acceptance is self-acceptance. You have not yet attained sainthood. You are not yet perfect. Sometimes the stresses of caring for a person living with a dementia illness get to you. You may lose patience. You may not be as gentle or kind as you want to be.

   Give yourself a break. You have just proved you are only human. Let go and proceed from there.

2. **Plan for action**, based on your knowledge, skills, and experience. Much of the Savvy Caregiver program equips you in specific ways to plan effective action.

   Planning is a gathering together phase. It is the point at which you say to yourself, “Enough. I am going to do something about this.” Sometimes this phase can be characterized by your feeling frustrated and using that energy to focus your attention on the problem. Create a plan to do something about it. This step gets you from lower left to upper left in the diagram. You are taking control.

3. **Put the plan into effect**. Act. Do something that might have an impact on the situation. The energy will evaporate if this step is not taken. Your feelings may slip back into the lower left. They may be worse than before.

4. **Evaluate**. There are at least three possible outcomes to putting the plan into action.

   - The plan works perfectly. The situation gets better. You feel good. This represents a real accomplishment.

   - The plan does not work or works imperfectly. The situation does not really change. You recognize that you have done something just by trying. That makes you feel good. This outcome reinforces one of the central points of the workshop. You have to be "experimental" and "clinical" in your approach as a Savvy Caregiver. This creates or reinforces an attitude to try to develop and implement other strategies in the future, and offers ideas on how to adjust the plan you have developed.

   - The strategy does not work. You do not appreciate that even trying it was a good thing. You slip back to the lower left quadrant. The basic Savvy Caregiver strategy approaches disappointment with the spirit of experimentation. Not all experiments work. You can learn something from almost all of them. Try to see if there was something you learned even in the face of discouragement.

Time and Activities for Yourself

A second important element of self-care involves taking steps to develop a set of activities that you can do if free time becomes available. Many caregivers become so immersed in caregiving that they lose the sense of what it is that delights and refreshes them. They do not actively seek time for themselves. They are often unsure what to do when they do get time to themselves.

> **Try this short exercise.** This exercise stresses that it is crucial for you to take time to refresh yourself. Caregivers will never take the time for themselves if they wait until everything is done and they feel caught up.
>
> *Imagine you have a fairy godmother who has granted you five wishes. Those five wishes are different amounts of free time. You can choose to do whatever you want during your free time, BUT you* ***cannot*** *choose "doing chores" as an activity. The exercise purposefully excludes chores. Caregivers likely will always feel behind in their chores.*
>
> *Now imagine:*

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?

> What would you do with each of these blocks of time?

It is sometimes difficult for caregivers to give themselves freely to this exercise. They are often out of the practice at thinking about themselves and their own wellbeing. They may consider it selfish to think about themselves. They may even feel guilty about doing so. Well done if you have found ways to make time for yourself. Keep it up!

Listed below are reasons people choose certain activities. As you read the list, note that many of the reasons that people give have to do with renewing themselves. The Savvy Caregiver recognizes that the work s/he has taken on is taxing. It takes a lot out of you. You have to find renewal in order to continue with the work.

People do activities to feel more:

- Energized
- Calm and centered
- In touch with themselves
- Connected with their person living with a dementia condition
- Connected with the rest of their family
- Connected with their community
- Connected with friends

More reasons people do various activities:

- They simply enjoy the activity.
- It helps them sleep.
- They learn something.
- They add something different to their life.
- They want to experience something new and/or different in their life.
- It helps them enjoy being with the person they care for.

Think about these reasons. Consider whether one or more of them would motivate you to engage in activities for yourself. Think of your own reasons.

The object of this exercise is for you to make a list of activities you could do if/when you are able to make time for yourself. Write them down here so you do not have to spend free time recreating the list. When time becomes available, pick something from the list and do it. You may want to share the list with close family or friends who could encourage and reinforce your self-care. Here are the time categories once more:

Things I can do with my free time!

1. With **15 minutes** of free time I could:

   ____

   ____

2. With **one hour** of free time I could:

   ____

   ____

3. With **three hours** of free time I could:

   ____

   ____

4. 4. With an **entire day** of free time I could:

   ____

   ____

5. With an **entire weekend** free time I could:

   ____

   ____

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The Effect of Dementia Illnesses on Persons' Abilities to Shape Their Own Behavior

This section of the manual begins with two main thoughts:

Everything we do is behavior. Eating, reading, asking questions, and walking are behaviors. Interacting with each other is behavior. Sitting quietly and shouting are behaviors. "Behavior" includes all the actions we take in the world and how we are responding in any given moment.

All behavior has meaning. Although we may not think about this in the moment, all behavior communicates something. Generally, when we are dealing with people, we can figure out what their behavior means. We can typically see what produced a particular behavior and what the person means by it. When we see parents crying at their child's wedding, we can be fairly sure that the tears relate to the wedding. We know that they are crying partly out of joy for their child and perhaps a sense of loss they may be feeling.

These thoughts are important because, for most of the day, every day, a caregiver is concerned with the behavior of the person living with a dementia illness. To meet the goal of guiding the person through days that are as safe, calm, and pleasant as possible, the caregiver has to see how behavior works and to understand the important factors that shape it. The caregiver needs to be able to understand behavior as communication and be able to figure out what the person is communicating through behavior. And, finally, the caregiver needs to have ways of thinking about behavior that allow him or her to help shape or guide the person's behavior. The caregiver has to be able to help or guide the person to do – or stop doing – some particular thing.

This section of the manual presents four frameworks for thinking about behavior and how to guide it, all of which are taught in the Savvy Caregiver program. We provide four models in the hope that one of them – or perhaps a combination of them – will "click" for you and help you in this core caregiving task of guiding behavior.

A Simple Model of Behavior

This is the first model of behavior that is introduced in the Savvy Caregiver program. It is meant to provide you with a very straightforward way of thinking about behavior. As the diagram on the next page portrays, three things influence a person to behave in a certain way:

- ***Person***: The person him/herself is usually the main source of behavior. How the parent feels about their child's wedding is probably the single biggest factor in their behavior. How a person feels about his or her health is likely the biggest factor in the food choices s/he makes.

- ***Others***: Other people who interact with the person prompt or reinforce behavior. For example, friends commenting on the bride or groom in the reception line may intensify the parent's feelings and reinforce the tears. Or a partner reminding the person about a commitment to healthy eating may deter the person from having a second dessert.

- ***Surroundings or Setting***: The place or environment in which the action happens may have strong associations for behavior. Seeing the child coming down the aisle during the wedding ceremony provides a compelling context for tears. Or seeing a creamy pastry in a bakery might edge a person away from a "good eating" resolve.

A person in good cognitive health holds the key to his/her own behavior.

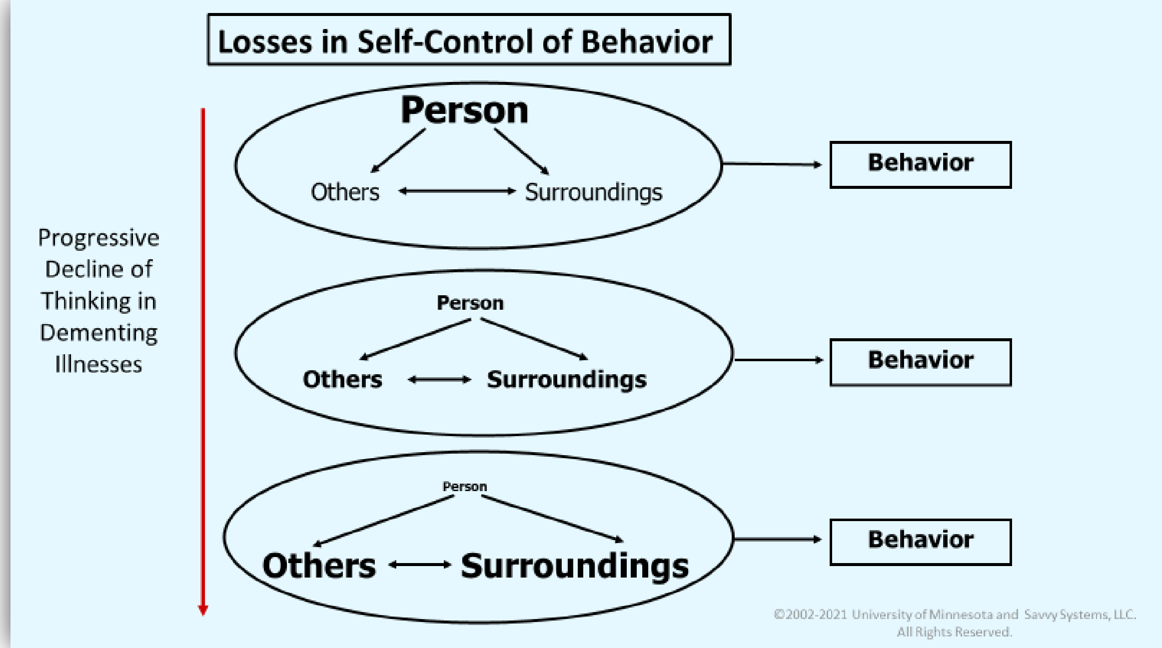
- The person thinks about choices and possible outcomes.
- S/he is swayed by personal likes and dislikes.
- S/he takes personal safety and comfort into account
- His/her ethical concerns and personal values affect behavior.

Typically, the person has the strongest influence on his/her own behavior.

Other people's influence can be strong. The influence of others can be seen in a number of ways:

- Persuasion, suggestion, or force can affect how someone acts.
- Others may keep a person behaving in a certain way by rewarding the behavior. This is known as reinforcing the behavior. They may also discourage a behavior.

- Influence may come through direct communication using words or text. It can be through what we indirectly communicate through tone of voice or body language.
- Influence can even be exerted through direct physical contact like steering someone away from a curb.



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Surroundings can be powerful and affect choices.

- Settings can make certain kinds of choices undesirable or uncomfortable.
- A walk outside is not ideal when it is very hot or very cold.
- A person is more likely to read than watch TV if there is no TV around.

The diagram on the previous page may help you think about how behavior and dementia illnesses mix. As you have learned, dementia illnesses affect the powers that a person uses to control behavior. So, as the illness progresses, the caregiver is called on to play an ever-increasing role in the behavior of a person living with a dementia. The caregiver has to take steps to shape the setting within which behavior occurs and to guide the person's behavior as s/he has less control over what s/he does.

Here are some key elements in this part of the Savvy Caregiver's role:

- **Assess.** The caregiver has to gauge just how much real choice the person is able to make in a given situation. It is also important to assess how comfortable the person is in making choices.

  Keep in mind that some people have good verbal skills well into the disease. They talk a better game than they can actually play. They may seem to be able to make choices. You have to decide just how realistic the choices are.

  You also have to decide how important the choices are. Whether the person has hot cereal or cold for breakfast is not too important. Whether the person wears a warm coat on a cold day is. Do not fuss over unimportant choices.

- **Structure.** Encourage choices the person is comfortable making and the person's remaining strengths allow him or her to make. Help to limit the choices if the person is confused. Having too many options may lead to confusion. S/he may be able to focus on choosing between two acceptable options. You can limit the choices and let the person select between them. S/he can choose between the blue sweater and the brown or between chicken and fish.

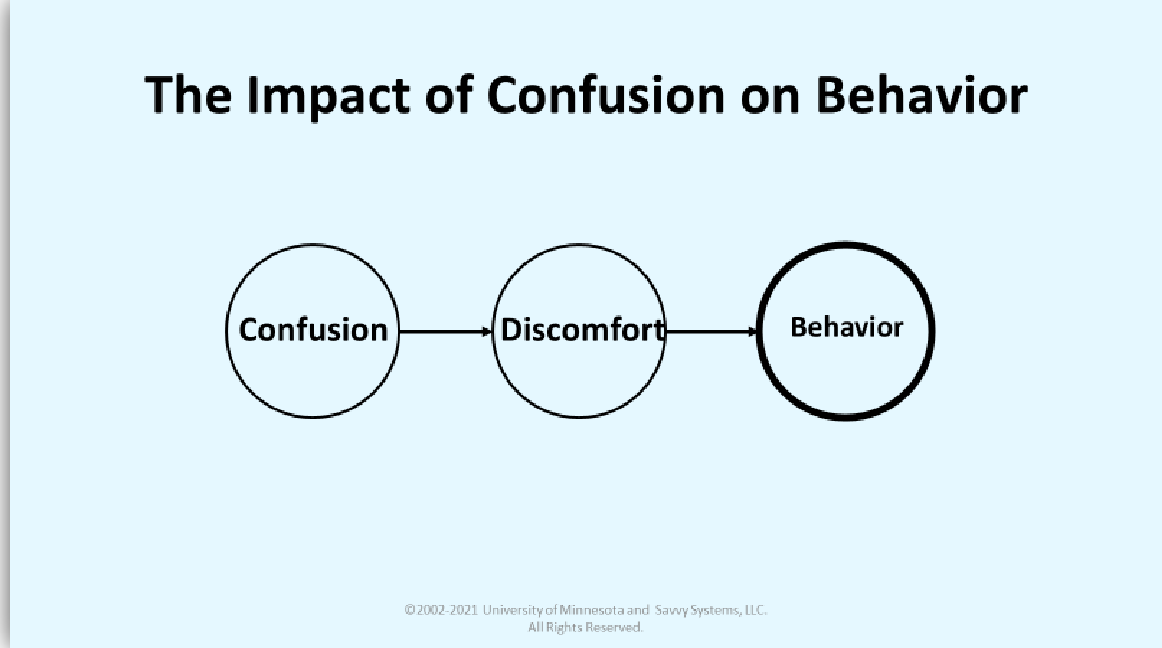
- **Support.** Do not offer choices that you know the person will have trouble making, and use care in how you present the choices. Later, we'll discuss communicating with a person living with a dementia condition. As a caregiver, you'll need to adjust how you guide and encourage the person so that your message can fit his or her current abilities.

The Effect of Dementia Illnesses on Emotional Responses

This section of the manual continues the focus on the caregiver's main task – managing daily life. It explores what happens to the person living with dementia illnesses when the world seems to press in on him or her and becomes confusing.

Why Focus on Confusion?

Confusion is a central problem in dementia illnesses. It is often the link between the losses that occur in the person's abilities to interpret the world around and the behavior you see as a caregiver. This inability often shows itself first in signs of confusion. The main idea of the section is illustrated in the diagram below. This diagram indicates a three-step process that is at the heart of the challenges that caregivers face when attempting to provide guidance for their persons' behavior.



The Impact of Confusion on Behavior

Confusion → Discomfort → Behavior

The Role of Confusion in Behavior

The process described in the diagram goes like this:

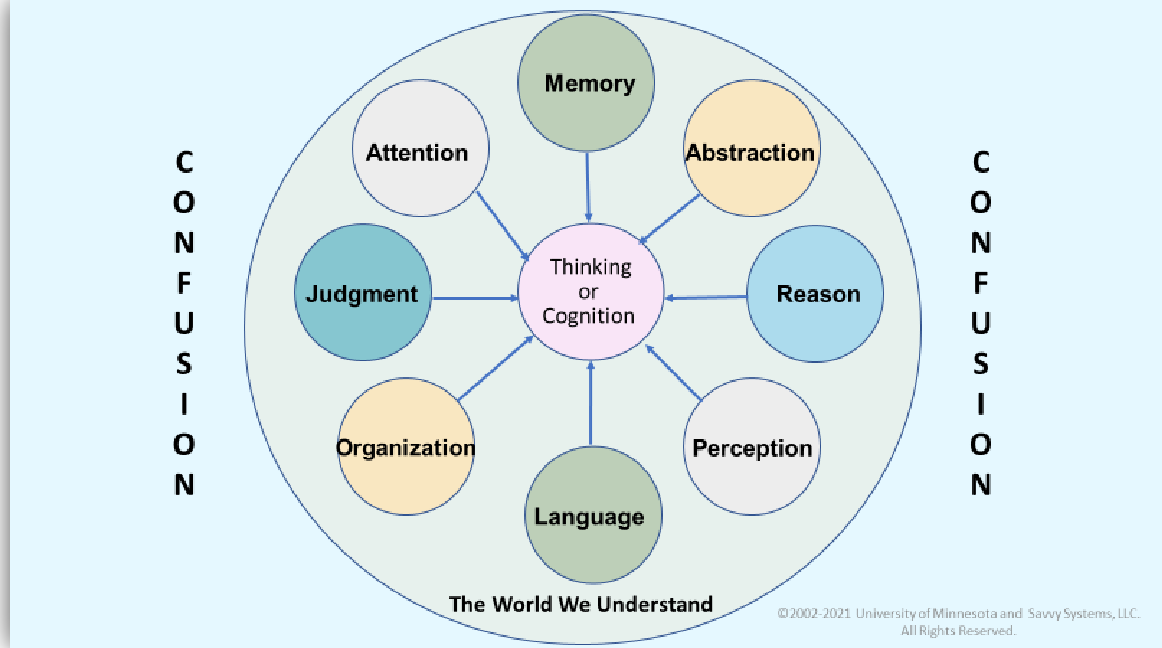
1. Confusion. The powers of mind of the person living with a dementia illness are weakened. The mind cannot manage all the information it is receiving. The person becomes confused. This part of confusion has to do with the thinking powers discussed in the first weekly session.

2. Discomfort. Confusion produces discomfort – here's where emotions enter the picture. It is unsettling not to understand what's going on. It is uncomfortable to feel as though the universe is swirling around or closing in. This part of confusion has to do with feelings; it produces an uncomfortable emotional response.

3. Behavior. People who are uncomfortable generally react in some way. They ***do*** something. They may become agitated. They may shut down and withdraw. These reactions are what the caregiver has to deal with in daily life. These behaviors can be of all sorts, as we will discuss.

What's Being Lost?

What's ordinary? The diagram below represents an ordinary situation. All thinking powers (reason, memory, etc.) work together to define a world the person understands. The person operates effectively in this world.

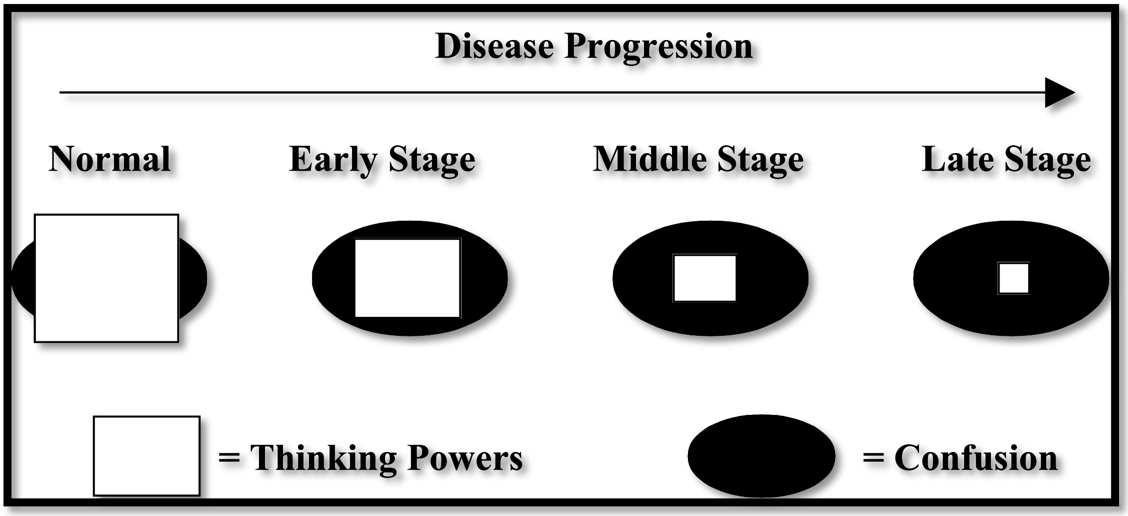


How the brain maintains control and keeps confusion away. Usually, people's thinking ability allows them to understand enough of what's going on to feel in control. There are limits to the world in which people feel comfortable. Most people experience confusion when situations and events push them to go beyond the limits of their thinking ability and they become emotionally unsettled.

The mind is normally on guard. Even for people whose brains are working well, going beyond the limits is uncomfortable. Going way beyond those limits can be frightening and produce unexpected reactions. However, for people with healthy brains and not living with a dementia illness, serious confusion is not a frequent event. The mind stays on guard. It tests situations and events to see if they may be threats. Mental and physical "alarms" go off, signaling people to back away from something that may be too much to handle. And, people have strategies for backing away from such moments.

How Do These Changes Affect Daily Life for Your Person?

Dementia illnesses profoundly change people's abilities to keep their world feeling ordered. These changes affect the way people living with a dementia condition live in the world and how they interact with other people in it. They are at the heart of many of the problems caregivers face. The changes are discussed below.



Protections shrink. The diagram above is meant to show what happens to people as a dementia illness begins and progresses. Over time, powers of thought shrink. As they do, the world becomes more overwhelming and less understandable. As this shrinkage occurs, confusion becomes more possible. Confusion becomes a bigger threat, and the person may feel less secure. The ability to test for threats declines. The person loses the knowledge of his/her own abilities to handle situations. The alarms go off, if at all, too late to protect the self.

Confusion expands. The diagram illustrates that over the course of the disease confusion can be a larger part of the person's reality. As the disease progresses, the mind's ability to interpret or manage confusion declines. The person living with a dementia illness faces the universe without the normal filters and protections. All the feelings that go along with confusion are more present.

Confusion produces strong feelings. There is a powerful emotional part to this. Being confused like this can be terrifying. The world outside the person is large and a lot is going on that s/he no longer understands. The person must feel very small and vulnerable. The person may have the experience of feeling out of control.

An Exercise in Confusion

We cannot know what a person living with a dementia feels, but it is possible to experience what it's like to feel confused.

Imagine that you have agreed to take care of a neighbor's three children. Now imagine that this is the setting you find yourself in:

- All three kids are under six years of age.
- Two have earaches.
- The third is cutting a new tooth.
- They've all missed their naps.
- They have the TV blaring.
- Your allergies are starting to bother you.
- You have agreed to make dinner.
- But, you find that one of the key ingredients is missing, and the pilot light is out in the stove.
- In the midst of all this, a telemarketer calls.

Let yourself sink into this situation.

How do you feel? What would you like to have happen?

People who go through that exercise usually say they want to get things quieted down. They want to get things under control. They want to be calm themselves and see that everyone else is calm. The point of the exercise is that the swirling world of babysitting and loud TV and phones ringing represents what the confused world of the person living with Alzheimer's or a similar illness is like. And just like you in the exercise, we can imagine that the person living with a dementia condition has a strong need to be:

- Calm
- In control
- Secure

Like you in the exercise, people living with a dementia illness need things to move more slowly. They want to see and feel a clear order for things and to feel things are under control. They want a secure anchor – someone or something to hang onto.

Emotions can produce a wide range of reactions or behavior. As the disease gets worse, the world can seem to be closing in and becoming more confusing, threatening, and frightening to the person. When persons living with dementia illnesses become confused, they retreat, or they react. Retreat often takes form as withdrawal. The person refuses to interact and goes into a shell. They turn their backs on what they can't understand or control. They seem more focused on themselves.

Or the person might react, and this can take many forms. The person might seek help – may, for example, yell or call out. The person might engage in some kind of defensive action. By verbal or physical means, the person may try to create some kind of safe space. The person may go on the offensive. S/he may seek to attack the felt source of confusion by verbally or physically lashing out at something or someone. The person may become suspicious or feel threatened and so strike out. The person might seek to escape, and so wander.

Your person has fewer ways to express or control feelings. Our ordinary thinking abilities provide many ways to handle emotions, but these strategies are gradually lost as a dementia condition progresses. The ways that are left are less measured and more direct and explosive. Among the skills that can be lost are the ability to:

- Control emotions.
- Adjust responses.
- Judge the difference between major and minor things, and respond accordingly.
- Interpret situations to determine more accurately both what the event is about and how to respond.

As the disease progresses, the person has a more direct experience of confusion and a much less secure sense of control. As the condition worsens, this has two important consequences:

- The onset of confusion becomes much more sudden and unpredictable.
- The feelings and reactions brought on by confusion are likely to be more dramatic.

Dealing with Confusion

Keep in mind what's happening.

Confusion can be frightening. Because the person can't figure it out, the world is confusing. People, events, movement, and noises are all around. And the person has a hard time putting it all together. This is likely a scary experience. For the person living with a dementia condition, confusion is their common experience of the world.

The fear that can be produced by confusion can be very strong. A lot of the behaviors and actions caregivers have to deal with can be traced to confusion.

Confusion has causes. Confusion typically occurs when there is more going on than a person can handle. It may be, for instance, that:

- There's too much going on in the environment (e.g., too much noise, too many things happening).
- There are too many people crowding in on the person.
- The person is being asked to do something that is too hard for his or her current abilities.
- Someone did something too quickly, startling the person.
- Someone got too close to the person too suddenly, again startling the person.
- There's too little going on. Under-stimulation or boredom can also produce confusion. Unoccupied people are open to inputs they cannot filter or interpret. It is good to have the person's remaining powers of thought focused on some task or activity.

Confusion can affect behavior. Dementia illnesses alter people. Thinking about confusion provides caregivers with a way to understand the differences they see. People living with dementia may be:

- **Changed**. Often people living with a dementia condition become simpler versions of themselves. Their personality remains, but in less complicated form. Nice people remain nice, and grumpy people stay grumpy. Sometimes, however, people do change and behave in ways that are quite different from how they behaved before the disease.

- **Self-absorbed**. Persons affected with a dementia illness typically become more wrapped up in themselves and less interested in others.
- **Impulsive**. Social graces learned over a lifetime gradually weaken. People may say and do things they would never have said or done before they were affected by the disease.
- **Blunt**. The person may not modify or filter what s/he says. Things might come out that are very direct, or even rude, by most standards.
- **Hostile**. The person may be on edge. Because s/he is unsure and defensive, s/he may be or appear aggressive.

Adjust Your Expectations

You are the emotional anchor. When the world is confusing, the person seeks calm, control, and security. That's you. The confused person will turn to you for security and assurance. A lot of the behaviors of a person living with a dementia illness can be traced to the emotional needs produced by confusion. When the person follows you around or keeps asking questions, s/he may just want to keep in contact with you.

It is important to recognize this central role you are playing in the person's emotional wellbeing. Here are two things to keep in mind about your role:

- **Have clear expectations.** A big part of caregiving is filling the person's emotional needs. The person *will* turn to you.
- **Develop tolerance.** Understanding why the person is following you or questioning you may help you interpret these behaviors. Understanding this may help you to live with them more easily.

Your own feelings matter a lot. Persons living with a dementia illness have extremely sensitive emotional radar. They readily pick up the feelings of those nearby, especially their close family. Be aware of how your own feelings can trigger similar feelings in your family member. This can work both positively and negatively.

Suppose you begin to feel frustrated or impatient. Your family member may sense this and become unsettled by it. S/he may then become agitated and distracted in ways that affect him/her in whatever s/he is doing. This may lead to greater frustration in you which, in turn, can lead to greater agitation in the person. Similarly, suppose you feel genuine delight for and with your family member. It is likely the person will sense this and be reinforced in his/her activity and in the enjoyment s/he is getting out of it.

Promote a sense of safety, security, and control. Think of home as a place of comfort and security. You want it to be a place where your person has an overall feeling of belonging and of contentment. It is important to pay attention to the way in which you strengthen this sense of calm and security.

Confusion is not always what it seems. Sometimes confusion and agitation are signals that something else is going on. The person may, for example, be unable to say s/he is unwell or experiencing some other form of pain or discomfort. S/he may not be able to express a need for food or to use the bathroom. Unusual confusion or agitation should be taken as a signal, and possible causes should be sought.

Develop Caregiving Strategies

The caregiver's main tools for dealing with confusion are prevention, recognition, and effective response.

Prevention. Create or strengthen routines. While the disorder may not allow a person to learn or anticipate them, routines provide a level of comfort and reassurance. This helps to lend a sense of calm and security.

Confusion poses a threat to being calm and happily involved in things. It can also be a trigger for various defensive behaviors. A person who is confused may react to protect him/herself from the discomfort s/he feels as a result of it.

Confusion and agitation frequently occur when someone tries to help a person living with a dementia condition to do something. These situations are especially prone to confusion and agitation when they involve getting close to or touching the person. For example, helping someone change clothes, wash up or bathe, or get to the bathroom. There's much that can go on in such activities that could cause confusion:

- **Lack of understanding.** The person might not understand what you want him/her to do or what you are doing, and feel threatened or attacked.
- **Intimate situations.** These and similar situations involve helping a person by touching him/her and seeing him/her in various stages of undress. They can easily produce discomfort, especially when mixed with a lack of understanding.

- **Pace and timing.** The action may feel “sudden” to the person. S/he may be surprised by what you want him/her to do or s/he may not associate it with whatever s/he’s just then doing.

Below is a checklist of things to keep in mind that may prevent confusion when you are trying to help your person do things:

- “Read” the person to determine if s/he’s ready to do whatever comes next.
- Carry out an activity in a way that makes the person comfortable.
- Convey a “message” of respect and understanding. Whatever will happen is going to be at the person’s own pace, with as much of the person’s participation as possible.
- Be sure the person can see you approach.
- Approach slowly and calmly, rather than quickly and efficiently.
- Give cues about what you plan to do.
- Keep the tone and volume of your voice low-pitched, calm, and at normal volume.
- Be sure your touch is slow and gentle and that the person sees it coming.

Recognition. Get to know the person’s early warning signs of confusion and agitation. There may be small signs the person gives before s/he becomes agitated, things like:

- A slight tensing of the jaw, or other body stance
- A slowing down in what the person is doing
- A certain gesture, look, or sound
- Turning away
- Picking up a familiar object
- Pacing

Response. There are three main responses to confusion and agitation:

- **Back off.** Stop whatever seems to be causing the confusion. Stop trying to get the person involved. Suppose you see your family member becoming agitated as you help him/her to get dressed. Pause for a moment; let the situation be still. You might tell the person you’ve got to leave for a moment and hand him/her something to fold or hold. Then leave and return in a few minutes to start again.

- **Re-focus.** Divert or distract the person from whatever seems to be provoking the confusion. Try to get him/her involved with something that isn't confusing. Over time, develop a set of things you know work with your family member to distract him/her from a confusing situation and to help to restore calm. These might be favorite things (for example, having a cup of tea, looking at photos, taking a walk, or listening to favorite music).

- **Try to maintain your own calmness.** If possible, stay calm. Remember: the person is likely to be very attuned to your emotional messages and overall "vibe." We appreciate this is easier said than done. However, your best "tool" in situations of the person's discomfort may be the sense of reassurance you project. Projecting reassurances that "I'm here" and "Everything is alright" will help to relieve the pressures of confusion the person is feeling.

The Caregiver in Control: Taking on More Responsibility

The preceding sections seek to convey the message that dementia illnesses like Alzheimer's have a global impact on those living with them. We discussed how the powers of thought are progressively weakened by these illnesses. As those powers are weakened, the ability of the person to control his or her life through those powers is likewise weakened. We described how these illnesses affect a person's ability to direct his or her own behavior or to manage his or her emotional responses in a world that is increasingly confusing. Gradually, these illnesses erode a person's ability to control or be responsible for his or her own life.

From the outside – for example, from your perspective as a caregiver – the person may appear lost or confused. The person may seem unreasonable. The person may exhibit difficult or troubling behaviors. Often enough, how the person acts can be hard to figure out or manage.

This brief section of the manual raises one of the most difficult and sensitive challenges of the caregiving role. It speaks to the need for you to assume greater control of and responsibility for guiding your person through the world on a day-to-day basis. The section is based on the realities of dementia illnesses like Alzheimer's disease:

- These illnesses affect all aspects of thinking. They impair and eventually destroy the brain's ability to act effectively in the world.

- These illnesses gradually erode the person's ability to direct his or her own behavior. Over time, the person becomes less able to be responsible for his/her actions.

- Confusion is a constant risk, and it can produce discomfort for the person. The losses have a feeling-level impact on the person. Feelings of insecurity, anxiety, and fear are common. These may lead to a sense of being out of control.
- Confusion can lead to difficult behaviors. The person may withdraw or react in many ways that are problematic.
- What the person does may not be cooperative, considerate of others, or self-protective.

Does Taking Control “Go Against the Grain”?

Yes! Typical adult interactions are built on values like respect and independence. We expect to be treated as competent people. We expect to make our own choices, even if they are not the best. Adults make their own mistakes.

So, taking control and assuming more responsibility as a caregiver often feels awkward. Here are some suggestions that may help you feel more comfortable with this idea.

- **You are avoiding harm to your person.** A person living with a dementia illness is vulnerable. The ability to judge the safety of a choice dimishes. You have to protect the person from injury.
- **You are avoiding confusion for your person.** Choices can be hard at any point. Helping the person choose what to do can prevent confusion. This can prevent the upset confusion produces in the person,and may also ward off difficult behavior caused by confusion.
- **You are giving joy to your person.** Base the directions you give on your knowledge of the person. Guiding the person to things you know s/he enjoys only increases the chance s/he will be busy and content.
- **You are caring for yourself.** You are a critical part of the caregiving picture. The day-to day routine and demands have to work for you as well as for the person. You are doing the person a kindness by substituting your judgment for his/hers. You are also doing yourself a kindness. Watching the person be comfortable can be a reward. Avoiding hassles and frustration is certainly a reward.

Weekly Session 2 Notes

Weekly Session 3

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

Buddha

Contented Involvement and Concept of "Fit"

In this section, all of the ideas and information we've talked about in the Savvy program so far come together in a practical way.

In some ways, providing guidance as a caregiver comes down to solving one of two problems: "How do I help my person to do something?" or "How do I help my person to stop doing something?"

Take a moment and briefly review what you now know about dementia conditions and their effects on the person:

- The person has an incurable disease.
- The person's condition will continue to get worse.
- Thinking powers are declining
- The ability to direct one's own behavior is diminishing
- Living with the confusion of this disease must be troubling and scary for the person.
- Losses and confusion can lead to difficult behaviors.
- The person is becoming less able to do everyday things for him/herself.

Contented Involvement: A Target for Caregiving

"**Contented Involvement**" is a key term in Savvy training. It ties back to one of the core principles we introduced early in the manual. That is the principle that, even as a dementia illness progresses, the person remains, as does their capacity to become engaged in tasks and activities in ways that are satisfying and pleasant for him or her. The idea of "Contented Involvement" is meant to give caregivers an indicator for meeting the Savvy Caregiver goal of guiding the person to calm, safe, and pleasant days. The phrase suggests that the tone of the day and events in it are pleasant and satisfying. Successful caregiving boils down to trying to help the person to be as comfortable, involved, and happy as possible.

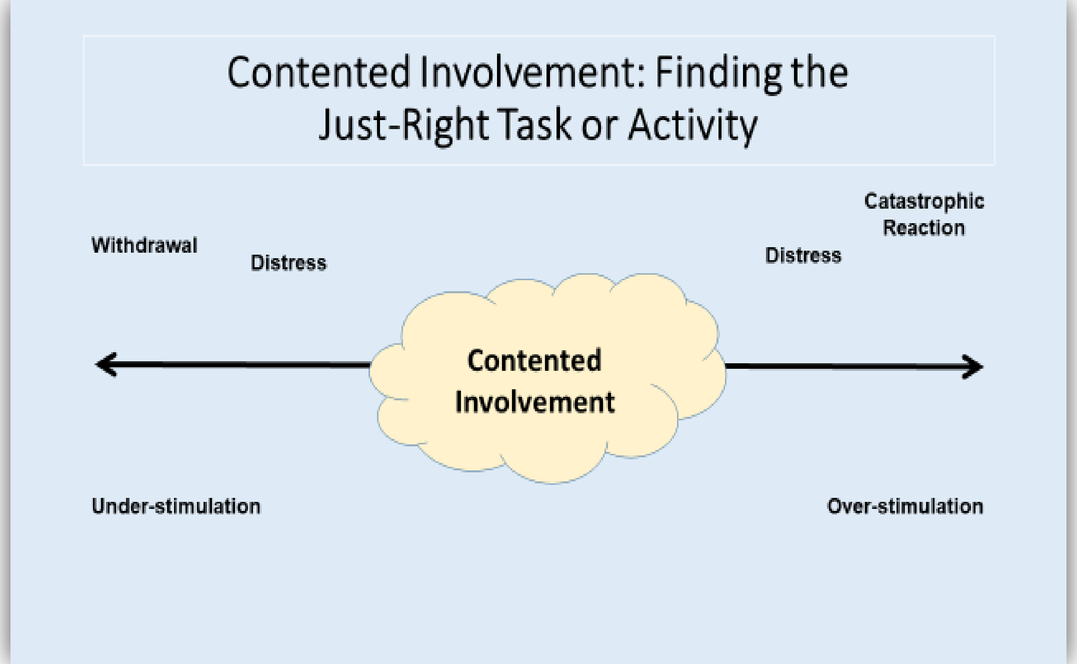
It is important to keep in mind that a person who is living with a dementia disorder can, with the proper structure and support, still:

- Zero in on a task or activity.
- Stay with a task for some time.

- Have a pleasant time doing it.

Helping the person be content and involved may help keep confusion at bay and reduce the chances of distress and difficult behaviors. Savvy Caregiving is not meant to mean that your person should be busy doing things non-stop. Contented Involvement is not meant to suggest the goal is big emotions like being overjoyed. It does reflect the meaningful job of caregivers to keep their person's emotions as steady and positive as much as possible, during each day. From the caregiver's perspective, enabling the person to become contentedly involved can be rewarding. It is a sign of effective caregiving, and the task or activity in which the person is involved may also provide an opportunity for feeling close or connected with them.

One easy way to think about helping your person to be contentedly involved is to recall the challenge of the fairy tale character Goldilocks. Goldilocks sought to find what was "not too much" and "not too little," but the solution that was "just right."



The diagram shown above is a way of thinking about Contented Involvement. A period of contented involvement is not stiffly defined. Its beginning and end points are likely not very sharp. If a task or activity is of interest to a person and if it is set up and presented in a way that fits the person's abilities, it has a good chance of promoting Contented Involvement. It won't be too difficult or too easy for the person. This helps lower the chances that it will result in behaviors that are difficult or uncomfortable (like withdrawal or an outburst). This is the target for the guidance you provide.

There is a pattern to the work you do in caregiving. There are general concerns in the day-to-day agenda of caregiving:

- Getting necessary things like dressing, eating, and bathing done.
- In between these times, having the person do things that seem to bring him/her joy.
- Keeping things calm and on an even keel.

Consider applying the goal of Contented Involvement to such daily tasks as helping the person to wash up or get dressed. Daily activities such as these can lead to frustration, angry outbursts, and resistance. Our point here, and for the rest of the program, is that these **tasks – and almost any task – can also provide opportunities for pleasant engagement and satisfaction**. For such daily tasks and events, the idea of contented involvement means that the task you present to the person:

- Fits what s/he can do.
- Somehow draws him/her in.
- Proceeds without conflict or distress.
- Gives him/her some sense of satisfaction or accomplishment.

This can help ordinary events transpire successfully and uneventfully so that the rhythm of the day remains pleasant and unbroken.

These ideas hold true over the course of the disease. It will be your job to shape your person's daily tasks and activities so they fit what s/he seems able to do at that point in time. Part of shaping activities comes from knowing the person. Different people find different activities enjoyable: some people enjoy nature or sports, or the arts, including listening to or playing music; others still like to work with their hands. The common thread is that these activities reflect the person's preferences and use his/her talents. At the same time, people living with dementia illness can enjoy activities they never did before. For example, people who never cooked may enjoy an easy task, especially if their caregiver is nearby.

Being successful at helping the person to be contentedly involved also relies on using strategies that are second nature to most of us. We recognize that activities should fit abilities. We know that directions should be understandable to the person we are directing. We realize that the environment can distract from a task or help a person focus on it.

Below is the outline of the exercise you did in class that was meant to emphasize the importance of fitting tasks or activities to abilities.

An Example of "Fit"

Imagine a situation in which you have to take care of four children for an hour. The children are 14, 11, 8, and 5 years of age. Imagine you decide to keep them content and involved by having them make a batch of chocolate chip cookies. Here are some key things every adult knows who might find him- or herself in this kind of situation:

- You would assign different jobs to each kid.
- The jobs would be more or less hard and complex depending on what you figured each kid could do.
- You would vary the kinds of directions and the way you gave them for each kid.
- You would watch and provide help differently to each kid.
- You would have different expectations for the "quality" of the work each kid would do.

The point of this is that we all have an intuitive capacity to fit tasks to our own and to other people's talents. That ability to apply "Fit" to situations is important in caregiving. As you develop a better understanding of the effects and progression of dementia illnesses and begin to see how the illness is draining your person's capacities, you will rely on "Fit" as an important element of guiding behavior.

How much Contented Involvement? Be realistic. Your goal is not to have the person involved and content every moment of the day. Nobody's day looks like that. You cannot provide it for the person, so give yourself a break. Take full credit where you can.

Think back on a day of caregiving. Can you recall:

- A time or two when the person was really focused on something and seemed happy?
- An instant when you felt the person was really connected with you?
- Some part of the day where a task or activity you thought up really clicked with the person?

- A moment when you saw things about to unravel and pulled something from your bag of tricks to get the person back on track?
- A moment when the person smiled with delight at something you did?

Any of these is the mark of great caregiving. You should congratulate yourself on meeting your caregiving goal if you can get even one of these a day.

The Effect of Dementia on the Performance of Everyday Tasks and Activities

The first sections of the manual explained how dementia illnesses affect discrete parts of a person's life. They affect a person's cognitive or thinking abilities. They can lead to confusion, loss of focus, and emotional upset. And, these illnesses affect the person's abilities to direct his or her own behavior.

The next two sections of the manual are meant to help you:

- Understand the global effect this has on your person's performance abilities,
- Determine what your person can do given the present stage of their dementia illness.

How Does a Dementia Illness Affect Performance?

Think about almost any common task like shopping for groceries, balancing the checkbook, or driving. Doing any of these common tasks involves three key elements:

1. **Purpose.** Almost everything we do in daily life is guided by a purpose. We set out to accomplish something. When we put on different items of clothes in the

morning, we’re doing that to “get dressed.” When we put together a recipe and cook a meal, we’re “making dinner.” We are acting with purpose.

2. **Order.** Most tasks involve an ordered set of actions. Many tasks involve a set of steps. Making a sandwich requires a person to go *in order* through a series of steps. The person has to get bread and take out a slice or two. Then, the person has to get the sandwich ingredients like ham and cheese. The person may want mayonnaise or mustard. Lettuce and tomato might be good. The person might want to cut the sandwich after it is made. The purpose may not be achieved if key steps are left out or if the order of the steps is switched. Putting mustard on the outside of the bread does not make for a good sandwich. The order of steps of most activities is deeply engrained. We do repeated actions seemingly without thinking. Many daily tasks like getting dressed rely on following an order of steps practiced over a lifetime.

3. **Proper Use.** Recognizing what things are and how to use them is one of the brain’s most basic jobs. Not much meaningful activity is possible if this function is lost. Each of the steps in the order puts a person in contact with some object. It might be a jar, knife, for some tasks, or a checkbook or computer for other tasks. A person has to be able to use objects properly in order to get through the steps. A person will not take steps that need items that s/he does not recognize or cannot use. This will mean that the purpose will not be achieved.

A Key Point: The elements of performance fade over time and in order in dementia illnesses.

- *The sense of* ***purpose*** *is compromised and lost first.* Complex tasks become more difficult for the person to grasp and organize independently early in the disease. The person becomes more easily distracted and has to be reminded of the purpose of what he or she is doing. Finally, the sense of purpose goes altogether as the disease progresses. What the person does is the result of direction by others or impulses suggested by the environment.

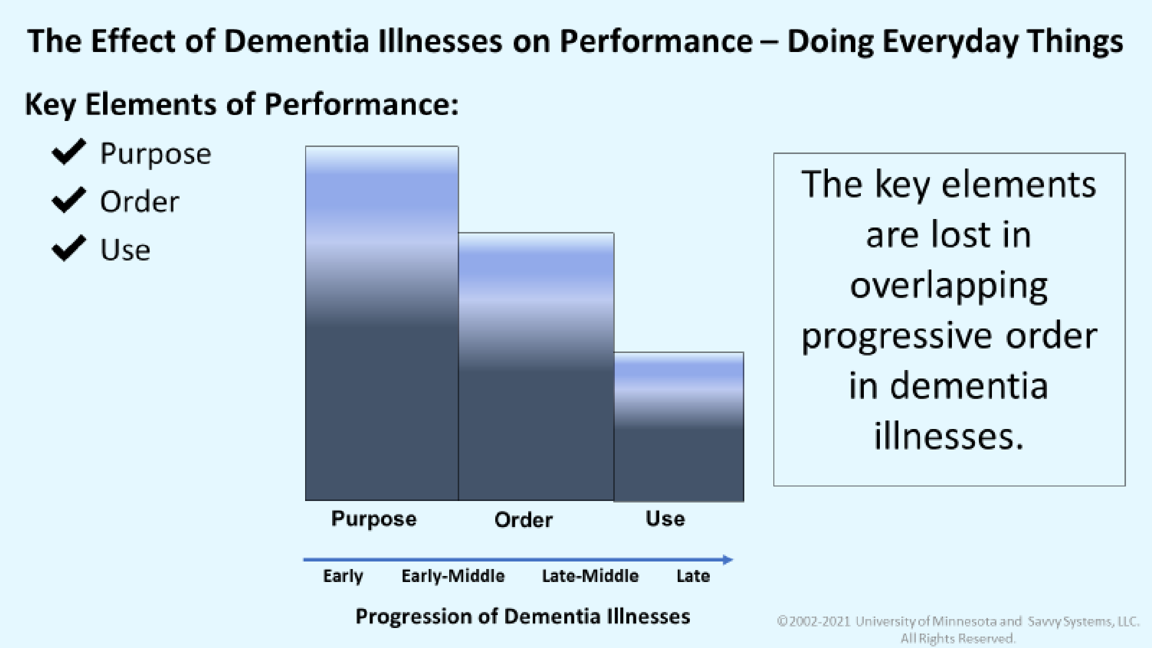
- *As the capacity for maintaining the purpose of an activity is fading, the ability to keep the* ***order*** *straight in an activity begins to fade and then is lost.* In a multi-step performance, like getting dressed, the person might be uncertain about where to begin. Or the person might take a first step but then be confused about what step is next. You may have to remind him or her, and the need to provide reminders and direction will increase over time.

- *At some point in the very late stages of the disease, things will lose meaning for the person. S/he will not know what they are for or how to* ***use*** *them.* The connection between the object and the person will become frayed and then severed. The caregiver will have to find workarounds or do things directly for the person. For example, use pullover shirts , or button the shirt for the person who can no longer manage buttons.

These losses occur over time. The realization that your person has lost the ability to relate to the purpose of an activity will begin as a suspicion. This will be confirmed only over time. The losses are seldom dramatic. They blend into each other. A person may hold on to some ability to recall the purpose of a task even as he or she starts to have trouble with the order of steps needed. S/he may have trouble using something even while seeming to sense the order in which it is to be used.

Persons living with a dementia illness can become frustrated at moments like these. Such frustrations may produce behaviors that you, as a caregiver, will see as being uncomfortable. It is at moments like this when what you have learned in the Savvy program can be useful. **You will be able to step back a bit and assess what is happening, understand what is producing the behavior, and create a response that is aimed at defusing the moment and leading the person back to a more comfortable state.**

The diagram below is meant to illustrate how the ability to do things declines in dementia illnesses. The three columns represent the three key elements of doing things. In each column, the area that is lightly shaded indicates that a person is able to carry out that part of doing things with most activities without much difficulty. The area that is darkest indicates that that element of doing things is no longer present. In between are shaded areas. These represent the period during which the person is gradually losing that element of performance ability. As the disease progresses, the shaded areas get darker and finally become black; at that point, the element is no longer available to the person. This is a conceptual diagram, and doesn’t represent a fixed, consistent course.



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.

Problems are noted first in keeping a clear sense of purpose. This shows especially with complicated tasks and activities. This ability becomes less reliable through the early and middle stages of the disease. The capacity is more or less lost by the time the person reaches the late stage of the disease. The same thing happens with the capacity to follow an order or sequence and to use objects appropriately. Losses in order and use are seen later in the disease than those related to purpose.

It helps to keep some things in mind when thinking about loss of ability to do things:

- **This is not sudden**. It is not that the person is able to keep the purpose of an activity in mind one day and then not able to do so the next. You will find that you will be less able to rely on the person’s sense that what s/he is doing has a purpose over time. And so, you will increasingly have to supply and re-supply that purpose.

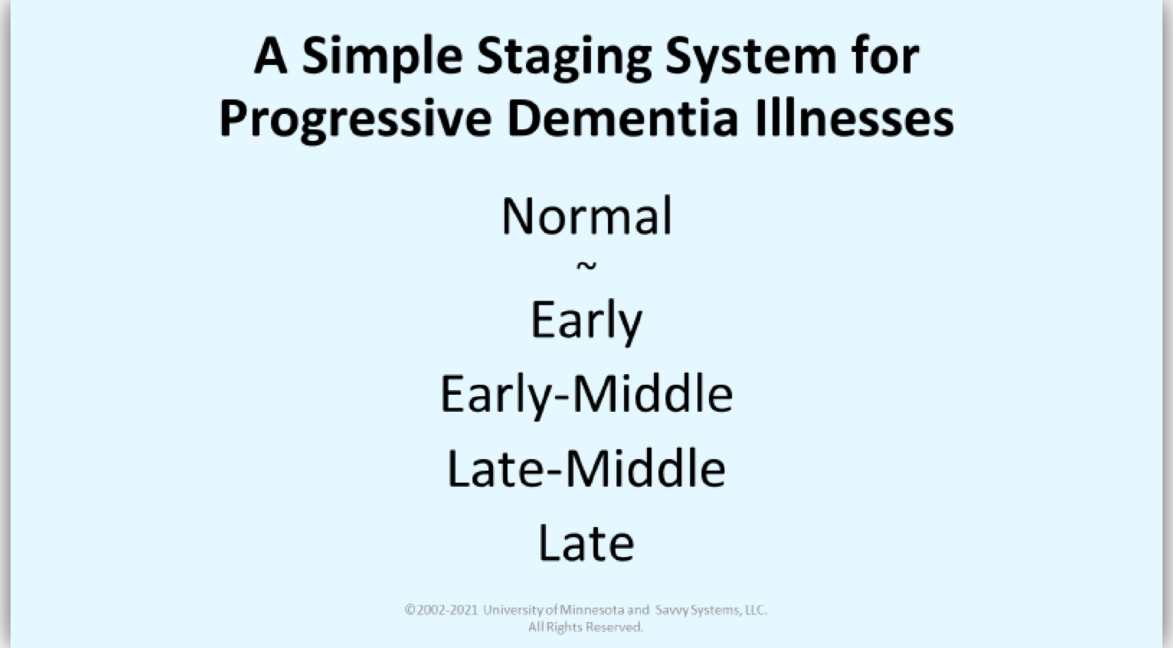
- **There is overlap**. Decline in one area begins while decline in another becomes more advanced. You may notice the person is having problems with the order of a task or keeping its purpose in mind. You may see that the person is confused about the object as well as the order of things later.

- **People have good days and bad days**. How well the person slept and whether there might be something else wrong affects that person's ability to do things. Consider how hard it is to do even simple tasks when you have the flu.
- **The nature of the task will affect performance.** A person who is early on in a dementia illness might have problems keeping the purpose of a complex task in mind. That same person might be able to keep the sense of purpose with simpler or over-learned tasks.

Introducing a Staging System for Dementia Illnesses

This section of the manual outlines a framework for describing the stages of a dementia illness. Stages are distinguished by the effects of the disease on a person's ability to do things. We provide a broad staging framework here as a foundation to build on. Savvy caregivers take the stage into account when designing activities and choosing communication methods that fit with the person's abilities and that promote positive engagement. Having a general sense of the stage of your person's strengths and needs helps you to design or select an activity that fits their capacities.

The Savvy Caregiver program uses an intuitive and descriptive framework to describe the effect of dementia diseases. The staging system we use is linked to a performance-based framework that comes from the field of Occupational Therapy; the framework was developed by Claudia Allen.[3] Occupational Therapists have special expertise in helping people to use their available strengths to be occupied in doing everyday tasks.



A Simple Staging System for Progressive Dementia Illnesses

Normal
~
Early
Early-Middle
Late-Middle
Late

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[3] For more information, go to www.verywellhealth.com/what-is-the-allen-cognitive-level-screen-4129962.

The Savvy Caregiver descriptive staging system portrays the illness as a process that begins with a condition of healthy cognitive performance and then passes through **four stages: Early; Early-Middle; Late-Middle; and Late**. Note that there are two “Middle” stages. This is because the ‘middle’ stages typically last a long period of time in which persons living with a dementia condition can reside in the community while they undergo progressive losses in their abilities.

Healthy Cognitive Performance

People who are not affected by a dementia illness can perform tasks that are within the scope of their abilities. At this level people can:

- Establish, understand, and maintain the purpose of an activity. They can analyze what is asked for in a task. They can create a plan for doing the task. They can choose tools or objects that relate to the task. They can set aside those that do not relate. They can complete the task according to plan.
- Establish or follow the order of actions leading to successful task completion.
- Effectively use the objects needed in the task.

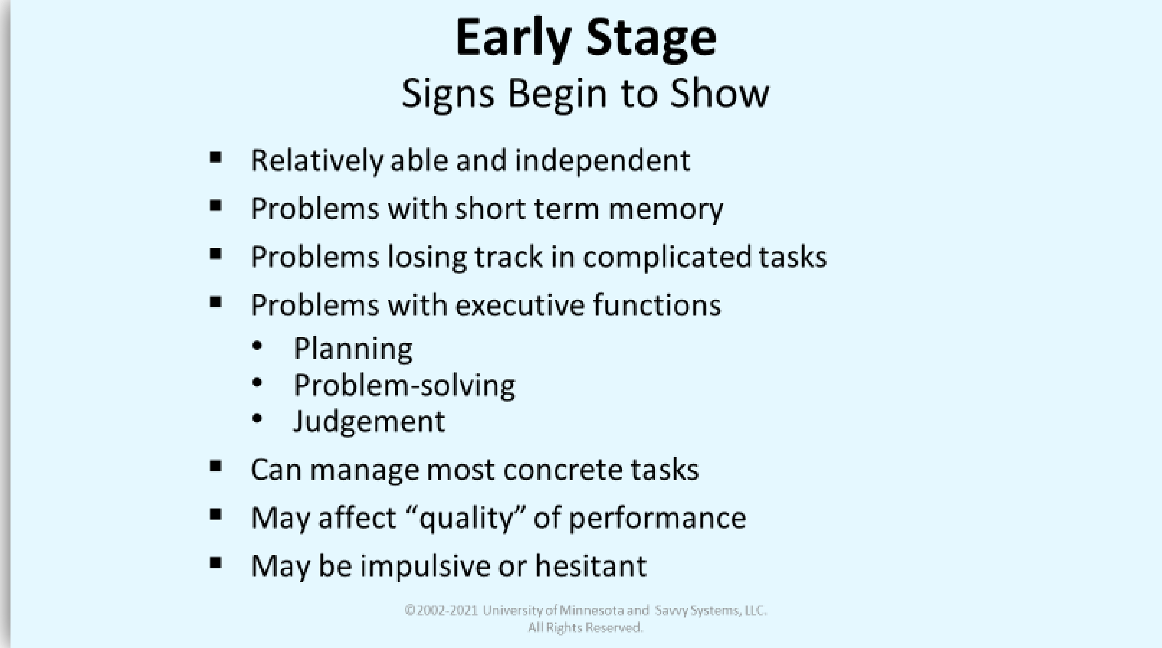
People at this level know how to make the best of a complicated situation. They know:

- How to set things up so that everything gets done that needs to
- How and when to ask for help
- What they like to do and how to ask others to do things they do not enjoy as much
- When they are starting to be over-stimulated
- How to keep the situation enough under control so they do not overreact
- How to deal with distractions and how to get back on track when distracted

This is the level of the everyday abilities of people who are not affected by a dementia illness. People functioning at a healthy cognitive level can get the family out the door every day. They balance all the intertwined tasks. They keep their goal clearly in mind. They get back on track after a phone call interrupts them. They can direct others. They can ask for help. They know when things feel too close to the edge of their stress threshold. They have ways to back away from losing it. They even know how to steal a few moments for themselves. They are zeroed in on their tasks throughout the process. Accomplishing tasks gives them satisfaction.

Early Stage: Signs Begin to Show

Dementia disorders often seem to sneak up slowly. The clues that these diseases are present are usually subtle and vague. Some things seem a little “off” or “out-of-sorts” with the person sometimes. Family members may not think of themselves as ‘caregivers’ for some time. Often, it is only when the family looks back over the few years before a diagnosis was given that the signs and clues become clear. The early stage of the illness can last for several years. There can be no doubt that it is a stage of the disease. The effect of the disease on the person is progressing.



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

People in the early stage are still relatively able to do things independently. They may have difficulties with short-term memory and will show other early signs of the effects of the disease. They will probably be able to do most routine daily tasks without help. They will mainly have difficulties when faced with more complicated tasks. New situations that call on the person to handle a lot of information can also be problematic.

There are a number of things to look out for at this Stage. Persons in the early stage may:

- Have trouble with the more executive cognitive functions like planning and judgment
- Have difficulties in problem solving, and possibly trouble planning ahead to prevent problems
- Begin to show signs of having trouble with abstract thought, and/or difficulty grasping “the big picture”
- Have difficulties with complicated tasks they were previously able to perform well and with satisfaction

Caregiving Strategies for the Early Stage. Here are some caregiving strategies when helping a person in the Early Stage of dementia illness:

- **Encourage independent activity.** People at this stage perform basic everyday tasks with little or no difficulty or assistance. Encourage success. Encourage the person to do things s/he likes to do and that s/he is likely to do well. It might only be necessary to simplify tasks and schedules for people and to help them to plan ahead.

  People at this level can still successfully work with others and may even be able to help others whose performance is more severely limited than their own. Some caregivers report being able to get people at this level to attend adult day programs by suggesting they are volunteering to help with other participants.

- **Monitor activity.** People at this stage might not fully understand the difficulties of some tasks. They might rush ahead in tasks and make mistakes. They might get bogged down in a detail.

  Watch how people handle situations and tasks that are new or complex. People living in this early stage of their illness may seem fine in routine settings, but might have trouble with new or different settings. They might become confused if they were to travel to an unfamiliar location. The onset of a dementia disorder may produce confusion in the person when s/he travels to that location even when families have vacationed there for several years.

  It is possible that people will not be able to tolerate change and will become confused. They might then become agitated or withdrawn.

- **Monitor financial transactions**. Persons living with dementia illnesses will eventually lose the ability to manage these matters and can be vulnerable to financial scams or even abuse. This can begin in the early stage, so start now to supervise this activity subtly. Sadly, family members, friends and strangers can and do take advantage of persons living with dementia illnesses, so watch for that as well.

- **Provide directions when needed.** This can be done subtly and in the background. People who are showing the early signs of dementia disorders will generally be able to listen to and follow directions. They may also be aided by written instructions like notes and lists.

- **Pay attention to key activities.** Not following directions about taking prescribed medicines or following prescribed routines can have serious consequences. Additionally, monitor financial transactions and management more closely. The process of getting the person to give up driving should also begin as soon as the diagnosis of a dementia condition is received. A person at this level may still be able to drive; however, their ability to react effectively in a crisis may already be compromised. This concern about safe behavior should extend to other potentially dangerous activities in which the person might engage, like using power tools or handling firearms. In this early stage, the person may well be able to have meaningful conversations about such issues and collaborate in decisions about when and under what conditions safety measures should be taken.

- **Watch the person's feelings.** Watch for signs of anxiety or depression. About one of every three people living with a dementia illness becomes depressed at some point. Most of the depression occurs in the early stages of the disease. Anxiety is also common. Both conditions should be looked at by a doctor. Both can and should be treated.

  People may also deny the condition. Denial may be an effort to mask something they know. It may also really be that they do not see a problem, if they are losing insight (another cognitive ability). Challenging denial is probably not a terribly effective strategy. Do not argue with or try to convince people they are ill. Give emotional support by showing concern and giving reassurance.

- **Encourage discussion.** Many people at this stage are aware something is wrong. Talk about what is happening and about how both of you are feeling about it. Don't be shy about getting help with this conversation. Try the Alzheimer's Association or other relevant organizations, members of your family, a member of the clergy, or a professional like a nurse or physician, a family counselor, or psychologist.

- **Make any plans you can.** Some years down the road, hard choices will have to be made. People in this early stage of the disease can still think, reason, and take part in making important plans and decisions. Usually, they are able to recognize their own feelings. They can still play a meaningful part in shaping choices. At this point in your caregiving career, you should consider involving the person in conversations about:

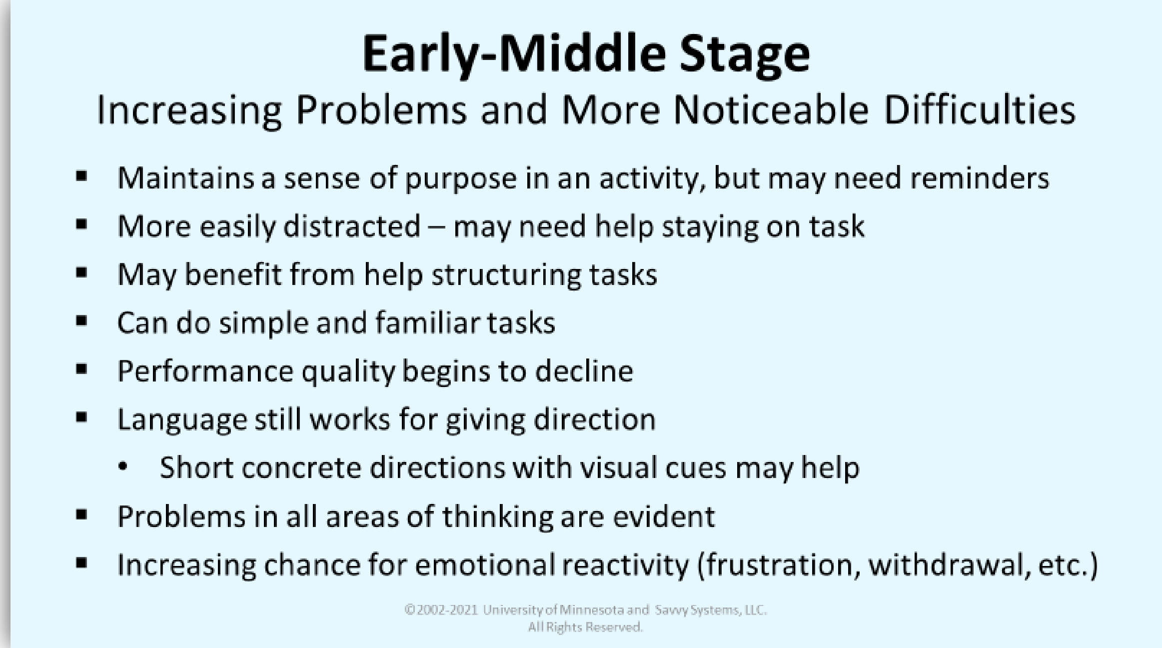
    - **Advance care planning.** Talk about what the person wants as s/he becomes more ill. Who does the person want to make healthcare decisions for him/her? What about reviving the person if their heart stops? If s/he develops an infection or pneumonia when s/he is very late in the illness, should s/he be treated or go to a hospital? Does s/he want to be given food or water by tube if it comes to that? Once you and the person feel clear about these things, write them down. Check with a nurse, doctor, lawyer, or social worker to find out how to make sure that documents are "official" and legally binding.

    - **Living arrangements.** Where you live can affect caregiving and quality of life. Aging presents challenges, and the living space can reduce or contribute to these. If, for instance, mobility were to decline, would living in a multi-level setting become a problem? Can the bathroom be remodeled to make bathing easier? A walk-in shower with a bath chair might be easier and safer than a tub. This is a good time to talk about moving if you think that is something you want or may need to do. Moving early in the disease might help you and your person establish routines and relationships in the new place.

    - **Care help.** You will need help as the disease progresses. You might want some time for yourself. Adult day programs or in-home help can give you a break. One-on-one caregiving can be overwhelming later when every part of care has to be provided. Institutional care like in an assisted living or a nursing home will become an important option. Take steps to make these choices easier by discussing them while your person can still reason about them. This is a good time to see what benefit or help program might be available to you and to learn about options in your area.

Early-Middle Stage: More Problems and More Noticeable Difficulties

Caregivers see that problems are apparent in the Early-Middle Stage of the disease. People have clear difficulties doing things, although many independent activities can continue. They begin to more frequently lose track of what they started to do. They get distracted easily. And they need help, even with routine tasks. The Early-Middle Stage can extend over a long period of time, just like all stages of the disease. The person's ability to do things declines within this stage.



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.)

A Time of Increasing Problems. People at this stage still usually look good. They appear to be performing rather normally, though cracks are showing. The higher thinking powers like reasoning, abstraction, planning, etc. are more affected by the disease. Emotional reactions may be more sudden and unexpected and may seem a bit out of proportion to the stimulus. Performance is more affected. The person is becoming less clear about the larger purpose of an action. Errors show up more often. Things are not done as well or as smoothly.

You may see that people at this stage look to caregivers for more direction or help. They may do things quickly without considering results. They may work in a trial-and-error manner. They may not know where to start or what to do. Distraction and frustration can occur with tasks that are complicated.

People usually still understand that their activities are directed toward a purpose or goal, but they may not be able to keep track of the exact goal. They may need to be reminded of the goal to help them stay engaged with an activity. People at this stage should be able to perform most daily tasks without difficulty given enough time and help. They should be able to manage most self-care activities and help with household tasks.

Impairments are More Noticeable. Confusion and errors in performance are seen more regularly as the disease moves further into the Early-Middle Stage. People do less on their own. Their thinking powers are clearly weakening. They need more help with even daily activities like getting dressed. This help often takes the form of prompting and reminding. That means you are keeping tabs on the person. They may have limited attention and be easily distracted.

People may become hastier or more hesitant. They will likely turn to caregivers more for help or direction. It may be that you will see more erratic behaviors. People might retreat, become sad, or lash out for reasons that are not clear.

Caregiving Strategies for the Early-Middle Stage. Observation and your experience with the person will guide your work at this stage. Here are some general caregiving strategies to consider when working with a person in the Early-Middle Stage of dementia illness.

- **Establish routines.** Routines are a good means to promote positive engagement in activities for a person in this stage. Simple, familiar, well-structured tasks are most helpful. The person will not always recall the tasks or the steps from day to day. Repetition may foster familiarity. This can provide a sense of safety, comfort, and control. Find a few activities the person enjoys. Do them regularly.
- **Start taking over to guide performance.** Simplify and organize tasks and activities. Design and set up the task. Tell the person exactly the steps you want him/her to do. This frees the person from the planning but lets him/her take part in the activity. Encourage the person to make choices that will not confuse him/her. Do not involve the person in choices that will be confusing or distracting. The kinds of choices a person can make will change as this stage

goes on. They will be less able to make complicated choices. You may have to take full control even at this relatively early stage**.**

- **Think about the setting.** The person may be more easily distracted or confused at this stage. Decide where you want the person to do the activity. Remove as many distractions as possible to simplify the environment. At the very least, it should not be confusing or over-stimulating. Put everything the person needs for the task within reach.

- **Provide support.** The person will likely need prompting. You might have to help the person start a task. It is highly likely you will have to help the person stay on track. The person may need to be reassured while doing the task. It is helpful to speak in a calm, respectful, and caring way.

- **Give directions that work.** Adjust the way you direct the person to fit with what they can still do at this stage. A combination of verbal and visual directions may prove effective. Verbal directions should be simple, short, and direct. Simple written notes or labels may help early in this stage, but assess this often. The person may get them or not. (It is worth a try.) Eventually, written instructions will not work. Visual cues become more and more important as this stage goes on. Point to the things you want the person to focus on.

- **Keep watch.** Observation and guidance are needed and will help. Try to correct or redirect in a way that is supportive. Try to not call attention to the person's inability or mistakes. Let errors go when you can. A person at this stage is not likely to learn from errors, as s/he probably won't remember. It is more likely s/he will just feel badly for being corrected.

  You may be able to leave the person alone for times at this stage. It is important to check back regularly when away. Determining how well this can work is person specific. Safety checks are important. The person's judgment is no longer strong. You will have to watch carefully to be sure the person is not using things or going places that could be hazardous. A person who used to walk to a nearby store should not be allowed to do so alone anymore at this stage. The person's abilities to cross streets safely, to find his/her way back home, and to manage money are all compromised.

- **Allow enough time.** Be relaxed about performance. Try not to plan too many activities into a day. It may also be useful to allow the person to rest or take a break from a task.

- **Think about “workarounds”**. So, you don’t want the person to make mistakes or get into binds, but, you also don’t want the person to feel over-protected or somehow “managed” or monitored by your caregiving. Are there ways to make certain arrangements that accomplish both ends? Can you, for example, set up a credit card account with a very small spending limit that the person can use but that won’t jeopardize your finances? Can you arrange with your favorite restaurant to have the person order, but to check with you to verify or modify it?

The Issue of Driving. People at this level have extremely poor and unreliable judgment and will respond poorly in a crisis. People at this stage should not be permitted to drive. Use all the help you can get.

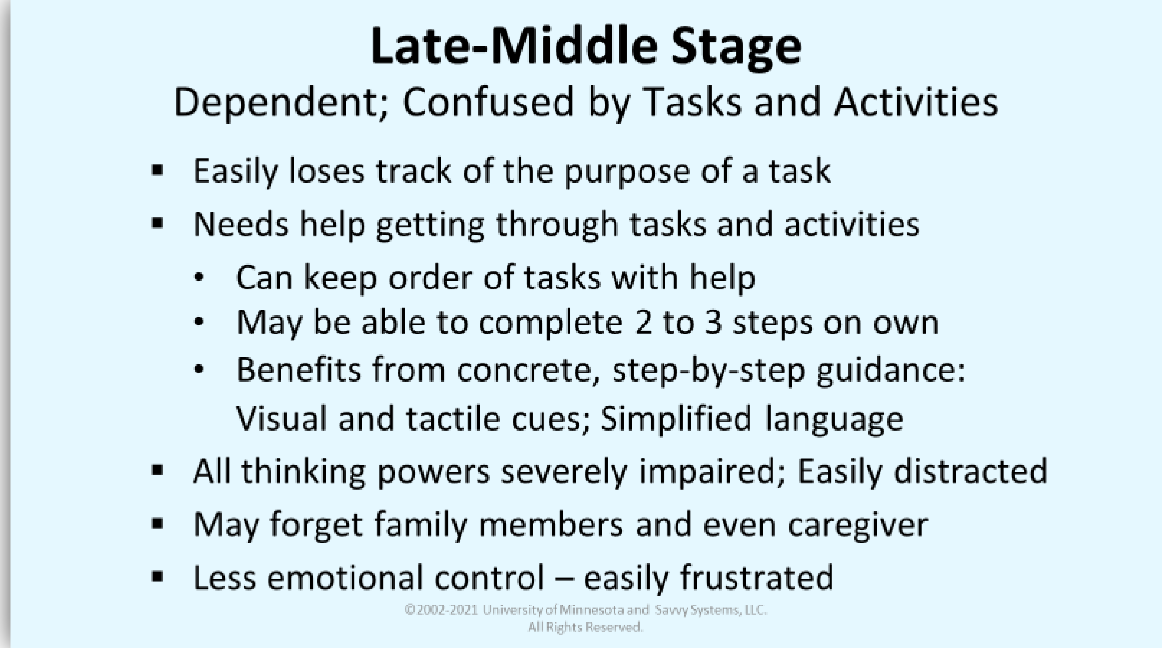
- Ask your physician to help get the person to stop.
- Bring in other members of the family. Get their support and help in getting the person to stop driving.
- Make the car less accessible by taking away the keys or disabling the car.
- Inform your local department of motor vehicles and/or police department of the person’s condition.

This is a serious situation. Your person and others are at risk.

Other Dangerous Activities. As noted elsewhere in the manual, over a lifetime, individuals safely use things like power tools, sharp instruments, guns, etc. As the illness with which your person is living progresses, his/her ability to continue with the safe use of these things is diminished. Continued use of such things, like continued driving, can pose a serious threat to the wellbeing of the individual and also to others. As with driving, seek the help of others to understand the person’s continued capacity for the safe use of potentially dangerous instruments and to limit or curtail the person’s use of them. One useful fact is that you can probably rely on “out of sight, out of mind” with your person. Removing potentially dangerous items from their environment is responsible caregiving.

Late-Middle Stage: Dependent and Confused

Persons living at this stage of the disease need help doing most things. They need direct help to begin and get through most tasks. Safety is an increasingly important concern. Their growing confusion may lead to unpredictable reactions. The work of caregiving does increase. Caregivers will benefit from help from others. The Late-Middle Stage can extend over a long period of time. The person's ability to do things declines, sometimes dramatically, within this stage.



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

Becoming Dependent in Daily Basic Tasks. In general, people at this stage can do little on their own. There are few actions they will begin themselves, and they will need help throughout. They probably need help even with basic routine daily tasks. They will likely need help getting out of bed or to the toilet, getting dressed or feeding themselves.

People at this stage do not act with a plan in mind. They do things without a sense that there is a purpose to the action. They seem to follow whatever cues are presented. Their sense of order is now clearly affected. People may perform two or three steps in a sequence. They then may get stuck or distracted. People can use objects, but they will likely need reminders about what they are supposed to be doing with the object.

You might direct your person at this level to brush his/her hair as part of morning grooming. The person will likely begin to brush after you hand them the brush and give a direction. Then any number of things may happen. S/he might:

- Get stuck in one spot and brush it over and over.
- Begin to use the brush in some other way (for example, use it to scrub the wash basin).
- Become distracted, put down the brush, and move toward something else.

In any of these cases, you will need to redirect your person's actions.

The world around is confusing and may be threatening for people at this stage. Their powers of thought are so weakened that they are of little help in interpreting the world. They cannot sort things out. People are likely not to know where they are or who others around them are. They may even no longer recognize family members. People have an increasingly difficult time making words work. They have trouble finding words. They have trouble using them to communicate meaningfully. They may have trouble forming sentences.

People at this stage still have a strong emotional radar. They are likely to pick up on the feelings and emotions of those around them. They will sense impatience, frustration, or annoyance coming from others. They are likely to be extremely sensitive to negative feelings from another person, even – and maybe especially – close family or friends.

People at this level may have a number of reactions to the world around them.

- **Restlessness**. They may seem to have a lot of energy. They may pace or want to walk a great deal.
- **Anxiety**. Confusion is strong and can make people fearful or anxious. They may become hesitant or uncertain about taking part in a task or activity.
- **Withdrawal**. They may not understand something or be intimidated and so pull back from taking part in activities.
- **Misinterpretation/paranoia**. They will only grasp part of the world that is in front of them. They may sense that parts are missing and not know what to make of this. This can lead to accusations that others (including you) are

stealing things or plotting to do some harm. They may not be able to put the parts together and become threatened or confused.

- **Striking out**. Confusion and misinterpretation can produce reactions. These may be verbal or physical, or both. People may misunderstand something and take it as a threat. They might feel overwhelmed and become defensive. A negative or scary memory may be triggered. Even frustration can produce a violent reaction.

The Person Experiences General Confusion. Expect people in the Late-Middle Stage of a dementia illness to be very confused about what is going on around them. They will not be able to act with a goal in mind. They will need help and prompting to be able to maintain one or two steps in the order of a task. Their sense of what objects are and how to use them is clearly slipping. They benefit from short, concrete directions without explanations. Communication should emphasize visual and tactile cues.

People at this level can be easily upset due to the fact that they are so confused. Inability to handle a complex world can produce many reactions. They may:

- Seem anxious or restless
- Become agitated
- Have trouble sleeping or getting back to sleep once awakened
- React to things they misperceive
- See things that do not exist (hallucinate)
- Behave as though people are stealing from or threatening them

Many things can upset a person at this stage. Over-stimulation, fatigue, physical illness or pain, changes in routine or in the environment, or excessive demands on limited abilities can all be problems. Things the person might have been able to handle under normal circumstances may produce such reactions.

People at this stage may need to be watched and helped with almost everything they do. Eventually, they will come to need help with all daily care tasks and with any activities. Caregiving is a full-time job at this point. A person trying to provide care on his or her own will be very busy. This is when many people living with a dementia condition move to long-term care settings that give full-time care.

Caregiving Strategies for the Late-Middle Stage. Here are some general caregiving strategies to consider when working with a person in the Late-Middle Stage of a dementia illness.

- **Accept control.** The basic design of your person's day is up to you. Make sure the routine of the day is set. The day should be simple. Keep as undemanding a schedule as possible. Have a clear plan for what you will want the person to do for each part of the day.
- **Keep things simple.** Decide what you want the person to do for each task in which you want them to take part. The tasks you ask them to do should be one- or two-step tasks. Passive involvement – for example, sitting with you as you make a meal – is still involvement. Helping the person to become passively engaged can represent a caregiving success.
- **Keep routines.** The person at this stage will do best with simple, well-structured tasks. Stick to routines you have already built. Look carefully at your days if you think you do not have any routines. It may be that you have built routines but not named them.
- **Lower your expectations.** Be prepared to scale down your plan for and expect less from the day. Do not be concerned about the quality of a person's performance in a task.
- **Actively manage the setting.** Plan where you want things to happen. The environment should be increasingly simple. Remove any distractions that you can. Put everything the person needs for the task nearby. Set things up in the order in which the person should use them. Remove all potential dangers.
- **Manage all tasks.** Expect to help. There is little the person will be able to do without help and direction. You will have to help the person by gesture or word to begin a task. Watch the person throughout. Be ready to provide cues and visual demonstrations for each step. Keep your person on track with simple directions like "keep going," "that is all," or "put it down now." Be prepared to draw the person back to the task when s/he becomes distracted or disinterested. It is highly likely you will have to bring the task to an end.
- **Use appropriate cues.** Get the person's attention. Verbal directions should be simple. Use only one or two words. Use more visual cues. Hand objects to the

person and show him/her what to do with them (demonstrate). Guiding by touch may be helpful. Allow extra time for him/her to process information.

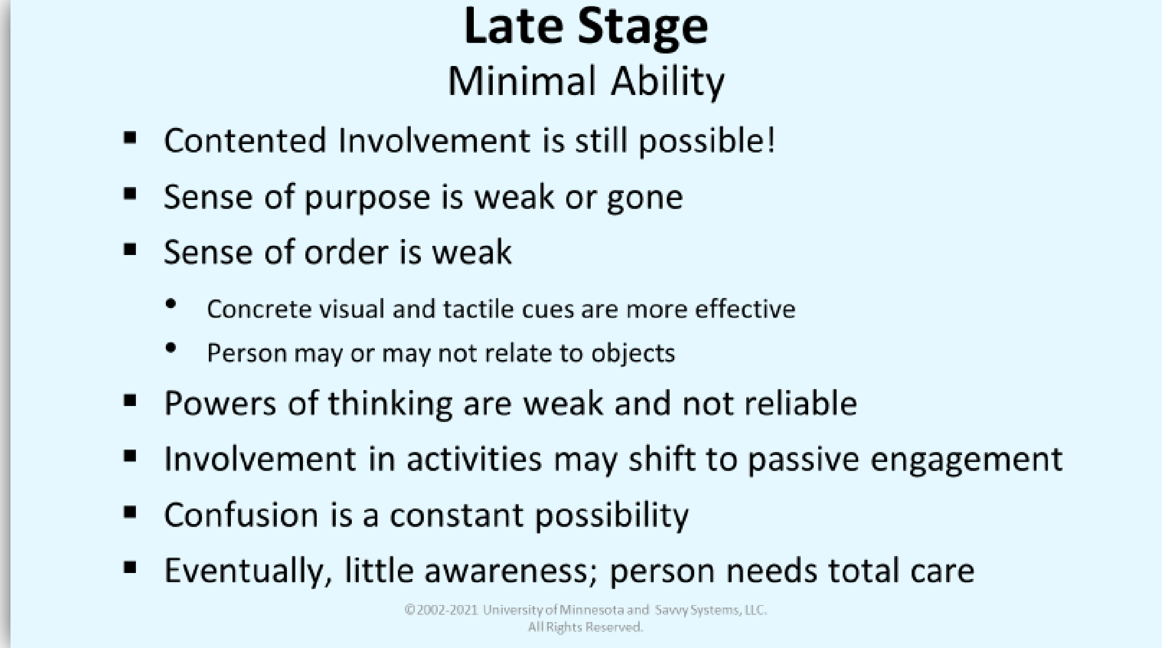
- **Assist directly.** Support the person in trying to do things like dressing with your help. But jump in if the person is not cooperating in the task, it is taking longer than you can bear, or if the person seems to be frustrated by it. Sometimes the best thing is just to do the job yourself.
- **Refocus.** Redirect him/her back to the activity at hand when your person's attention wanders.
- **Watch over everything.** Safety and wellbeing will have to be watched carefully. Dangerous objects should be kept out of reach. All daily activities have to be monitored. This includes basic activities like eating, bathing, using the bathroom, etc.
- **Judge when a task or activity is over.** Errors, completion, and quality are unimportant. A task or activity, or even a social interaction, is good and useful only as long as the person is happily occupied with it. Do not push if the person becomes bored with a task or is clearly not interested. End the task and move on to something else.

  For instance, you may notice as you guide your person through the steps of getting dressed that, at some point, s/he is becoming fidgety. That may be the time to stop trying for active involvement. It may be the moment to say, "Good job. Let me help you," and finish dressing the person yourself.
- **End the task.** Signal the person that the task is done. Praise the person for whatever part of the task s/he did, or, if engagement was more passive, tell him/her you enjoyed the time together.

It's easy to advise that there should be no pressure during any stage of guiding an activity. This is a kind of ideal but think of it as a guideline for caregiving. Be ready to "back off." Try to avoid putting pressure on the person to finish an activity within a certain time frame, or to achieve a certain quality of outcome. Reassurance and rest breaks may also be useful. As they reach the end of the Late-Middle Stage of a dementia illness, people may benefit from just watching and being passively engaged.

Late Stage: Minimally Able and Unresponsive

The late stage of the disease is a time when people cannot care for themselves. They seem to lose their connections with the world. In simple terms, those connections are hard to find or to make. It is still reasonable to consider that they can be drawn to things and take pleasure in them, even though they require help in all parts of their daily life. They should be expected to take part passively at this point.



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

Caregivers can observe that the person is expressing pleasure or contentment in passive participation. Comfort and keeping confusion and fear away from the person are important care concerns at this stage. The Late Stage may be the most variable of all in terms of how long it lasts.

Functioning with Minimal Abilities. The world and the objects in it are no longer familiar. The person can make no effective use of them. Everything about the person's ability to do things has diminished. Speech is gone outside of occasional words and sounds. There is little left of attention. Movements or touch may draw the person's attention briefly. They may resist care, or may even strike out.

People living in the last stage of a dementia disorder will need more or less total care. The family may have already moved the person into a structured environment like an assisted living or a skilled nursing setting where care staff and a range of care services are available.

The focus of care at this level is on promoting passive involvement and some level of comfort, caring, and contentment. The person is very unlikely to be able to do things. S/he may take part in a quiet way and enjoy being entertained.

In bed and unresponsive. This is the end stage of the condition. People at this stage of the disease require total care. They are usually quiet. They sleep a lot. They respond to little outside themselves. Comfort care is the entire focus at this stage. Skin breakdown and infection are the big worries. Well-established advance directives should govern treatment and preventive care.

Caregiving Strategies for Late Stage Dementia Illness. The senses are the best way to continue to occupy and provide happy moments for people in this stage.

- Calming touch is always important. This may be the most important way that they feel connected to you.
- Gently applying oils and lotions can promote a sense of pleasure and connection. Hand massage can be soothing.
- Sensory connections to the past – rituals from early life (for example, religious rituals) – may be engaging.
- Music remains a pleasure for many people.
- Some people like the presence of companion animals.
- Comfort objects like dolls or blankets can be pleasurable.
- Favorite smells may please the person.
- Soft comfort foods like shakes might be pleasurable. (People at this stage may have a hard time eating even finger foods.
- Non-threatening stimuli like colorful moving objects may be enjoyable.

The person should be made as physically comfortable as possible by gentle basic care. How you approach and address the person is important. Be careful not to startle or surprise the person. Gentle touch, massage, and very slow and gentle range of motion exercises may be pleasurable. A calm, quiet environment is helpful.

A Word of Caution about Staging Framework

This presentation on stages of dementia illnesses is meant mainly to alert caregivers to a pattern of decline in dementia. The framework provides an *overview* and guide to the progress of illnesses like Alzheimer's disease. It provides a general way of thinking about the decline that is brought about by a dementia disorder.

However, the stages should be viewed with some caution:

- **These are not absolute states.** The changes are gradual over a relatively long period of time. A person does not move from one to the next overnight or in predictable ways. People who are described as being at one stage do not remain fixed until they pass to the next stage. There is continuous and gradual change across them.

- **People have good days and bad days.** Someone estimated to be in the Early-Middle Stage may sometimes seem to act with clear purpose and so look more like they are in the Early Stage. On another day, the same person might seem more confused and so appear to be more like a person at Late-Middle Stage.

- **Each individual experiences his or her illness in an individual way.** The staging framework suggests there is a kind of path through the illness. It is important to recognize that each individual has his or her own path.

- **The dimensions of tasks need to be fitted to the capacity of the individual, and estimating the person's stage should help with designing tasks.** Thus, a person in the Early Stage might become frustrated when dealing with a complex task like balancing a checking account but might enjoy and be able to stay focused on a simpler or more familiar task like helping to make a cake. (We will learn about this in the next session.)

- **Many other factors can affect performance.** Factors such as feeling ill or having the flu, or not sleeping and eating well, can contribute to a decline in performance. There might be a decline in performance if there is more noise or confusion than usual in the environment.

It is important to remember that these stages are starting points for you. Your person is unique. You can help out where needed when you best understand his/her pattern of performing.

What Stage Is Your Person In?

At What Level Is He or She Performing?

There are two practical reasons why it is helpful to know the answer to this question.

- You need a way to estimate or monitor the progress of the disease. Understanding the stages gives you a "feel" for the spectrum of the disease. It is simply a good thing to know where your person is in the progress of the disease. You can look ahead from where you are now. You can plan for the care tasks facing you and begin to enlist more help. You can think about alternatives to the present situation.
- It will guide and promote Savvy Caregiving. Having an idea of your person's disease stage and level of performance gives you a practical starting point for reaching your caregiving goal on a daily basis. The next section of the manual provides a practical guide for helping people living with Alzheimer's or a similar illness become and remain involved and content while doing things. The guide is linked to the staging framework presented above.

A key part of the Savvy Caregiver program involves *estimating* where the person is in the disease and what the person's ability to do things is. You will be asked to do two things to arrive at an initial estimate:

- View the video in class that shows people at various stages in the disease performing an everyday task, making a sandwich. This viewing will be accompanied by a talk from your instructor.
- Re-read the material in this section.

These exercises should allow you to arrive at a useful working estimate of the stage at which your person is in the disease. Think of this as a starting point, a "ballpark figure." You will certainly be able to figure out what stages and levels your person is *not*. You will almost surely be able to arrive at an "either-or" estimate.

The estimate is just a tool. Its only real value is in helping you to design the help you provide to the person. You will likely be able to say s/he is either this stage or the next one up or down from it. That is all you will need for now. The surest way to get at the right level will be to apply the principles you will learn in the next section. Your ability to see the person become involved and happy in tasks and activities you design will be the test.

Another option would be to identify a Neuropsychologist or Occupational Therapist and seek a professional evaluation.

Weekly Session 3 Notes

Weekly Session 4

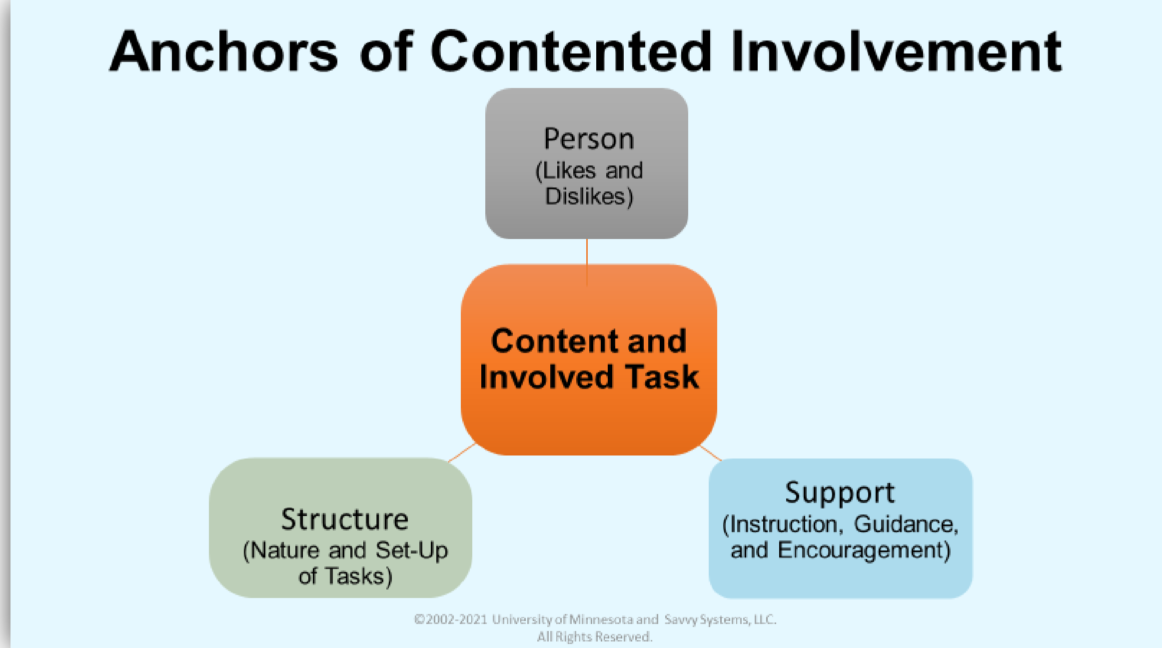
"Human behavior flows from three main sources: desire, emotion, and knowledge."

Plato

The Anchors of Contented Involvement

Being involved and happy means doing things one likes to do. It also means doing things that fit what one is able to do. A task that is too difficult can overstimulate a person. The person can become rattled and erupt and fly off the handle if there is too much going on. The person can become bored and withdraw if there is too little going on. The diagram below displays the possibilities.

This section focuses on **the three anchors that promote and maintain Contented Involvement: Person, Structure, and Support.** The three anchors are strongly linked to the stage to which the person's illness has progressed and the extent to which the illness interferes with the person's Performance capacities. The stage estimate gives you a kind of yardstick for gauging what might be too much or too little and what might be just right for the person to do. The stage gives you a good clue about remaining strengths and what activities might be enjoyable. This is a key to helping the person be involved and happy. And knowing the stage can alert you to the kinds of problems s/he might have in doing things, which in turn provides information that will help you to make appropriate caregiving choices.



Anchors of Contented Involvement

Person
(Likes and Dislikes)

Content and Involved Task

Structure
(Nature and Set-Up of Tasks)

Support
(Instruction, Guidance, and Encouragement)

A Closer Look at the Anchors

Person. This anchor relies on common sense. A lot of what you will do will be to choose tasks and activities for the person and help the person to be content and involved with them. **The starting point for success is in knowing or finding out what they like to do.**

People have preferences. They like to do some things and do not like to do other things. You have an idea from experience the kinds of things the person likes to do. At the heart of all strategies for managing day-to-day life is your knowledge of your person. This can be a little tricky. The onset and progress of a dementia disease can alter people's preferences.

- They may continue to enjoy doing things they enjoyed doing before the disease. They may lose interest in these things.
- They may surprise you and show interest in things in which they were never interested before.

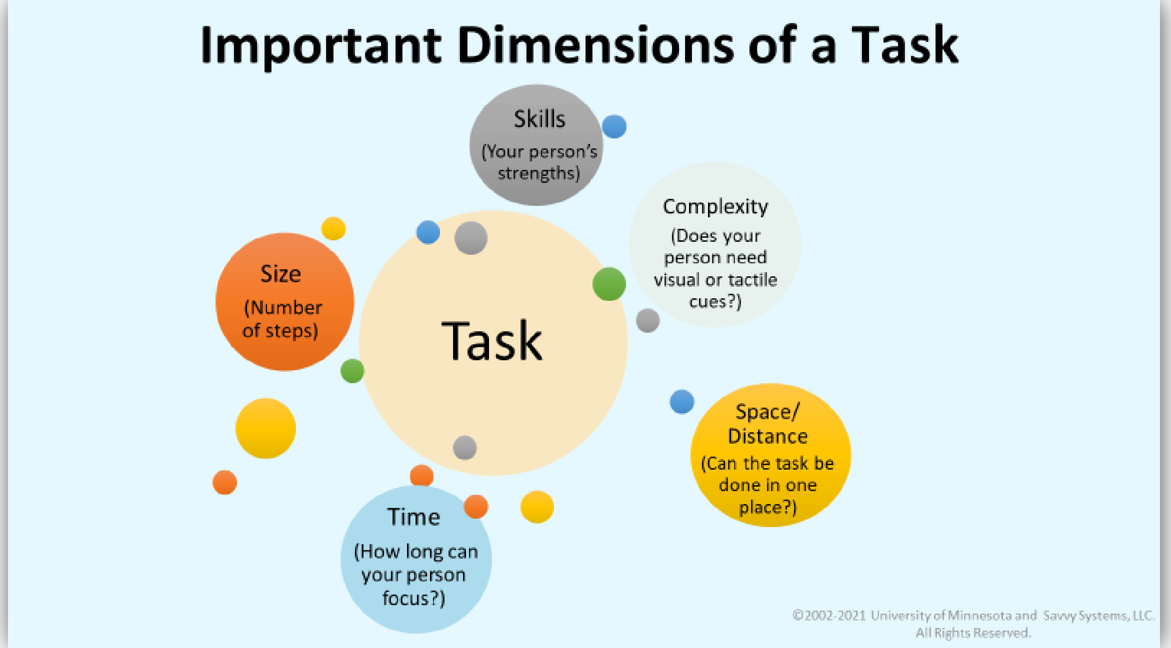
  It is especially important to keep this idea in mind when thinking of household tasks that may be associated with men and women like linking cooking with women and tinkering with tools with men. Do not eliminate tasks to try just because the person previously left those tasks up to a spouse.
- Sometimes interests change. People might be no longer interested in things they previously enjoyed.

People like to do things that are not so complicated and demanding that they leave them feeling frustrated and defeated. And, they do not want to be bored with overly simple tasks. Usually a caregiver knows what the person used to enjoy and was able to do before the illness.

The problem is that the dementia illness is eroding the person's abilities including the ability to do things s/he enjoyed doing. So, the person may no longer be able to do something s/he was once good at. The question then becomes is there some part of that activity that s/he may still enjoy? Would the person who used to like doing the laundry now enjoy folding the washed and dried towels? Would the person who used to make things in the shop now enjoy assembling already cut pieces? Having a reasonable estimate of where the person is in the disease will help you make these choices.

Structure. Structure concerns the design and layout of tasks. It has to do with the way in which tasks and activities are presented to the person. This also includes the environment within which the task is presented. In terms of the Simple Model of Behavior covered in Section 2 of this manual, set-up relates to the nature of the task and the influence of the environment.

Structure involves managing all aspects of the task presented to the person. Tasks and activities are seldom as simple as they seem. They typically involve many elements. You have to decide just how much of a task the person can do so s/he is content and involved. This means deciding which part(s) of a task, how many steps in the task, and the location of the task the person can handle without confusion. You have to reduce distractions in the surrounding environment that could divert the person's attention.



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?)

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Size, complexity, and environment are important dimensions of any activity.

- **Size.** This is a simple idea. There are big jobs and little jobs. There are easy tasks and hard ones. There are tasks that exceed a person's mental capacities. There are tasks that are well within their grasp.

  It is important to recognize that tasks and activities typically can be broken down into smaller parts. Take the person's abilities into account in giving him/her tasks or activities.

Think about a common household task like “doing the laundry.” This task has many parts that need to be accomplished to get the laundry done.

- Sort the laundry into light and dark clothes
- Match the wash cycle to the clothes
- Load the washer
- Put in detergent
- Start the washer
- Wait for the washer to run the full cycle
- Unload the washer
- Put clothes into the dryer except those that cannot be dried
- Start the dryer
- Unload the dryer
- Fold and put away the clothes

“Doing the laundry” might be a task of the right size for a person in the Early Stage of the disease. The right size task might be unloading the washed clothes into the dryer and then starting the pre-set dryer to a person in the Early-Middle Stage. Perhaps the right sized job would be sitting and folding the towels for a person in the Late-Middle Stage. A person in Late Stage might enjoy being in the room with you as you fold the clothes.

- **Complexity**. Some activities are complex. They have many steps. They involve parallel tasks that relate to each other to form a larger whole. Others are simple and concrete with few steps. Complex tasks usually involve planning and organizing a set of related activities and then carrying them out in the proper order. Concrete tasks are generally very immediate; everything is right in front of the person and what has to be done is clear.

  - Does the outcome of one part of a task determine the next step? (“If you get home by noon, go next door for lunch. Otherwise, heat up what is in the blue container in the fridge.”)

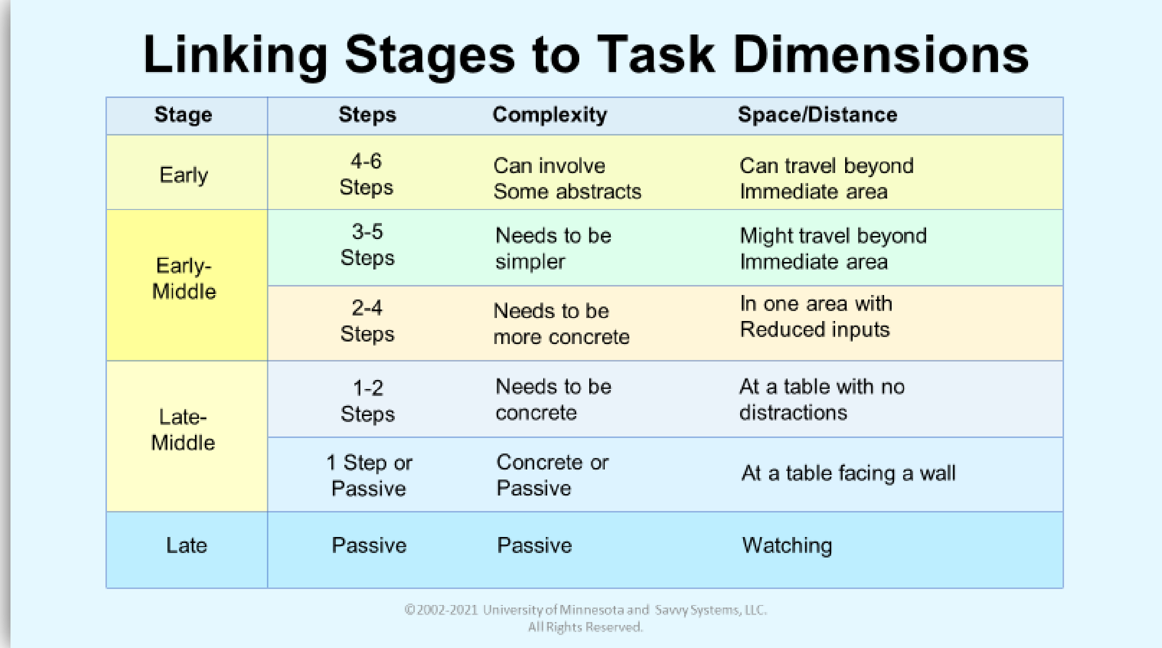
  - Does the task require a lot of abstract thought? Does it involve numbers and arithmetic? Does the person have to think in terms of “what if”? (“After you have folded 50 flyers and put them in envelopes, then take them to the post office and mail them. But, only do that if it is not on the weekend.”)

    - Does the task require a lot of short-term memory? Does the task involve keeping in mind different steps and remembering the outcome of previous ones?
    - Does the task require a lot of reasoning? Does the task require thinking through different parts of a problem in a certain order? Is there any safety risk if the task is not done exactly to plan?
    - Are all the parts of the task in front of the person, and is the order of steps apparent? ("Put the nuts and bolts together, then, put them in the jar.")

- **Environment**. This relates to where a task takes place. Some tasks, like picking up groceries, may need a person to travel outside the home to complete. Other tasks, like doing the laundry, involve moving from room to room within the home. Still other tasks, like stuffing or sealing envelopes, take place right in front of the person within the circle of his or her reach.

  The fit between activity and ability is important. Will the person be able to move from room to room without losing the sense of the task? Will this present too many distractions? Might it be better for the person to stay in just one room to work on the task? Should the person be seated and not moving around with everything within reach?

  Time is an especially important part of the environment. It helps if you can judge how long it will take your person to complete a given task. This allows you to establish realistic expectations for performance. This helps you guard against becoming frustrated or communicating frustration to the person.



Linking Stages to Task Dimensions

Stage	Steps	Complexity	Space/Distance
Early	4-6 Steps	Can involve Some abstracts	Can travel beyond Immediate area
Early-Middle	3-5 Steps	Needs to be simpler	Might travel beyond Immediate area
	2-4 Steps	Needs to be more concrete	In one area with Reduced inputs
Late-Middle	1-2 Steps	Needs to be concrete	At a table with no distractions
	1 Step or Passive	Concrete or Passive	At a table facing a wall
Late	Passive	Passive	Watching

People's ability to deal with size, complexity and environment declines as the disease progresses through the stages. Complex tasks get harder. They will finally be simply out of the person's reach. Tasks spread out over large spaces become difficult, and then impossible, for the person to manage. People need tasks that are right in front of them. They need tasks that are within easy sight and reach. Things take longer as the disease progresses.

Set-up strategies should be adjusted to fit your person's abilities. The table above provides some general guidelines for deciding on how to set up tasks in which you might want to involve your person. The key here is the overall pattern suggested in the table. The table points out that there is a basic link between the stage of a person's disease and the size, complexity, and environment of a task the person can handle.

- **People living in the Early Stage of dementia illness:** Ability to relate to the set-up of activities will be fine for most daily tasks like dressing or eating. People will understand and act with purpose. They will be able to put the multiple steps of the activity together and follow them without error. They will have no problems using familiar objects. People's difficulty with activities might have to do with the size of the activity or the environment in which it is carried out. They might lose track of the overall purpose while following one or more of the related tasks if asked to do something overly complex or abstract. Driving to a place they have never been to before and having to find their own way could be beyond their abilities.

- **People living in the Early-Middle Stage of dementia illness:** In this stage, people still understand that actions have purpose. They might sometimes forget the exact purpose, but they will know there is a purpose even when the exact purpose is forgotten. Their actions are goal-directed. They will be able to return to purposeful activity with a reminder. Their sense of the order of steps within an activity will remain intact if the task is not too complex. They will have little difficulty using familiar objects properly.

  During this stage, your person might be able to select clothes and put them on by him/herself. The size and many related steps of the task may begin to overtax their capacities. Errors might creep in and/or the task may take longer than it used to. You might see poor color and style choices or dressing in the wrong order. You might decide that these errors and the length of time the task is taking are manageable. So, you might let the activity continue independently. Or, you might detect frustration in the person or in yourself. You may then feel the need to do something by providing better set-up. You might decide that pre-selecting and laying out the clothes might be the kind and amount of help the person needs.

- **Moving into the Late-Middle Stage:** People at this stage may still feel that actions have purpose, but this feeling is fading. Rather than focusing on the goal, they may begin to focus more on the process. They will refocus when reminded, but they may not stay focused for long. The number of steps they can put together in a row is decreasing. They may perform the steps for part of an activity. They have to be reminded of the next steps. They may not be able to keep in mind all the steps of "getting dressed." They may still be able to take the steps for part of that activity. They may be able to "put on the shirt" where this involves putting the shirt on and buttoning it. They will not have trouble using most familiar objects properly. It is likely they will take longer to do something than people in the Early-Middle Stages.

- **Transitioning between the Late-Middle and the Late Stage.** Purpose is no longer there for persons living at this stage of their illness. They act from moment to moment. They may be able to perform two or three steps in a row when doing over-learned activities. Their activities will mostly have to be guided step-by-step. Their sense of what things are and what to do with them is weakening. Their role is more passive, but they can still engage and enjoy.

Tasks that are familiar and have very few steps are best. Seek also to reduce distraction. Tasks that do not require the person to move about are suitable. People at this stage can no longer prepare a meal, but they might be able to help with meal preparation steps. They might be able to sit at a table in the kitchen and shell peas, peel carrots, or tear washed lettuce into a bowl. They might be able to stir pre-mixed things together or to roll cookie dough into balls. They will not be able to reliably read and follow a recipe or to measure ingredients out.

- **People living in the Late Stage of the disease:** People do not act with any sense of actions having goals by this stage. It is very unlikely they will be able to do any of the steps of an activity. They will not likely have a sense of objects or their use. Passive enjoyment is the appropriate caregiving goal at this stage. Set-up should concentrate on helping the person to focus on something pleasurable that is going on in front of him or her.

  The basic set-up for tasks is making sure the person is comfortable; selecting something that might hold the person's attention; and removing as many distractions as possible. Passive activities might include:

  - Listening to music the person likes such as music from when the person was a young adult
  - Looking through picture books or photo albums
  - Having a hand or foot massage
  - Holding a comfort item like a doll or blanket
  - Watching while others do things

Support. You have just learned about Person and Structure, the first two anchors of Contented Involvement; now let's move on to Support, the third anchor. Support includes all forms of helping through communication, guidance, encouragement, and redirection. **There is always a link between the task you plan and the way you help the person to start and stay with it. The link relates to the stage of the disease and to what the person is able to do and understand at that stage.**

Providing support is done more or less automatically. For caregivers of persons living with dementia illnesses, support requires new skills. Take a look at the main things that Support involves.

- **Focusing**. One of the first concerns in getting people living with a dementia condition involved in tasks is to be sure to get their attention. Trying to get people started on something while they are doing something else might startle them. That may add to confusion. Make sure that your person knows that you are there and that they are focused or zeroed in on you before trying to get your person involved in something.

- **Informing**. Tell your person what you want him or her to do. The telling is important, even if they may not understand. Your voice will draw the person's attention. "Telling" may mean more than just using words.

- **Instructing and Demonstrating**. Give the person usable information about how to do what you want him or her to do. You may just be able to give directions verbally if the person's performance is not yet seriously affected by the dementia illness. People need more than words soon into the disease. They may need you to demonstrate a task so they can see how it is done. They may need you to demonstrate it a few times. They may need you to lead them physically through the task. Take the person's hand and guide it in the motions.

- **Initiating**. You may have to tell or show your person that it is time to begin the task. Giving help with getting started is an important part of Support, particularly after people's illness moves to the Early- Middle Stage.

- **Prompting and Cueing**. You will have to help your person follow the steps in a task often after the Early-Middle Stage.

- **Monitoring**. You will have to check to see how they are doing with the task.

- **Ending**. You may have to provide cues that the task is done, particularly once a person is in the Late-Middle Stage.

- **Reinforcing**. There are two ways to think about reinforcing people in their tasks and activities. The first is to be sure to provide positive feedback for their involvement and their work in the task. The second is to remember that the quality of the work is not, in itself, important. Criticism should be avoided at all cost.

- **Refocusing**. You will need to pull them back into the task if they are distracted or become disturbed while doing a task. Techniques for this are discussed more fully below.

Re-Focus: Dealing with Distraction

In some impossible ideal world, a caregiver would eliminate all distractions in advance. Eliminating or reducing obvious distractions is a good idea, but distractions will occur. So, try to call the person back to the task if he or she becomes distracted. This should be done in a manner that fits the person’s abilities. It should be done using communication techniques appropriate to their stage.

- This may be something external like a noise in the hallway or movement outside a window. External distractions can often be removed or blocked. Close the door or draw the curtain. They can sometimes be “removed” by having the person sit so s/he can no longer see them.
- The distraction may have to do with the set-up of the task. There may be too many steps for the person. The task may be too difficult or cause the person to become stuck. Alter the task to better fit the person’s abilities if you see this. Then draw him/her back into it.
- The distraction may be internal. The person may be ill or feeling pain or discomfort. The person may not be self-aware enough to recognize the source of distress. Check the person for signs of physical problems. Check with their doctor.

Re-Focus: Dealing with Emotional Disturbance

If individuals living with Alzheimer’s or a similar illness become disturbed in any way, they will have a hard time being involved and happy in a task or activity. People are more likely to be affected by confusion when they become less absorbed by an activity. They are more likely to become upset or disturbed by this feeling of confusion and of being lost or out of control.

The way in which a person shows s/he is disturbed may change in two ways as the disease progresses.

- The signals a person gives off may change. They will almost certainly be less able to say they are upset because verbal skills are declining. They may develop other ways of signaling, perhaps through other kinds of body language. These may be more disruptive.
- The number of clues that a reaction is about to occur may be decreased. The time from the onset of clues to a major reaction may shorten. You might get only one or two clues something is bothering your person before an outburst or catastrophic reaction occurs.

Try to help restore calm and a sense of safety and control if the person is showing signs of frustration and/or agitation. Use what you have come to know about your person to help him/her focus on something s/he likes. This will vary from individual to individual. It may be:

- Looking at a photo album
- Having some tea
- Sitting in a chair and watching the outdoors
- Holding a familiar object
- Listening to music
- Taking a walk
- Holding your hand

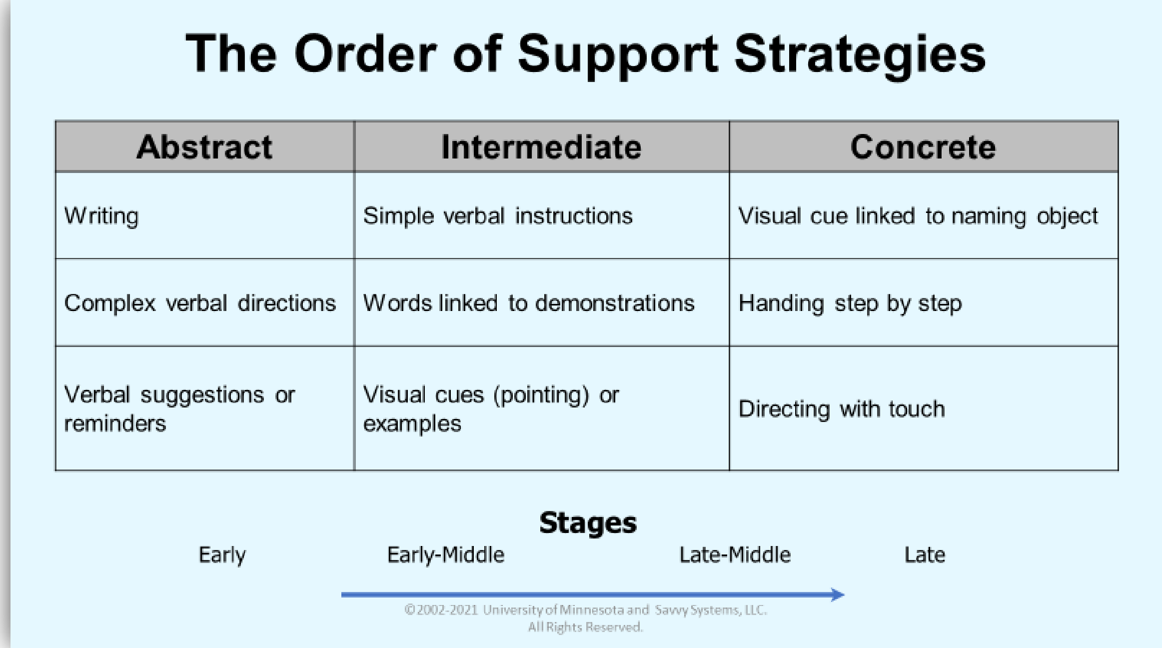
Try to discover the cause of the distress and attend to it. Take care of any discomfort. You can help your person re-focus on the task once you have restored calm.

Types of Support and Stages of Dementia illness

Knowing it is important to provide support to help a person living with a dementia illness is not very helpful by itself. What is helpful is to know how to provide support in the right way. Here it is useful to link stages with the choice of support strategies. The person's capacities decline as a disorder progresses. The Savvy Caregiver tries to match the method of Support with the person's Level of Thinking. Support can be thought of as proceeding from abstract to concrete strategies.

The Order of Support Strategies

The more abstract forms of communication are the ones we most use often in daily life. Most of our typical interaction involves either writing or complex speech. We would have every right to expect to be understood when using these with someone not affected by a dementia disease. But, the "message" is unlikely to get through when using these strategies with those already affected by a dementia illness. This attempt may result in confusion and frustration. So, **it is important to use increasingly concrete forms of support as a dementia illness progresses.**



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

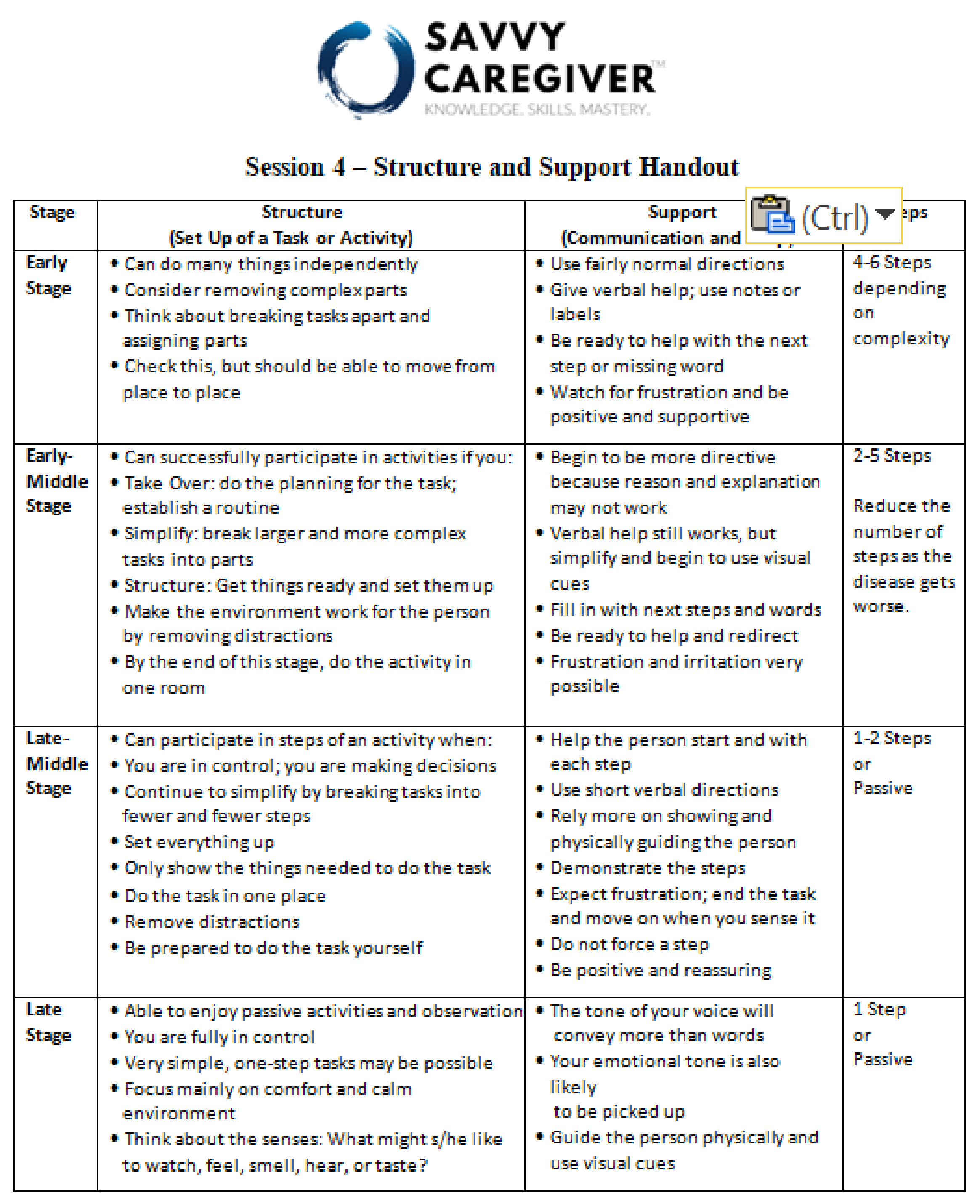
Stages

Early Early-Middle Late-Middle Late

Linking Set-up, Support, and Performance
The Savvy Caregiver pursues a goal of seeing the person involved and content in tasks and activities. Reaching that goal depends on a caregiving strategy that uses Support and Set-up techniques that fit the person's level of performance. The following table provides general guidelines for fitting support, set-up, and task size (steps) to the various stages.

Note that the columns in this table summarize material already covered in this section of the manual. Below, we will discuss relating the columns to each other.

- **Set-up**. This column shows the way in which tasks can be organized to take advantage of the abilities your person still has. It particularly stresses the kind of control you have to take in setting things up.
- **Support**. This column has to do with the way you direct and guide your person as well as with the most effective ways to convey information. The column also addresses issues of emotional sensitivity. Reassurance, a positive approach, and humor should be built into support at every level. An avoidance of pressure about time or quality should also be built into support.
- **Steps**. This column provides a rough guideline for the size or number of steps of tasks appropriate for the various levels.



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Session 4 – Structure and Support Handout

Stage	Structure (Set Up of a Task or Activity)	Support (Communication and	eps
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

The table helps to show how your person will need more and more support and set-up assistance as his/her disease goes on.

- The need for set-up increases as performance declines.

- The attention you need to pay to the person's emotional state also increases as performance declines.
- Communication strategies become more concrete and specific as performance declines. Physical directions with very simple words may work to help communicate intention in late stages.
- The size of the task has to shrink as performance declines.

Using Structure and Support in Everyday Activities of Life

Large parts of every day are spent doing things just to get through the day. We get up, wash up, and get dressed. Then there is breakfast – preparing it, eating it, and cleaning up. Same with lunch and dinner: prepare, eat, clean up. Throughout the day, we need to use the bathroom. For most of us, there are medications to be taken. At night, we get ready for bed. Each of these daily tasks is organized, set up, or **"structured"** to ensure success. **Savvy Caregivers must think through and provide clear structure to enable the person to manage.** The tables on the next two pages illustrate the use of **Structure and Support** principles in guiding a person in "washing up" and "getting dressed" activities.

Getting Washed Up in the Morning

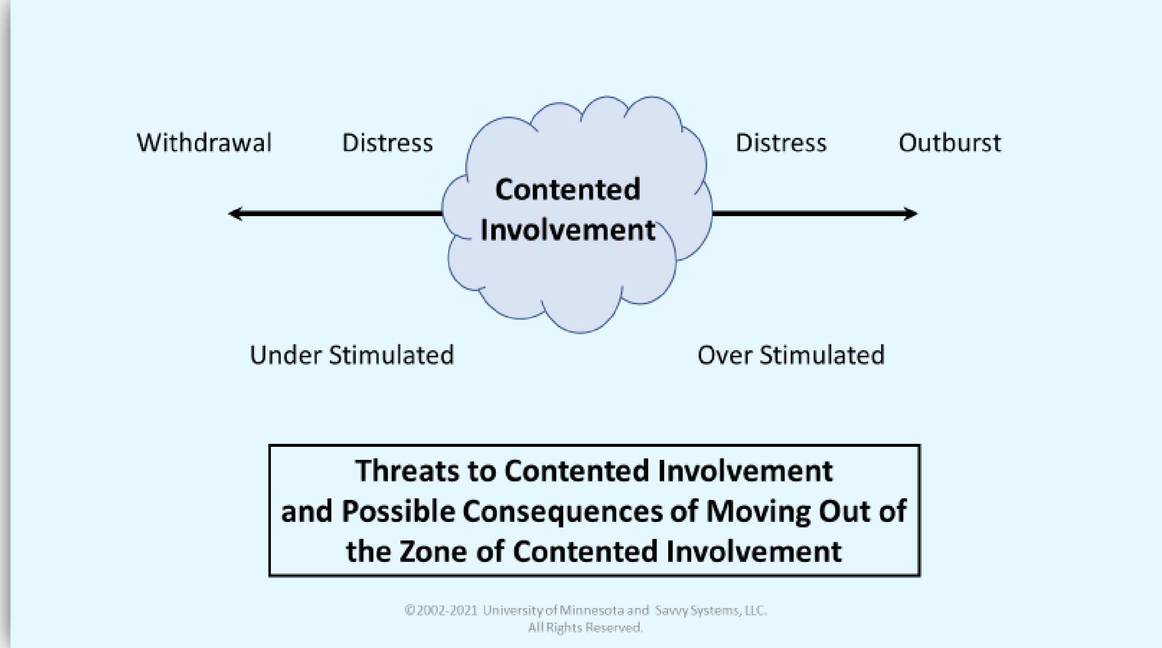
Stage	Early	Early-Middle		Late-Middle		Late
Activity/Role	Able to wash up, shower and groom by self.	Able to wash up, shower and groom by self, but may lose track of the task at times.	Can perform the physical activities involved in morning washing up, but may need support to stay on task.	Able to perform 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

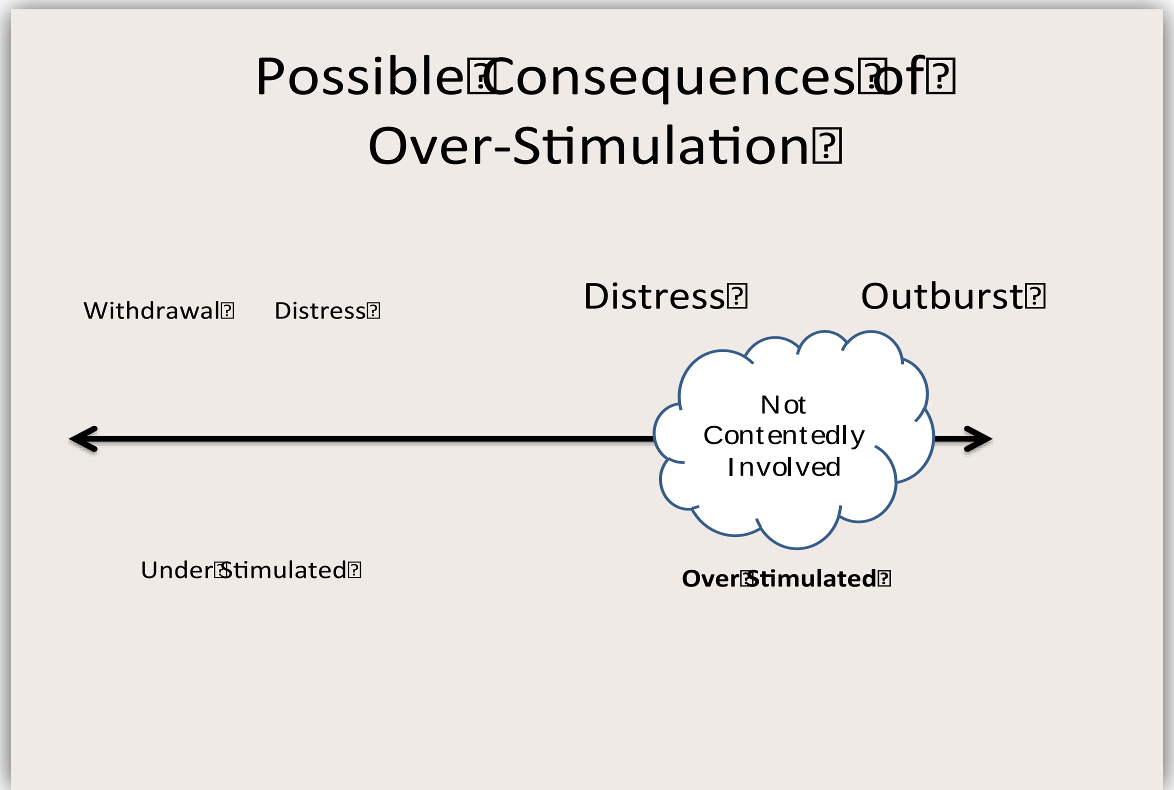
Stage	Early	Early-Middle		Late Middle		Late
Activity/Role	Able to dress by self; able to choose own clothes and put them on without error or assistance	Able to dress self; able to choose and put on clothes, but may make poor choices (e.g., want to always wear same thing or not dressing for the weather).	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

Staying in the Zone

You may recall the diagram at the beginning of the section on Contented Involvement that showed an ideal situation: the three anchors of Contented Involvement (Person, Structure, and Support) are working in balance to keep the person in a condition of being content and involved (or within the “cloud” in the image below). The person is engaged, and the uncomfortable behaviors (withdrawal and catastrophic reaction) are being avoided.



Now, let’s take a look at what happens when those anchors are not working together. Look at the next image. Here you can see that the target – Contented Involvement – is off center. The person is drifting away from the zone of Contented Involvement. S/he is over-stimulated and heading toward an eruption.



Possible Consequences of
Over-Stimulation

Withdrawal Distress

Distress Outburst

Not
Contentedly
Involved

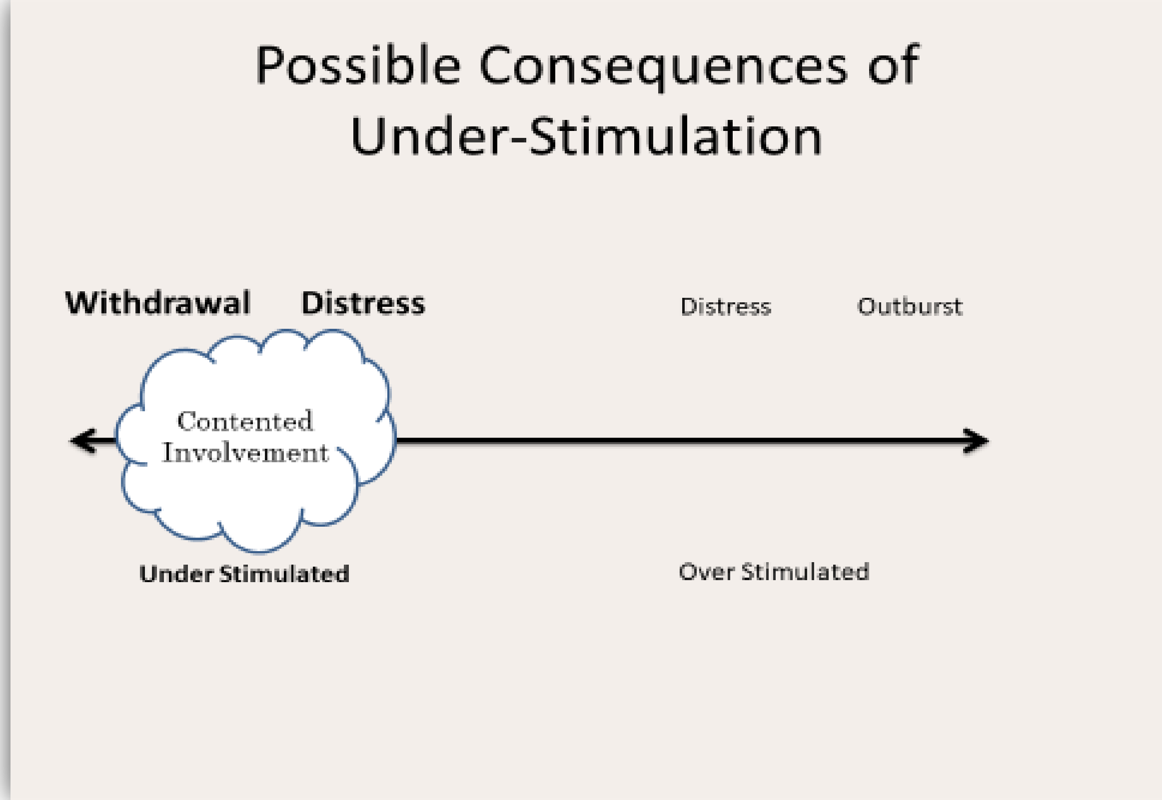
Under Stimulated

Over Stimulated

The task may be one the person should enjoy. It fits the person’s history of favorite pastimes. But in this case, the person designing the task misestimated the person’s ability, or the impact of others and the surroundings.

The person is less able to perform the task than the caregiver thought. The task was not structured enough or controlled in the best way.
There was too little support – or not the kind of support that fit the person. As a result, the person is becoming confused. The task is too much for him/her to handle. Too much is going on.

The next image shows a different problem. Here, the caregiver has chosen an activity that does not fit well with what the person likes to do. The support and set-up strategies are not well thought out, either.



Possible Consequences of Under-Stimulation

Too much structure and control are being exerted. The help and guidance are too much; the directions are more than the person needs. The task is being presented at a level that is lower than the person's ability. S/he may feel belittled, and/or is getting bored. Soon s/he will withdraw. There are some lessons in these images.

- The person's behavior will let you know how well balanced the anchors are. The task fits if the person is involved and happy. The way you helped the person begin and stay with it are just right. Take a step back if the person is becoming agitated or seems to be withdrawing. The checklist below will help keep your person in the Contented Involvement zone by assessing the balance of the anchors:
    - **Does the task fit the person?**
    - **Is it the right size?**
    - **Is the set-up right?**
    - **Am I using the proper support strategies?**
- Dementia illnesses make "fit" a moving target. You know that it is important to fit tasks to what the person likes and can do. You also know that you have to be flexible. You have to try various tasks and activities to see what captures your person's interest. You constantly have to tinker as a Savvy Caregiver. You are

always trying new plans.

- Change the size of the task. Add or drop a step.
- Change the amount of control you have. Take more or less control.
- Change the way you give help. Use more or fewer words. Monitor more or less. Demonstrate more or less.
- Tinker with the environment. Use a bigger space. Try reducing the stimuli in the area to limit distraction.

The main thing is trying.   Some things are more effective than others. Things that worked yesterday may not work today.

The Savvy Caregiver is willing and able to try new things and learn from them.

Two Additional Models of Behavior

In session two, we learned about A Simple Model of Behavior. In this session, we will learn about two additional frameworks that help explain your person's behavior.

1. The ABC Model of Behavior
2. The Progressively Lowered Stress Threshold Model

The ABC Model of Behavior

Professor Linda Teri from the University of Washington described the ABC (Antecedent-Behavior-Consequence) model of behavior and particularly how well it works in people living with a dementia condition.[*] The model can be applied in two ways: 1) It can be useful in encouraging a person to do something that might be engaging; or 2) it can help in situations in which a person is already doing something that seems uncomfortable or distressing. It can guide you in deciding to approach these situations, both now and in the future.

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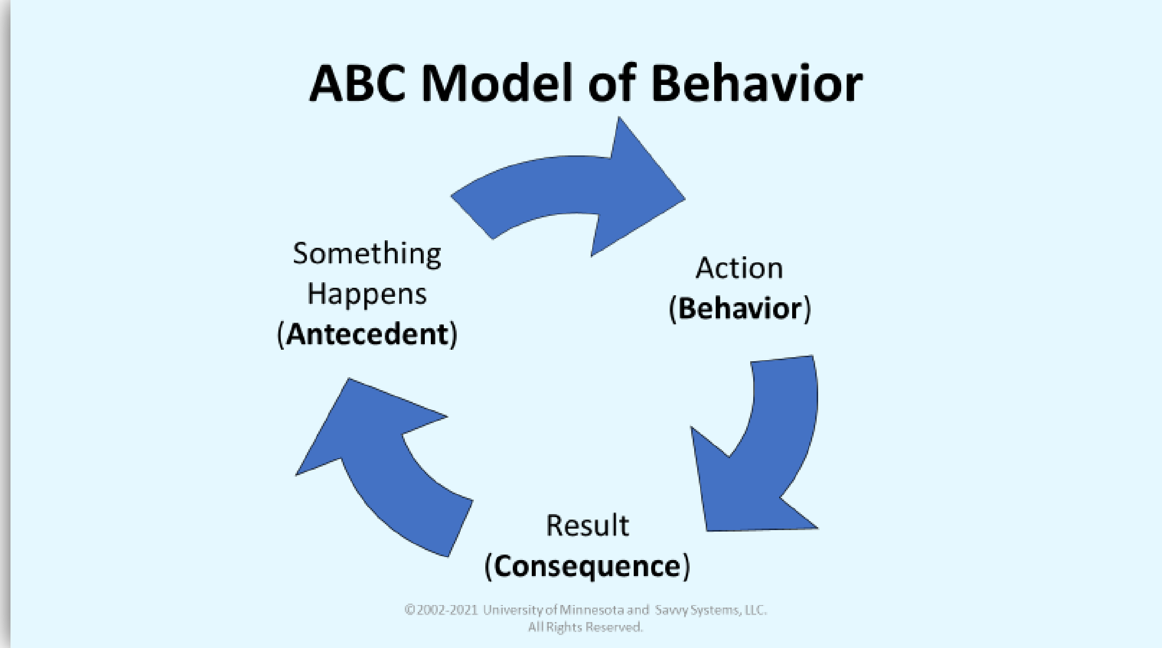
[*] Dr. Teri is part of the Alzheimer's Disease Research Center at the University of Washington. The Center's website at www.depts.washington.edu/adrcweb/ contains a great deal of helpful information about dementia illness and behavior.

We describe the ABC Model in great detail because it provides a way to think about and understand how you, as a caregiver, can both shape and respond to your person's behavior. The ABC Model may help you to see the various ways in which the "Other" element in the Simple Model – that is generally you, the caregiver – can act to help shape the person's behavior.

Something Happens (Antecedent). Remember that all behavior has meaning. Every action a person takes can be traced to some prior cause. When you see your person do something, you know that it was caused by something else.



ABC Model of Behavior

Something Happens (**Antecedent**)

Action (**Behavior**)

Result (**Consequence**)

- *This may be an internal cause.* Nothing someone else did and nothing in the environment caused the action. A person may be thinking, feeling, or sensing something and take action as a result. A person may feel something and similarly take action. A person may have a headache and so take pain medication. The action of treating the headache (the behavior) has its beginning in the pain felt inside (the antecedent).
- *There may be something in the environment* that causes the person to act. The world around often gives cues for behavior. It rains (antecedent), we put up an umbrella (behavior), and go for a pleasant walk (consequence). The stoplight turns red, we stop, and we remain safe. You lay out the clothes for the day, the person you are caring for gets dressed, and the two of you go out to breakfast.

- *Things that trigger behaviors* in the person *may not necessarily be clear to you* as a caregiver. They may be the result of how the person living with a dementia illness perceives or experiences them.

  - The person may be focused on something and not see you approaching with a cup of tea. The person may be startled or feel threatened. S/he might do something to defend against this perceived threat or yell at you to stay away.
  - The person may misunderstand what is going on around them or what others are doing. You may only be trying to help wash the person's face. S/he may think that you are trying to do harm and might try to knock the washcloth out of your hand.

- *The cause may be external.* Someone may say or do something that causes the person to respond. This may be a threat or an offer of a reward or treat. It may be a request for help. Someone creates a strong motive for the person to behave in a certain way. Some examples.

  - The cat scratches at the door. You let him out.
  - Your friend asks you to meet for coffee. You go.
  - The dog growls. You back away.

- *OR:* ***The cause might be you.*** You may want your person to do something (get dressed). You prompt the action. So, you serve as the antecedent.

  - In this case, it is your deliberate action that produces the behavior in the person.

Action (Behavior). In this model, behavior, an action, is simply what the person does. Keep in mind that an action is often more complex than it looks. It may actually involve a set of related actions rather than one simple action. Almost any action by your person can be thought of like this. Any activity of daily living involves a series of actions. Brushing teeth is a simple example that requires:

- Getting to the right spot
- Using tools by opening the toothpaste tube, squeezing out an appropriate amount of paste, and closing the tube
- Performing correctly by brushing all surfaces and rinsing

This is important. Each of these actions can be affected by what happens in the next part of the model, the Result.

Result (Consequence). Actions provide information. They provide information to the person about whether or not what is happening feels good. The actions and the person's reactions to them provide important caregiving information to you. You can read the result of people's actions in two ways. What you read should guide you in what to do next (the consequence):

- **Content or Pleased.** Does the person seem engaged? Interested? Calm? Relaxed or neutral? Focused? Satisfied?

  Your person is doing a thing that feels good if you answer "yes" to those questions. Your task is to figure out:

  - What might have helped the person to get to this state
  - How to help the person continue what he or she is doing
  - How to get the person to do it again and perhaps apply it to other situations

- **Discontent or Unhappy.** Does the person seem distressed, annoyed, angry, bothered, or agitated? Frightened or defensive? Is the person yelling, crying, hitting, withdrawing or moaning?

  Your person is doing something that does not feel good if you answer "yes" to the above questions. Your task is to figure out:

  - What might have led the person to do this action
  - How to help the person to stop what he or she is doing
  - How to keep the person from doing it again in this or other situations

How do you use this model? This model can be used to shape engaging behaviors and to deal with difficult behaviors. You have to "take a step back" (being clinical) from the situation a bit. You have to look carefully at what s/he is doing. You also have to recognize that "solving" a behavior problem involves a lot of trial and error.

The place to start when dealing with what seems to you to be an uncomfortable behavior is with the behavior itself. Here are some tips to help you first understand what you are seeing.

- **Give the problem time.** Behaviors that you think of as difficult or problematic usually occur more than once. They usually happen over and over before you think of them as a problem. Unless there is direct danger, don't treat a problem as a crisis that has to be solved right away. Give yourself time to think about it, come up with options, and try different ways to respond to it.

- **Study the behavior carefully.** We tend to name the problems that we see. The person is wandering, rummaging, acting out, etc. Names like these do not necessarily describe what the person is actually doing. They just identify a broad category of actions into which the person's behavior falls.

  Work at understanding a problem in detail before you try to "do something about it." Try to describe what is taking place in detail. Name each step in the action. Suppose the problem is labeled "striking out." Here are some questions to ask in arriving at a detailed understanding of the action.

  - Does the person go straight from being quiet and calm to hitting? Are there steps in between?
  - What happens before the hitting starts? Does the person:
    - Make any sounds or gestures?
    - Move toward or away from the person s/he hits?
    - Fidget, move arms or hands, get a different look on her/his face?
  - When do the person's actions begin?
    - Do they begin at all times during an activity or do they somehow relate to a certain point of an activity?
    - Do they occur in a certain place, or with a certain person?
  - What happens right after the striking out?
    - Is there just one blow or follow-up blows?
    - Does the person hit and then speak?
    - Does s/he move back or keep going forward toward the person whom s/he is trying to hit?

  Observingcarefully so you can answer questions like these will give you a better understanding of what is happening. It will also help you in describing the situation to someone else like your doctor.

- **Look for the source of the person's discomfort.** Try to find the meaning of the person's behavior, especially if it is troubling or unusual. Dementia conditions are not a cause of a behavior although some symptoms might stimulate behaviors. People with Alzheimer's do sometimes wander. This is typically because they are confused. They may be looking for something that they cannot name. They may feel restless and do not have any better way to work that out. Some persons living with Lewy Body Dementia regularly experience vivid hallucinations. These hallucinations, which are often quite detailed, can produce frightened behaviors or they can be pleasant experiences and the person might behave in an engaged and pleased manner. Frontotemporal Dementia, particularly the behavioral variant, affects the brain in ways that enable impulsive behaviors.

Studying a person's behavior in detail may offer some clues about what triggers it and what the behavior means to the person. It may suggest ideas that you can pursue in trying to find ways to stop or decrease the behavior.

You might be able to do something that will trigger a different and more contented behavior. You can help him or her find something s/he is looking for. You can suggest an activity that will be engaging if s/he seems restless.

- What the person does after the first blow may suggest whether s/he is acting defensively or aggressively if they strike out by hitting.
- Striking and moving away more likely means that s/he is reacting to a perceived threat than acting in anger. S/he may continue to hit and might move forward to drive the person away if angry.

Look for what happened just before the hitting if you think the person is feeling threatened. Was there something that might have been happening in the environment? He or she might have been startled if the lighting was poor and s/he did not see you coming. Something else may have startled the person like something on a television program or a loud noise in the street. It may have been the way you did something. Maybe too many things were happening at once. Perhaps you were talking, moving quickly, and coming very close all at once. Think back on the scene. Try to remove anything you think may have caused the discomfort from the scene. Then see if the behavior happens again. Try turning off the TV, turning up the lights, or approaching more slowly. See if the person is as defensive as the last time.

Studying the behavior may also help you understand the signs to look for that tell you a problem behavior is likely to occur.

A common cause of disturbing or unusual behavior is a person's discomfort.

- This might be emotional discomfort. The person feels overwhelmed or overtaxed by a task. It could be that there is too much happening in the environment. S/he might feel lost about what is happening or what to do. [The next behavior model, the Progressively Lowered Stress Threshold model, covers this possibility nicely.]

  - The discomfort may also have a physical cause. The person may be in real pain and unable to tell anyone about it. S/he may not even realize that what s/he is feeling is pain. The only thing that is registering is that something is going on that does not feel good.
  - The discomfort might be from fear. Something may feel threatening to the person.
  - Other sources of discomfort could be fatigue, hunger, the need to use the toilet, a fever or infection, constipation, or some factor in the environment.

  Any of these things could produce agitation in the person. It is important to find and address the source of the discomfort in order to prevent or calm agitation.

- **Look for patterns in the behavior.** Look for patterns if your person has behaviors that are difficult or troubling.
  - Do they occur only at certain times of the day, or only during certain tasks or activities?
  - Do they seem to happen more when you are alone, or when other people are nearby?
  - Is there anything (or a combination of things) that seems to set the person off?
  - Are there ways you react to the behavior that seem to make it keep going or get worse?
  - Are there strategies you use that seem to calm the person?
- **Have a well-thought-out plan for how you will try to alter a behavior.** You will likely come to four conclusions after you observe the behavior over a period of time:
  - *Cause*. It is likely that you will be able to offer one or more possible reasons why the behavior starts. This is what triggers it.
  - *Meaning*. Watching closely may also give you ideas about what the behavior means. This is why the person is doing it.

- *Pattern*. You may find patterns in the behavior. This is when it occurs and what happens just before it occurs.
- *Effective response***.** Study may enable you to pinpoint moments during the behavior when it is more possible to stop it than at other times.

These conclusions allow you to build a plan to deal with the problem. The plan may be focused on one or combination of cause, meaning, or pattern. You might begin to do the following:

- *Develop caregiving strategies to prevent troubling behaviors***.** You might be able to prevent your person from becoming agitated or combative if you can predict the cause of such behaviors. Try to avoid those situations that you know or suspect could cause troubling behavior. Intimate activities like washing up can be a source of distress. Be prepared to try other things if the person becomes upset and shouts when you try to help him/her wash up first thing in the morning. Try waiting until after breakfast. Try other methods for helping him/her to wash.

  Your approach may be the beginning point for the action. Work on changing the way you approach the person if that is the case. This is especially important during more intimate tasks like activities of daily living (ADLs). ADLs include helping the person with bathing, dressing, getting to the toilet, or eating.
- *Develop sensitivity to the beginning signs of a behavior.* You may be able to identify one or more key actions that are signals that the problem behavior is about to occur. Some of these signs may be as small as the changing of an expression. You may be able to back off or redirect the person before the behavior takes place as you learn to recognize these signs and signals.
- *Develop strategies to help control troubling behaviors*. How you “behave” when faced with a troubling behavior may have a big impact on whether the behavior continues or stops. You will need to know what the first signs of discomfort look like in your person. It will be important to know when and how to:
  - **Back off.** It is almost always better to stop something rather than to risk letting it grow into a source of real discomfort and some kind of outburst. Keep in mind that the task or activity at hand is not the point. It is often the case that a particular activity does not have to be done at that particular

    time. Stop the activity if it seems to be leading away from a time of contented involvement and moving more toward a moment of upset or discomfort.

    - **Divert/distract/redirect.** It is important to restore calm and a feeling of safety to the person. You will learn what works to divert or distract the person from a situation that is turning sour over time. Build a toolkit of diversions that work. Some ideas about distractions include bringing up a particular topic the person likes to talk or hear about, giving a drink or snack the person might enjoy, switching to another activity the person likes, or moving to a place the person likes to be.

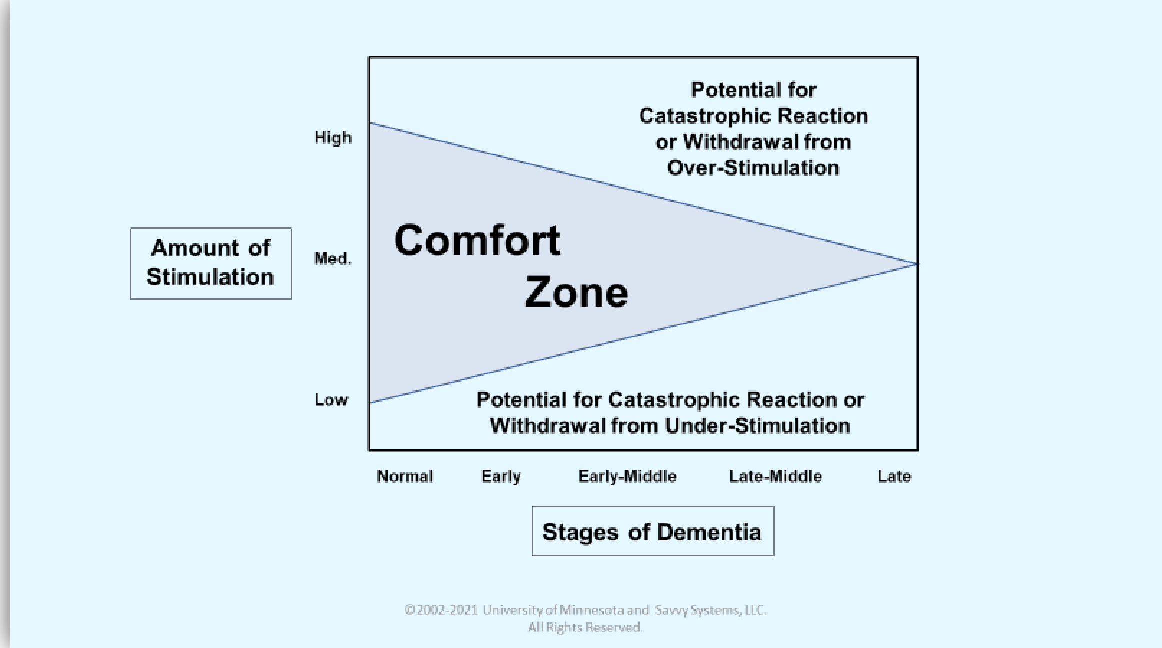
- **Assume a detective's outlook.** Working out a solution to a troubling behavior is like solving a mystery. The ideas that you come up with have to be given a fair test and their results evaluated. Congratulations are in order if the idea and the proposed solution work the first time out. Do not be discouraged if they do not work out the first time. **Patience, tolerance, and humor are some of your best tools.**

- **Be Savvy.** You will not succeed all the time. You will succeed even less often on your first try. Managing behavior is hard. Solutions that do not work provide important information. Look again at the information you have including the new information about what did not work. **It is important that you remember that the person is not doing something to intentionally hurt or upset you.**

The Progressively Lowered Stress Threshold Model

The Progressively Lowered Stress Model may help you to better appreciate the role that "Setting" plays in the Simple Model of Behavior.

Two extreme kinds of behavior – outbursts and withdrawals – can be especially troubling for caregivers, and they do not appear to be comfortable for persons living with a dementia illness. Two nursing professors at the University of Iowa have been successfully dealing with agitation in people living with a dementia condition using an idea many caregivers find extremely helpful. They refer to their idea as the Progressively Lowered Stress Threshold™. The core of this idea is that one can think about agitation in dementia illness as a reaction that occurs when the person's tolerance for stress or stimulation has been exceeded. Agitation can also occur when a person's attention is not sufficiently engaged. The following diagram helps illustrate how this concept works.



People who are not living with dementia disorders and who are living typically in the world are used to handling many stresses and activities at the same time. People often speak of themselves as having a number of balls in the air. They also seldom become agitated due to boredom because they have the capacity to find things to do that are engaging. The other thing about people who are not affected with dementia disorders is that they typically have an idea about their limits. They know when they are getting close to these limits. They usually have techniques they use to back away from overload when things get to be too much. People usually also have ways of expressing that they are past their limit and of finding ways of reducing stress.

There are a couple of things to keep in mind about the idea of a Progressively Lowered Stress Threshold. As a dementia condition progresses:

- The comfort zone, or tolerance, shrinks. The person is more easily overwhelmed by things going on around and more readily disturbed by not having enough to do.
- The ability to recognize and express that he or she is close to a limit fade.

- Techniques that used to help him/her to back away from stress are forgotten and unused.
- There is often less warning that the person is nearing his or her threshold. The reactions are sometimes sudden and unforeseen.
- The person has fewer ways to express the discomfort he or she feels when the threshold is crossed. An explosion or catastrophic reaction often occurs.

The term “catastrophic reaction” refers to situations in which a person reacts in an agitated or explosive manner. Such reactions are triggered by the demands of a situation exceeding the person’s capacity to meet them. There is also a clear sense that these reactions come on quickly and unexpectedly. The strength of the response is out of proportion to whatever was happening before it. There is also the sense that bringing emotions back to a normal level is going to be hard.

It will fall to you as the caregiver to try to help your person regain calm. Below are some things to try. You will notice they follow the pattern of suggested ways to deal with behavior problems in general.

- **Look for a physical cause.** A person living with Alzheimer’s or a similar illness may not be able to tell you s/he has pain or discomfort. Look carefully at the person. Is there something different about his/her coloring? Is s/he pale, ashen, red, or darker? Is s/he sweating or shivering? Is there anything different about his/her breathing? Is s/he panting? I s the breathing labored? Does s/he just look “different”? Is there any change in sleep or eating habits like being very sleepy or pickier at meals? Is there any change in bathroom habits such as more or less frequent urination; constipation; or diarrhea? The person may not know or be able to tell you that something is physically wrong. Call your doctor and describe what you are seeing if you see any of these or just feel something is wrong.
- **Look for a cause in the environment.** Did something happen to trigger the agitation? Is there some beginning point for the behavior? Is too much going on? Try changing or removing what you can identify is the source. See what happens.
- **Is anything causing the person to repeat the behavior?** Can you see anything or anyone that is reinforcing this behavior? Try to change it.
- **Can you divert the person?** Can you engage the person in some activity that will get him/her occupied? Getting the person involved in doing something may help change the behavior and lead to calm.

Managing Daily Care and Complicated Behaviors

Earlier, this manual discussed behavior. It emphasized that, as the illness progresses, you have to assume control of behavior. Or, if it feels better to put it this way: you have to accept greater responsibility for guiding behavior. Either way you put it, what happens during each day depends increasingly on you. This section discusses how to accomplish that part of your caregiving role.

You will spend a lot of time doing two things as a caregiver:

- Getting the person to do things
- Getting the person to stop doing things

A goal of Savvy Caregiving involves trying to get the person to do something he or she enjoys. Another way of thinking about this is that Savvy Caregiving entails helping the person enjoy doing things. Most of the time, these things are ordinary, day-to-day things.

Contented Involvement occurs whenever people are focused, doing something they like or are (or used to be) good at, using their abilities, and feeling like they are doing something well. Plus, people at all stages still like and need to feel useful. All of the many daily things like doing dishes, getting dressed, folding the laundry, and helping with housework can be the source of enjoyment.

The manual does not provide a list of possible activities. That list already exists:

- In the person – and what s/he always liked to do
- In everyday life – and what has to get done to get through the day
- In you – and what you like to do and like to share with the person

So, make up your own list. Keep revising it as you go.

The section on the Anchors of Contented Involvement provided tips and guidelines and a framework for how to help your person get involved at different stages of the illness. That section was meant to help you think about

- How much or what part of any activity to try with the person
- How much and what kind of control to exert
- How much and what kind of help to give
- What to watch out for that tells you when to back off or try something else

The Anchors framework serves as a guide for setting up, starting, and keeping individuals contentedly involved in tasks and activities. Much of the time, that strategy will yield good results. But, you are guiding a person who is living with an illness that can produce behaviors that don't seem contented and that are far from pleasantly involved.

How the person's illness progresses can expose the person to acting in ways that you may experience as difficult, unpleasant, and even dangerous. The information in this section is intended to help you identify and understand these kinds of behaviors and respond to them in ways that restore calm to the situation. Once calm is restored, you can again try to engage the person in the task or activity you have designed – or choose another activity.

Important Savvy Caregiving Strategies You Can Use Anytime

Before discussing specific behavioral problems, here are four suggestions that apply to Savvy Caregiving at all stages.

- **Be positive**. Frustration is always just around the corner for you and your person. It changes the mood of a task or activity once it hits. It takes the fun out of things. It can set both caregiver and care receiver on edge.
    - People living with a dementia condition may or may not recognize they are having difficulty doing something. Savvy Caregivers see in advance that a task will be hard or take longer. Perhaps they break the task into parts and focus on just one part. Or they move from one part to the next, depending on how things go. These caregivers adjust their own expectations about performance. This can help prevent frustration in the caregiver and perhaps in the person.
    - Savvy Caregivers can see the success the person is having in the task when their expectations are realistic. This success can and should be recognized and encouraged. Praise and a pat on the back reassure the person and raise the person's mood.
    - Successes are good for caregivers, too. They provide opportunities to see that there is still a connection with the person. They provide a chance for the caregiver to see s/he is doing well in the caregiving role.
- **Avoid pressure**. Everything will take longer. Your person will likely feel under pressure if you feel under pressure to get a task done. Pressure can make the person anxious, defensive, or irritated. It can bring on any number of other

emotional responses. None of these emotions promotes contented involvement. It is also not good for your wellbeing.

Plan to do and accomplish less. A basic caregiving strategy involves simplification. Simplify the day. Simplify life. Put less pressure on yourself and the person by removing things from the schedule.

- **Use humor**. There is nothing funny about dementia symptoms or conditions, but humor is not lost. People living with a dementia illness can still laugh. And, so can you. Laughter still has a positive effect. Sharing a laugh is something a caregiver can do with the person late in the disease. Humor can provide a meaningful point of connection when a person is living with a dementia illness.

  These illnesses cause people to make mistakes. Sometimes mistakes can be funny. Do not be afraid to laugh with the person at these mistakes. This may help relieve any embarrassment the person might feel. It also is a way to let the person know you are right there. You are sharing and connecting with him/her.

- **Adjust expectations**. Relax your standards with regard to performance. It is the doing and being involved that is key to Contented Involvement. Task outcome is not that important. The quality of the work is not that important. **Whether the person was involved and happy is what matters.**

  Do not gauge performance by what the person used to be able to do. This can be difficult when people are doing something they used to do very well. It can be hard and sad to watch them struggle through an activity they used to be good at. It can be frustrating to see how poorly they now perform. At these times, it is helpful to keep the care goal in mind. It is the doing itself, not the product, that is important when aiming for Contented Involvement.

Common and Uncommon Behavioral Issues

People living with a dementia illness might do things that others find difficult to understand, disturbing, or uncomfortable. You can find ways to guide these behaviors that are also considerate, understanding, and effective. In this part of the manual, we discuss a number of issues you might face, and provide some general guidelines and strategies for dealing with them.

Whether or not a behavior is problematic is sometimes a matter of judgment in dementia caregiving. A behavior considered difficult or problematic by one caregiver might be thought unimportant by another. Sometimes there is little question about whether you need to do something about it. You have to act or guide your person's behavior if they are doing something that could cause harm to self or others.

There are other times when what the person is doing does not create a condition of immediate or even eventual harm, but those behaviors may still "get to you." Caregivers have reported many behaviors that got to them including their person:

- Sleeping many more hours per day than before the disease showed itself
- Spending 1½ to 2 hours a day "dressing and primping"
- Just sitting and staring for hours
- Re-reading a newspaper multiple times in the day
- Going to their workshop or hobby table and just sitting there
- Wandering "aimlessly" or pacing for hours
- Talking to people in the room who are not there

Ccan recognize over time that what troubled them about these behaviors was not just that the person seemed bothered or upset, but that the caregivers were bothered by the clear reality of their person's illness.

This is the message to the Savvy Caregiver: **Acknowledge the behavior troubling you and then try to figure out why you are troubled by it.** Work at whatever level you can. Work on yourself if the problem is your own discomfort. See if you can tolerate the behavior by allowing it to continue and working through your own discomfort.

So, what about behaviors you observe in your person that *should* be guided by you? Begin by assessing the behavior. Take the Savvy approach and step back. Remember the Savvy mantra: **Don't just do something. Stand there**. Using all of your knowledge and skill, and the Savvy Process, to come up with what seems to you to be a reasonable plan. Then, try out your plan and see what happens. The plan may work, or you may have to reassess and re-plan. This is the essence of Savvy Caregiving.

We approach most of the issues presented on the following pages as being the result of confusion. They are behavioral responses to the discomfort experienced by being hit by more stimuli than the person can handle. You may find that it is helpful to think about these responses through the lens of one of the models of behavior we discussed earlier in the manual.

There are three basic choices if you sense that the behavior results from a form of discomfort in or for your person:

- Wait to see if the behavior will stop by itself. Perhaps your person will be diverted from whatever it was that was causing the behavior and it will just go away.
- Wait a reasonable time and then use some of the ideas in this program manual to step in.
- Act immediately if you feel you must – but always act with a plan in mind.

In the page describing each behavior, we also provide suggestions that you might find helpful for observing the issues and for trying to change the behaviors.

Managing Daily Care and Complicated Behaviors

Behavior: Repetitive Questioning

It is not uncommon for people affected with dementia illnesses to ask the same question over and over. They might ask what time it is, when they are going home, or when they will see their mother. They might ask this question every five or ten minutes or every time they see you.

It is worthwhile to determine whether there is any pattern to it. Think about when and where it occurs and under what circumstances. You will be that much more prepared for the questioning to happen if you can figure out a pattern. If there *is* a pattern, be alert to changes in it. If the person asks you a different kind of question, it may mean there is a different source of the behavior, and you can start to figure that out and respond appropriately.

Assess and Plan

Cause? Where are these questions coming from?

- Repetitive questioning is often *a sign of confusion.* It may be that they do not know where they are.
- The questioning may be a sign that the person *is distressed, feels unsafe, insecure, or feels threatened* by something. The threat could possibly just be the confusion itself.
- The person may just *want to interact with you* but does not remember how to do so, except to ask the question.
- S/he may be seeking help for *something bothersome or painful*.

Consider the kind of thinking capacity your person has. *Will any kind of explanation be helpful? Can you reason with them or rely on his/her ability to think abstractly about time to get him/her to stop questioning? Would it help to try to discuss the question with him/her? Is the person's thinking at a level such that it is more effective to be directive? Might diversion work?*

Things You Can Do

What can you do to deal with this behavior?
- Get a snack or ask about favorite foods if the person is asking when the next meal is.
- Looking at pictures of relatives would be engaging if the person were asking about family.
- It might be useful to put a large-faced clock on the wall if the person is asking the time. This will likely not stop the questioning in this case, but it *will* give you an easy answer (like "Let's go check the clock") to use over and over.
- You might be able to use the topic of the question to try to get your person to talk about or reflect on it.

The most practical thing you can do is to accept you might have to live with the behavior for a while. You have to try to separate yourself from it somehow**. It is useful to have one or two answers ready for each time your person asks the repeated questions.** You might think of this as playing a role in a play. This scene will repeat itself many times during the day. You have a part in it, so develop your "lines." Rehearse them and learn to deliver them well. Whenever the scene happens, slip into the role and deliver your lines. All that is called for is a consistent "performance." You are not being mean or disrespectful in doing this. You are responding to your person's concern. You know that your person needs a reassuring answer to the constant question. This is a satisfying answer for them, and it is good for you. It takes you out of a situation that may feel oppressive.

Managing Daily Care and Complicated Behaviors

Behavior: Shadowing

Caregivers often report that their person will not leave them alone. They follow them from room to room. They always keep the caregiver in sight. This can be unnerving. It can be a problem for getting work done when it comes to the caregiver's other responsibilities. It can also make the caregiver feel that it is impossible to find any time or space for him/herself.

Assess and Plan

Cause? Shadowing likely has to do with the person's need for security. The confusion produced by dementia conditions is likely the problem. The person is looking for something to hold onto in the storm of stimuli swirling around. What better anchor point than someone who is kind and attentive? So, shadowing seems a way the person keeps him/herself calm and secure.

Be aware that, as the disease progresses, people may pass through periods where the world ***feels*** more confusing. This might mean the person feels a greater need for security. So, you may observe shadowing at different times, like with a decline in function.

Things You Can Do

- Set up a routine throughout the day and more or less stick to it over time. This may help to produce an atmosphere of calm, security, and familiarity. And, it may enable the person to focus on a task or activity and reduce shadowing behavior.

You can also try the slow introduction of other ways to provide security:

- Involve your person more in doing things. Slowly introduce him or her to other tasks.
- Help your person help you. Encourage him or her to shadow you in purposeful activities. Have him or her do things with you like going with you to get things from the laundry or the kitchen and then carrying some of them back.
- Have your person do tasks on his or her own. Ask him or her to do something specific by him/herself. Situate him or her somewhere and give them a task. Be nearby and in sight. For example, ask the person to fold towels or a similar task while you do something else in the room.
- Find an object or activity that provides security. This is a matter of developing and adding to a "bag of tricks." You will discover what calms your person over time. For some it will be an "alone activity" like looking through a book or album, reading the paper, gazing out the window, rummaging through a drawer, or having a treat. For others, it might be a particular place or an activity with a particular group. Some people living with a dementia illness identify "comfort objects" in the later stages of the illness. They may want to keep near them things like blankets, shawls, stuffed animals, or dolls. Use any comfort object your person has. Help the person find security wherever s/he can. Do not take this away from the person. Do not let yourself be embarrassed by his/her having such an object.

Behavior: Pacing and Wandering

Many people living with Alzheimer's or a similar illness walk a lot. It is important to distinguish good walking from disturbed or troubled walking.

Assess and Plan

Cause? It appears that pacing provides a way to wear off excess energy for some people living with a dementia illness. Walking is a good outlet and should be encouraged for these individuals.

Others who walk or pace a lot seem to be searching for something. There is often a troubled quality about their walking. They can appear as if they are lost, looking for something, or upset.

Things You Can Do

Here are some ideas about what to do about pacing:

- Provide walking pathways. It sometimes helps if you can arrange a circular walkway for your person. You could consider letting your person walk alone in a fenced in backyard. Use caution in allowing the person to walk outside alone. You always have to keep in mind the chance of the person's getting lost.
- Be supportive. Reinforce the walking if your person seems to benefit. Taking walks with the person can be as good for you as for him or her.
- Try to identify any cause of "troubled" wandering. Be aware that this or any seemingly agitated behavior may represent an effort at communication. Consider whether the person is in some physical discomfort, perhaps because of the need to use the toilet, or possibly some physical pain.
- If you cannot pinpoint a cause for the pacing that might be addressed, try to divert your person to a task or activity.
- Monitor your person. There can often be a frantic and focused quality to the activity. The person could become agitated if this focus is suddenly or unexpectedly broken.
- Be sure your person has good shoes. Good walking shoes will assure balance and support and may help the person avoid falls or muscle aches.
- Pay attention to your person's feet. Check to see there are no blisters or ingrown toenails when you help the person with dressing or bathing. This is especially important with people living with diabetes.

Another kind of wandering can be a problem. For some people, the boundaries between "mine" and "yours" fall away as dementia illnesses progress. The person may wander into what you consider your space. This harmless behavior can cause disruption. You may or may not find it upsetting to have your person looking through your things. In some cases, things go missing. It is good to be prepared for it, even if you think you would not be bothered by it. Make sure to secure any items you need, like keys and wallet.

The only reasonable response to this kind of wandering is vigilance. Keep an eye out for where your person goes if it is important to you to keep some private space and places. Quickly cue him/her away from areas you would like to keep off limits. It is important not to introduce any kind of judgment into this process. This may make the person feel bad without really understanding why. If you notice that they like to rummage through your drawers, create one or more "safe" rummaging areas in their own room.

Managing Daily Care and Complicated Behaviors

Behavior: Uninhibited Actions and Language

One of the consequences of dementia illnesses on individuals' thinking abilities is that they forget manners and "proper" social behaviors learned over a lifetime. The person also loses the ability to see the effect of actions on other people. The basic result of this is that sometimes people living with dementia illnesses do not monitor or filter their actions and words. They can become impulsive and uninhibited. This loosening of social control can take any number of forms. The person may:

- Grab at food and eat with his/her hands.
- Use derogatory or vulgar language they would not have used previously.
- Enter intrusively into other people's personal space.
- Make insulting or demeaning comments.
- Become immodest. This may mean exposing themselves, making propositioning gestures or requests, or urinating in public.

Assess and Plan

Cause? Look for triggers for such behaviors. Sometimes it is possible to identify beginning points for them, or to remove or change them. Remove the wastepaper bin if your person urinates in it.

Other times it is not possible to remove the trigger. Sometimes people make comments about someone in a group gathering who is of a different race or culture. You cannot remove the person. It might be possible to avoid contact by sitting elsewhere. Also, you need to be prepared to explain the behavior and apologize. When possible, consider alerting people to the situation to engage their patience and understanding.

Things You Can Do

- Look for the initial signs of the behavior and intervene. You can act to divert the behavior if you develop a sense for when it is about to begin.

- Watch for the person who urinates in public to begin to become slightly agitated by the discomfort produced by the urge to urinate, or to begin fumbling with his/her clothes. Gently guide him/her to a bathroom and cue to use the toilet.

- Attempt to introduce a change in behavior. Try to find a point where a change might be introduced. For example, try seeing if different utensils like a large-handled spoon and high-sided plate might introduce enough sense of control that the person does not feel the need to grab handfuls of food when hungry. See if serving just one food at a time might help, or consider serving finger foods.

Managing Daily Care and Complicated Behaviors

Behavior: **Sundowning**

The late afternoon and early evening can be difficult times for some people living with a dementia illness. They become restless and agitated. They pace, become demanding, and are clearly uncomfortable.

Assess and Plan

Cause? This behavior may occur for any number of reasons.

Hunger, fatigue, changes in the body's rhythms, and change in the quality of light have all been suggested. It may be that the accumulation of fatigue in the course of the day results in a shrinking of the comfort zone described in the PLST model.

These things alone or in combination may contribute to sundowning.

Things You Can Do

Below are suggestions for things to try if this becomes a problem:

- **Lighting**. Turn on lights in the living space even though it still seems early in the day.
- **Snacks.** It may be that cookies and milk, or some other snack, will both ease hunger pangs and provide needed energy.
- **Rest.** A post-lunch nap may be useful in giving your person more energy and helping him/her to get through the afternoon.
- **Activity.** Is there some favorite task or activity your person can get involved in to feel contented at this time of day? It may be that an activity with others would "energize" your person. It may be that being in a social setting requires too much energy right now. Tailor the activity to your person's mood and to the occasion.

Make allowances. Try scaling things down if this is really a low point of the day. You may need to change the way you approach your person or the types of activities you plan. You might plan any outside activities involving other people for the morning. Afternoons may involve taking a quiet walk to help your person relax.

Managing Daily Care and Complicated Behaviors

Behavior: Nighttime Wakefulness

People living with dementia may have periods of being awake at night.

Assess and Plan

Cause? This may be the result of waking to use the bathroom and not understanding that it is still time to be asleep.

Sometimes the sleep cycle itself may be disturbed by the disorder. This may mean that the person can sleep for only short periods at a time.

Things You Can Do

Here are some suggestions for working with nighttime wakefulness:

- **Take preventive measures.** Experts in insomnia provide suggestions for promoting better sleep. Avoiding long daytime naps, limiting caffeine intake, and reducing fluid intake from the afternoon on are key suggestions. Be alert, though, to concerns about dehydration if fluids are restricted.

- **Guide your person back to bed.** This cueing may be enough to reinitiate sleep. This guiding may be more effective the sooner it is done. Your person may not get into a "being awake" mode and simply get back to sleep.

- **Stay with your person for a while.** It may be that some people will be more confused during these periods of wakefulness and will need more than cueing. They may benefit from the comfort and security of your presence. This may be enough to get them back to sleep.

- **Try some form of a comfort snack** (like cookies and milk). if your person does not seem ready to go back to bed. He/she might have this snack alone, or the two of you can sit quietly together. Either way, try to keep your person calm in an effort to foster sleep.

- **Provide a quiet activity.** Try to get your person to do something quiet on his/her own. Rely on what you know about your person to make this choice. Tailor it to what you know about the wakefulness pattern. Try to get him/her involved in something that might keep him/her focused for the time you know they need to wind back down. You might ask your person to help you with some of the evening chores if it takes them longer to go to sleep or they seem to have a lot of energy.

- **Talk with your doctor or nurse practitioner.** Careful management of drugs can help your person to sleep without being drowsy the next day, but some medications can also increase confusion and falls risk.

Managing Daily Care and Complicated Behaviors

Behavior: Tearfulness

People living with Alzheimer's or a similar illness may become tearful at times. It can seem like the emotional 'filters' that people rely on are less present.

Assess and Plan

Cause? The effect on emotions is one of the mysterious areas of the disease.

- There is often not an obvious reason why.
- They may not be able to tell you what's wrong or why they are sad.
- On the other hand, the person may say something that provides a clue about the cause.

Knowing your person will be crucial just like it is with every other behavioral issue with this disease. This knowledge will help you select some task or activity that is most likely to capture and hold your person's attention.

Things You Can Do

- Diversion and activity are the chief ways to deal with this. A period of one-on-one time with your person may be useful in breaking the cycle of tearfulness.
- You can also get your person to become involved in some other activity. You may be able to bring your person out of the loss-of-control situation that is tearfulness and help him/her to regain focus.
- The easiest and most effective way might be to try to draw your person's focus to yourself. Physical comfort like hugs may help. Never underestimate the power of reassurance. Once you make a connection, slowly try to help the person put his/her focus on something s/he enjoys doing.

Managing Daily Care and Complicated Behaviors

Behavior: Suspicion and Accusation

These behaviors take many forms in people living with dementia disorders.

- People may believe others have taken or are looking to take something from them.
- They may believe people are watching them.
- If things go missing, they may accuse people of stealing them.
- A person may accuse a spouse of infidelity or a child of lying.
- The person living with the disease may not recognize his/her spouse or child. This leads to thinking of the person as a stranger, and that can contribute to suspiciousness.

Assess and Plan

Cause? The causes of this behavior are a bit clearer than some of the others we have covered. Losses in memory and reason contribute to confusion about things and people. The feelings about those things and people are intact at some level.

The person "remembers" something about an object at some level. The object may come to mind. He/she may try to make sense of a confusing situation (cannot find his/her wallet) by trying to fill in the blanks. The person cannot remember where s/he left it. You are there. Your person is not at all clear who you are. These things together lead your person to suspect that you took whatever it is that s/he is trying to find (the wallet).

Things You Can Do

Below are a few suggestions for handling these complications:

- Do not dispute or argue with your person. Take accusations as requests for help. Immediately offer to help find something if your person accuses you of taking it.

- Do not challenge your person's assertion if s/he says relatives or others are out to get her/him. Make the area feel safe.

- Work with yourself. It is you who can be most hurt by these behaviors. It is painful when a spouse of 50 years does not know who his/her spouse is. Work at understanding the disease and its effects. Keep in mind that it is the disease causing this problem. This is not a choice by your person. Try to develop a set of responses for such situations. Suggest that you look through a wedding album together. Try to get her/him to talk about his/her feelings about the pictures in the album.

Behavior: Agitation and Yelling

Persons living with a dementia illness get upset just like people who are not affected with such conditions. You will know the signs. The person seems on edge. S/he is giving off signals that something is wrong. S/he may be physically or verbally active, like being agitated and/or yelling.

The problem is that your person usually cannot give you a clear explanation of what is wrong.

Assess and Plan

Cause? This behavior is not likely to occur until the person is well advanced in the disease process.

Calling for help or just calling out wordlessly and repeatedly is one of the most difficult behaviors. It will take a great deal of one-on-one time with your person to try to understand the behavior and to change it.

Yelling can be thought of as a behavioral response to confusion. It can also become a habit. It is more difficult to change patterned behaviors like habits.

Things You Can Do

- Rule out any medical or comfort issues, like constipation.

- Be willing to take a good deal of time to examine the behavior itself.
    - Exactly what is happening? Does the yelling begin “out of the blue?”
    - Are there any behaviors that go on just before the yelling starts?
    - Are there any beginning points or anything that seems to trigger the behavior?
    - Is there anything that you can do that makes it better or worse?

  This detailed look may provide some clues about ways to fend off the behavior before it begins. It will also give you information about responses to it that are more or less effective. The yelling will be more difficult to stop the more patterned it is.

- This is another behavior where the goal is not to find a source. Your goal as a caregiver is to get the person to refocus on you. Work one-on-one to get your person calm once you have his or her attention. Provide a sense of security. Then, try involving her/him in some task or activity.

Managing Daily Care and Complicated Behaviors

Behavior: Combativeness in Personal Care

Many caregivers report that their person resists them when they are trying to guide them through personal care tasks like washing up, getting to the bathroom, and dressing. The resistance can become verbally or physically aggressive.

Assess and Plan

Cause?

One of the most common areas in which troubling behaviors are reported is in providing help with activities of daily living like washing up, dressing, using the bathroom, grooming, and getting in and out of bed or a chair. These are all intimate activities. They all involve entering your person's space. Many of them involve intimate touch. S/he may feel threatened or assaulted if not ready for this touch. S/he may feel the need to defend him/ herself. This can lead to hitting. Consider his/her life history. Is the care triggering some difficult memories or feelings?

The principles of good communication in the next section provide a number of suggestions for how to approach and interact with a person living with a dementia illness. Some of the strategies identified in that section are included below.

Things You Can Do

- Before helping with any personal care, assess your person's "readiness" for the task. Are they sleepy? Hungry? Do they need to take a pain medication before the task is started so they will be comfortable?
- Be flexible. If this doesn't seem to be a good time for your person, or you, try to do the personal care late
- Keep things simple. Use short sentences and plain words. Avoid complicated questions or directions.
- Be gentle. Make allowances for negative responses. Outbursts are not unusual with dementia illnesses.
- Try to get on the same "level" as your person. Try to sit if your person is sitting or lying down. Stand only if s/he is standing.
- Be calm and use tact, even if your person is loud or abusive.
- Avoid distractions, including sounds or actions, that might be fearful (like running water in the tub or shower, moving quickly or rushing your support, or reaching across or in front of the person, which could be interpreted as too close and put you in a vulnerable position).
- Be Savvy. Plan. Take extra time. (How can you make the personal care a pleasant experience for your person: Conversation? Music? Humor? Warm and pleasant space?)
- Is there another way to accomplish the same goal? For instance, if your person resists taking a shower, would a good sponge bath suffice?
- Get help, if necessary. (Is this something that would go better if two people were providing support or assistance?)

Behavior: Physically Dangerous Behaviors

Physical violence is *not* a common behavior in those living with dementia illnesses, but it can and does occur.

Assess and Plan

Cause?

- Some dementia illnesses, for example the behavioral variant of Frontotemporal Dementia, are more likely than others to erode inhibitions against behaviors like verbal and physical aggression.
- It appears that military personnel who experienced post-traumatic stress disorder (PTSD) are more susceptible to acquiring a dementia condition and, if they do, they are also more likely to exhibit physically aggressive behaviors, as they forget the coping strategies they have developed in the past.
- Many individuals whose dementia condition is produced by chronic traumatic encephalopathy (CTE) have past history of engaging in physically aggressive activities, like sports or combat. In their cases, the learned aggressive behaviors may surface as responses to perceived threats.

Things You Can Do

- What to do really depends on the situation:
  - *Is the person bigger and stronger than you?* If so, **protect yourself**. If you are facing harm, avoid the conflict if you can. Fighting back is not a good strategy. Stay out of reach or, if need be, leave the immediate area and let the storm pass. This protects you and gives you the opportunity to continue your caregiving once your person calms down.
  - *Can you easily contain the person, even if s/he is striking out?* If so, one approach is to just hug the person and, if possible, say comforting or reassuring things until s/he becomes calm.
- **Learn the triggers**. Try to figure out if there is a pattern to the behaviors. *Are there things that set the person off? Are there certain "conditions" that appear to trigger such outbursts?* These may be particular kinds of situations or environments, or they might be times when the person's energies are at a low ebb. It may be that consuming alcohol, caffeinated beverages, or other stimulants serves to lower the threshold for violence. If you can figure out patterns and triggers, do whatever you can to avoid or defuse such situations or environments, perhaps through substitution, diversion, or distraction.
- **Seek help**. If this is not a one-time thing, but a pattern, get help fast. Consult immediately with the person's healthcare providers, including the Veteran's Administration (VA) if the person is a military veteran. If the person had previously been treated for impulsivity, PTSD, or CTE, the treatment plan likely should be revised to account for the co-existence of a dementia condition.

  There are other social service and legal avenues to explore. Every state has some version of an Adult Protective Services agency. It is mainly designed to protect adults from abuse, but it can also provide help in dealing with adults who have become abusive. Find the one serving your area through the Eldercare Locator. Law enforcement agencies can also be a resource for providing strategies for dealing with abusive and violent situations.

Facing a hard choice. There are situations that cannot be contained or controlled, no matter how skilled the caregiver may be. If your situation reaches that state, it may be better for your safety and that of your person to make alternative care arrangements.

Communicating with Your Person

Communication means getting across what you really mean and having another person understand it. This is not always easy under the best of circumstances. Communication with a person who is living with a dementia will be even harder. The disease will impair the person's ability to understand words, to read non-verbal cues, to find words to use, to put ideas together, and hold ideas in place.

Loss of the ability to communicate with others may frustrate the person living with a dementia illness. The person may feel cut off from you and others. He or she may feel a loss of control over things. This may make the person feel less secure and more anxious.

Difficulties in communication pose special problems. You will need to be aware of your person's changing and lessening abilities. You will need to become an expert in figuring out her/his communications. You will need to judge when your person does or does not fully understand what you or others say. You will have to set up new ways of communicating with him/her as time and the disease go on.

Good Communication

Communication is more than talking. Good communication involves three things:

1. **Active listening:** Watching and listening play a big part in good communication. The goal of active listening is to understand not just the words a person says but the meaning they are trying to get across. This is all part of living in a non-ordinary situation. You are called on to go the extra mile in communication exchanges. You have to choose your words carefully. You have to check to see that what you are saying is getting through to the person.

2. **The context of communication:** Some settings make communicating easier. Be sensitive to potential problems and eliminate distractions. It's not just noise and sound levels that can be distracting. Other kinds of stimuli, like a television on in the background, can divert the person's attention. It is possible that certain times of the day may be better or worse than others. It may be harder when a person is just awakening or when s/he is tired.

3. **Effective self-expression:** Over our lifetimes, we all develop styles of speech and communication. Be sensitive to your own style of communicating. Take note of how you say things. Are you saying what you really mean? Are you saying it clearly and

simply? Do you give different messages with your tone of voice, your facial expression, or your body as you talk and listen? Mixed messages will be confusing, and persons living with dementia illnesses can sense anger and frustration in your voice. Deliver reassuring words in a reassuring voice.

The sections below offer some basic tips about improving these three areas of communication. These tips are useful for everyday communication as well as for communicating with people with dementia illnesses.

Strategies for Making Good Communication Better

Improving Active Listening Skills

Here are some general “rules” for effective active listening.

- Stop talking. You cannot listen if you are doing all of the talking.
- Be patient. It may take longer for your person to understand or respond if a thought is hard or complex. Two or three minutes may be needed before the person can even begin to react.
- Keep things simple. Use short sentences and plain words. Avoid complicated questions or directions.
- Repeat if necessary. Keep in mind that you can repeat the question or idea after waiting a few minutes for a response. If you have to do this, watch that the tone of voice doesn’t convey impatience or frustration.
- Show interest. Let your person know that you care what he or she is trying to say. Maintain eye contact. Stay nearby.
- Do not interrupt. Your person may need extra time to express what he or she wishes to say.
- Be gentle. Make allowances for poor behavior. Outbursts are not unusual with these conditions.
- Try to be calm and to use tact even if your person is loud or abusive. Try to respond to any negative statements with understanding comments until the angry outburst ends.
- It is not personal. Sometimes the person will say things that hurt you very much. S/he will use language that offends you. Try to remember that they are coming from the disease. They are not meant personally.
- Double-check understanding. Avoid assuming that your person understands you. The best way to check understanding is to see what your person does.

Remember that your person will forget. The person will forget things you tell her/him. This can be very frustrating, but little can be done to help it. It is probably best to assume that you will have to repeat many things during the day. Hold off on sharing information until it is needed.

Improving the Context or Environment for Communication

Here are some things to do regarding the environment and communication.

- Make sure your person can see you well. Research suggests that people living with Alzheimer's or a similar illness don't see very well to the side.
- Sit or stand directly in front of the person. Look at her/him when you speak.
- Avoid distractions. Communication will be harder under these circumstances:
  - When your person is involved in some other activity that requires concentration
  - When the background is noisy like when the TV or music is on
  - When other things or people can attract your person's attention like at a shopping center or restaurant
- Avoid settings that are too bright or too dark.
- Set aside a quiet place. You may even want to set aside a certain area just for communicating. Try to find a quiet, simple place where you can go when you want to get something across to your person.
- Be Savvy. Plan. Take extra time. Try to observe your person's daily patterns. Does s/he seem better able to communicate at certain times of day? You can take advantage of good times for important activities and communications.

  You will also be able to anticipate problems during the more difficult times. You can be prepared to allow extra time for explanations.

Improving Self-Expression
Usually, our style emerges out of our experience of what has been effective in ordinary situations. Keep in mind that caregiving is an out-of-the-ordinary situation. So:

- Think ahead about what you will say. Know what information you want to tell or find out. Break this information down into small parts. Simplify everything as much as possible.
- Ask just one question at a time.
- Try to think of brief words and simple sentences to explain what you mean. Always speak as you would to any adult. Do not use "baby talk."
- Make eye contact before speaking. Sometimes a gentle touch can be a way of making sure you have the person's attention before you speak.
- Listen to how you sound. Is your voice louder than usual? You may sound angry or upset if it is. Try to speak in a clear, pleasant voice even if your person has a hearing problem. Speaking slowly and clearly will help.
- Anticipate problems. Be prepared to repeat yourself many times without losing your temper.
- Think about how much information the person is likely able to absorb at one time. It can't hurt to give just one direction or piece of information at a time.
- Try to get on the same "level" as your person. Try to sit if your person is sitting or lying down. Stand only if s/he is standing.
- Watch your "body language." Are you smiling or frowning? Are you at ease or tense?

  You may very well give a mixed message if your words and the way you say them do not agree with how you feel and what you really mean. People living with dementia illnesses do not necessarily lose the ability to "read" such non-verbal cues, and often retain strong emotional radar.

The Impact of Hearing or Vision Problems

Communication is made more difficult when a person is living with a dementia condition. The problem is bigger when the person is also affected with other problems that affect communication. Vision and hearing loss can make communication more difficult. The sections below deal with communication and these added problems.

Problems with Hearing Make Communication Harder

Hearing loss combined with the effects of an illness like Alzheimer's disease will make communication even harder. Good communication depends a great deal on a person's being able to hear well. Many people may not hear what is being said clearly. They still do not ask you to repeat yourself or to make clearer what you mean. These people may not know that something is wrong with their hearing. Many people "fill in the gaps" of a conversation including those without hearing loss. They interpret facial expressions, other gestures, and read lips.

Observation and Diagnosis

You may have noticed that your person seems removed from what is going on around her/him. S/he may seem distracted or not attentive. S/he may ask you to repeat what you say. Keep track of the problems you notice and try to answer the following questions.

- What problems of hearing or attention is my person having?
- When did you first notice the problems?
- Do you see any pattern to the problems? Does your person seem to have more trouble at certain times? Do better at other times?

Knowing the answers to these questions will be helpful when you see the doctor. You can give the doctor information that will help in understanding the problem. It is also important to develop a picture of the person's communication abilities.

Treatment

The problem may be partly due to hearing loss that can be corrected. A hearing aid may help. Hearing aids do not correct hearing the way glasses correct vision. Hearing aids make all sounds louder. So, background noises like the hum of a refrigerator or the sound of traffic are also made louder. These noises can lead to or increase confusion.

There are some issues to keep in mind when a person wears a hearing aid:

- Hearing aids can be misplaced. You will probably have to keep track of it.
- Hearing aids need to have the battery checked regularly.
- Sound level should be adjusted so that it is not too high or too low.
- The device has to be properly placed in the ear to be effective. This can present a caregiving challenge if you have to help with placement. Because

this can feel invasive, approach this activity with care. Be as sure as you can that the person sees what you are going to do and proceed slowly.

Caregiving Techniques

Here are some tips to improve communication with a hearing-impaired person.

- Always give yourself extra time when you take the person out of the setting s/he knows well.
- Approach the person from the front. Face them directly.
- Sit close enough for the person to see your face and mouth.
- Keep your hands away from your mouth while you are speaking.
- Check to be sure any hearing aid in use works, is turned on, and is loud enough.
- Anticipate problems. Be prepared to take extra time. You may have trouble even with routine activities if your person does not hear or understand well. Allow extra time to explain and reassure.
- Get and keep the person's attention. Wait to begin what you want to say until the person is as focused on you as possible. Keep in mind that his/her attention span may be short.
- Make sure no bright light is shining in the person's face to distract her/him.
- Try to get and keep eye contact with the person. Sometimes a gentle touch on the arm or hand will help you get eye contact. Physical contact is a powerful form of communication.
- Speak slowly, clearly, and distinctly. Do not shout. A shrill or loud voice will make you sound upset or angry. The person may react by becoming too upset to focus on what you are saying.

  The person may not be able to keep up with what you are saying if your words run together. It will be easier to pronounce your words more clearly when you speak slowly.
- Lowering the tone of your voice often helps.
- Use gestures to support what you say. A nod of the head or shrug of the shoulders may be better ways of communicating than words if the person can still interpret them.
- Find out how the person hears best. Perhaps the person has one good ear. You will want to speak on that side.
- Check regularly to see if the person understands. Watch to see what the person does rather than trusting what s/he says. Impaired people often become very skillful at concealing the fact that they cannot understand. Try to find a new, simpler way to say the same thing if the person does not seem to understand.
- Be alert to distracting background noises. Turn off or lower the volume on the TV.

Problems with Vision Make Communication More Difficult

Older persons often have vision problems. There may be problems with sharpness of vision, with telling colors apart, or with judging what is near and what is far. Many drugs can disturb the eyes' ability to focus well. Poor vision can increase the risk of falls and injury. It can also make communication harder.

Vision plays a big role in communication. We watch the facial expressions of other people as they speak and as they listen to what we say. Eye contact seems to mean a lot. Think how uncomfortable you feel talking with someone wearing mirrored sunglasses. And, we often use gestures like pointing or a shrug of the shoulders instead of words.

Difficulties from the dementia disorder can cause many problems communicating with your person. Communication will be even harder if the person is also having vision problems.

Observation and Diagnosis

You may have noticed that your person seems very clumsy. Perhaps s/he has fallen often or keeps bumping into things. If they are still reading or looking at books or photos, do they keep moving the item closer or farther away with their hands? Keep track of the problems you notice. Try to answer the following questions.

- When do these problems occur?
- When did you first notice the problems?
- Do you see any pattern to the problems? Does your person seem to have more trouble at certain times? Do better at other times?
- Does your person use glasses now? If so, they may need to be checked.

Keep track of the answers to these questions. This information will help the doctor in understanding the problem.

Treatment

Problems with vision can often be corrected or improved. Near-sightedness or far-sightedness may mean the person needs glasses. The strength may need to be adjusted if the person already wears glasses. Contact lenses are not advised. Helping someone to insert contacts is difficult under the best of circumstances, but a dementia condition can greatly complicate this procedure.

Cataracts, macular degeneration, and glaucoma are three other conditions that impair vision. An eye doctor can diagnose and treat these. A caregiver may be faced with a difficult decision if the person has a surgically treatable condition. For persons living with Alzheimer's or a similar illness, hospitalization and anesthesia pose risks of worsening the dementia condition.

Some problems may be caused by the person's progressing illness and not by failing eyesight. The person may see perfectly well and still be unable to act appropriately. The disease may have made the person's brain incapable of understanding or remembering what s/he sees. If your person does wear glasses, try to have an extra pair on hand since they may be easily misplaced.

Caregiving Strategies

These techniques may improve communication with your person in spite of vision-related problems.

- Anticipate problems. Be prepared to take extra time. The person may need extra time to do things we take for granted. Adjusting from a dark hallway to bright sunlight may take longer or even be startling and upsetting.

  You can prepare the person in advance if you can anticipate such problems. Tell the person you are about to turn on the light. Allow time for the person to adjust when there is a sudden change in the level of lighting.
- Eliminate visual distractions in the background.
- Make sure your person can see you well. Approach her/ him from the front. Suddenly appearing from behind may startle the person. Avoid sitting or standing off to one side.
- Avoid glaring light or a bright window behind you.
- Look directly at the person when you speak.
- Do not use gestures instead of words. Shrugging your shoulders or nodding your head may not be enough. The person may no longer notice or interpret these gestures.
- Do not assume the person understands. Watch to see what they do rather than trusting what he or she says. Impaired people often become very skillful at concealing the fact that they do not understand.
- Try to find a new, simpler way to express the same idea if you suspect that the person does not get what you mean.

Dealing with the "Emotional Truth" of Situations

The many effects of dementia illnesses on thinking will often result in people saying factually incorrect things. This can take a number of forms:

- Statements that are untrue or incorrect, like saying that a child will be visiting today when you know the child is out of the country
- Mistakes about identity, like denying that someone is your spouse
- False assertions, like saying that someone is looking in the window or trying to steal clothes

This kind of incorrect thinking can take other forms that are sometimes less clearly linked with losses in thinking ability:

- Repetitive questioning, as if each time is the first time (S/he doesn't or can't remember the answer that was already given.)
- Making things up
- Repetition of stories
- The use of "stock phrases" (The person relies on the same standard reply to different questions or topics of conversation.)

You can see patterns in your person's behavior. You can see that s/he has asked the same question over and over. You know the parent your person is expecting that afternoon died long ago. You have heard the same story over and over. You know there is no one outside the window looking in. You know that your person does not understand what is actually going on. The person may "feel" lonely for a spouse, child, or parent. The trouble arises when s/he cannot remember who the spouse or child is or that the parent is dead. All that remains is the feeling-driven wish to see or be with that person.

The question is: What can you do? How can you best respond to this kind of incorrect thinking on the part of your person? There are basically three responses you can provide:

- Confront the incorrect thinking. Give the person the facts.
- "Go along" with the person. Tell what some call a "therapeutic lie."
- Focus principally on your person's feelings. Respond to the "emotional truth" of situations.

Truth Telling

It is common for caregivers and other close family or friends to try "setting the person straight," and it's understandable that one doesn't wish to lie to the person. So, it may seem reasonable or even responsible to reply to questions or statements that are not factually true by saying: "No, you can't see Mom today – she died 20 years ago." Or, "You can't see your son; he lives too far away."

This approach attempts to present facts that will reorient the person and stop them from asking about or feeling the presence of someone or something that is unavailable. It's an attempt at reasoning with the person. Truth-telling can also be a way of showing respect for the person. However, **the problem is that reasoning with the person is unlikely to be successful, and truth-telling may produce an upset behavior.** It may even produce pain as intense as the first time it was experienced. The loss will be fresh.

There is a school of thought called **Reality Orientation (RO)** that asserts that the mind should be stimulated and focused regularly on the facts of the here and now. It is argued that this will keep the mind "fit." So, mistakes in thought should be corrected. People should regularly be told or quizzed about where they are; what time of day it is; what day, year, and season it is; and what events are going on around them. It is an attempt to help people remain focused on and alert to the world around them. RO can be an effective help for people not living with dementia illnesses.

RO is ineffective and can be irritating, demeaning, and even hurtful for people living with dementia illnesses. People affected with such disorders do not benefit from being constantly oriented to person, place, and time. S/he is also likely lacking the abstract thinking ability to make any use of such information. The person might feel embarrassed at not knowing or being able to recall the information depending on the tone in which the information is delivered. And, trying to orient people living with a dementia illness to the day-to-day reality can frustrate you. Your frustration may well communicate itself to the person.

The "Therapeutic Lie"

Another school of thought recommends dealing with situations in which the person's statements or requests are out of line with fact and reality by responding with **"harmless fibs" – or therapeutic lies – aimed at not disturbing the person.** This strategy is meant to avoid the potential upset of confronting the person with the truth.

Using this strategy, a caregiver, faced with a mother who is asking to see her long dead brother would not say, “But Uncle Bill died long ago.” Instead she might say, “I’d love to see him too, but we can’t today. Let’s visit with him this weekend.”

This kind of response is problematic in two ways. First**, it introduces the use of untruth – lying – into the caregiving relationship.** This can be seen as a form of disrespect for the person. Especially in light of the Savvy principle that “personhood persists,” this kind of behavior seems dismissive of the person. The second and more practical problem is that **the strategy can backfire.** Instead of being diverted by the therapeutic lie, the person might become more entrenched in the idea. The mother might insist on seeing the brother NOW!, not on the weekend.

Dealing with the “Emotional Truth” of the Situation

Our recommendation is to find and use the emotional truth of the moment. This is an idea taken from Validation Therapy.* The idea is to recognize that what a person says is a clue to what s/he is feeling in the moment. The accuracy of the statement is not important. The validation principle directs caregivers to use the person’s words to find the emotion at their core and to move with that emotion. Connect with the person not so much at the literal level (“I want to see my brother”) but at the feeling level (“I’m thinking about my brother”). Then use that understanding of what the person is feeling in the moment to help him/her to “be with” whoever or whatever the feeling is pointing to.

The content you have to work with may well be contrary to fact. People may speak of people who are dead or distant. They may wish for a visit from an out-of-town daughter or yearn for a parent who has died. They may speak of events long past or that never happened (like a wedding or family event, or trips to exotic places). They may alter the details of past experiences. They may speak of events or occurrences that will never happen (like getting a driver’s license or going to visit a summer home).

The goal with this approach is to accept those feelings. Be present with them and with the feelings, memories, wishes. We sometimes refer to this process as “flowing with your person.” Use the feelings as a chance for talking or telling stories about a person or event. Use them as a springboard for some related activity, like looking at

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* The Validation Training Institute website at www.vfvalidation.org provides further information about validation therapy. The site also provides links to books and articles on the topic.

old photos or mementoes. Use their feelings to engage and connect them with content in the present moment.

Once engaged, it is in the nature of dementia that your person’s focus on the feeling will likely wane rather quickly, and you will be able to find a way to use the engagement to move them to a different activity. [“Remember how much your mom loves afternoon tea; let’s you and me go make some tea.”]

Operating with the emotional truth of the moment is the Savvy program’s recommended form of response to incorrect thought among people living with Alzheimer’s or a similar illness. Employing this strategy requires a special kind of listening. It is a listening to the feelings and yearnings of the person even when s/he cannot express them reliably. It is important to emphasize that validation is acknowledgment of and working with the feelings of the person.

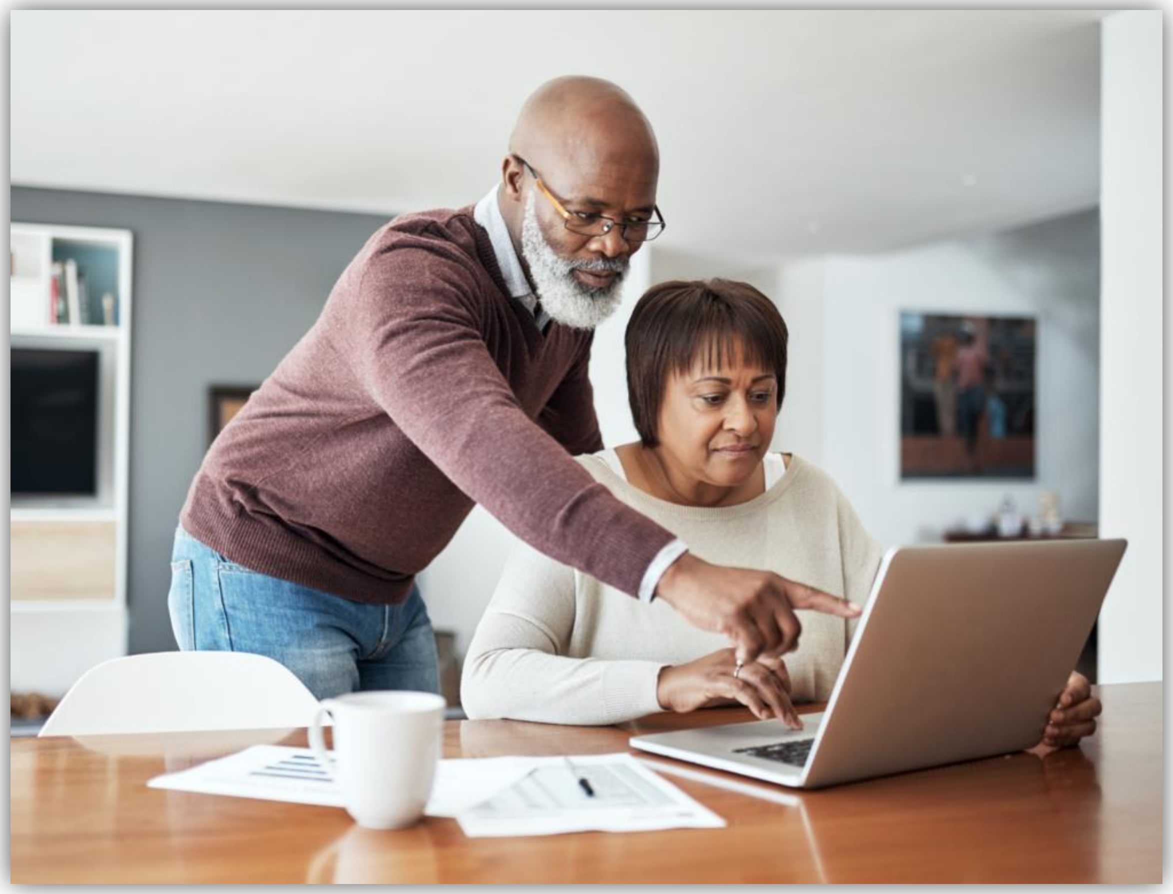
Here are some examples of dealing with the emotional truth of a variety of situations that may help to clarify the idea.

Person Says/Does	**Your Response**	**Desired Outcome**
“Mary (daughter) is coming to visit me this afternoon.” (Mary is out of town. She has not visited in three months.)	“I miss Mary, too. How about we look at some pictures of our grandchildren?”	Person will enjoy photos of grandchildren. The person will not be forced to recognize that her daughter is not coming and has not visited.
Person Says/Does	**Your Response**	**Desired Outcome**
“I liked the movie last night.” (There may or may not have been a movie.)	“I like movies, too. What do you like about movies?”	Person might reminisce using his or her long-term memory. They will not feel frustrated by specific questions about “last night’s” movie.
Person Says/Does	**Your Response**	**Desired Outcome**
“There are people looking at me through my window every night.”	“It is good our doors and windows are locked.” Or: “Maybe we can have some cookies and milk tonight before bed.”	Help the person feel secure and/or establish a routine rather than dealing with the hallucinations. Work to make sure the curtains are closed so the person does not see any reflection and misperceive it.

Dealing with emotional truth means you don’t have to tell lies, even though it might be easy to do so. It is true that a lie might help in the moment. It is also likely that the person would not remember the lie, once diverted. That means that you could “get away with” the lie. The person would likely not be hurt by it. Still, there is something in using a lie in this way that diminishes your relationship with the person. It has a way of eroding a fundamental sense of respect for the person.

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

A Decision-Making Guide for Family Caregivers

Along with guiding day-to-day life, caregivers become decision-makers.

- Decisions have to be made about caregiving itself: How much and what kinds of help do you need to provide in daily activities like bathing, dressing, or making and eating meals?
- Larger immediate issues must be faced: Who is to handle the finances? Is the person's will up-to-date? What advance directives are in place? When is it time for your person to stop driving? Have questions of guardianship and conservatorship been raised and addressed?
- Long-term decisions are inevitable: Should you – and can you – quit working? Is staying in the family home an option? When do you find a different care arrangement?

When a spouse or parent is diagnosed with a dementia illness, decisions still have to be made, but established practices will need to change over time (some sooner than others).

For some caregivers who now find themselves in this situation, major decision-making is a new experience and an added role and responsibility. This change of role may feel awkward and uncomfortable. Sometimes other family members can provide support in making decisions, but they may have different opinions about what to do, lack all of the facts, or live too far away to provide practical assistance or help.

This section of the manual describes an approach you may find helpful as you make decisions for you and your person. The Decision-Making Guide for Family Caregivers (or the OOVL Decision-Making Guide) was developed to assist caregivers in the decision-making task.[*] The Guide is a tool to help caregivers break decisions into a number of parts and consider them to make a decision. It was developed to enhance people's decision-making skills in general and can be used in many decision-making situations.

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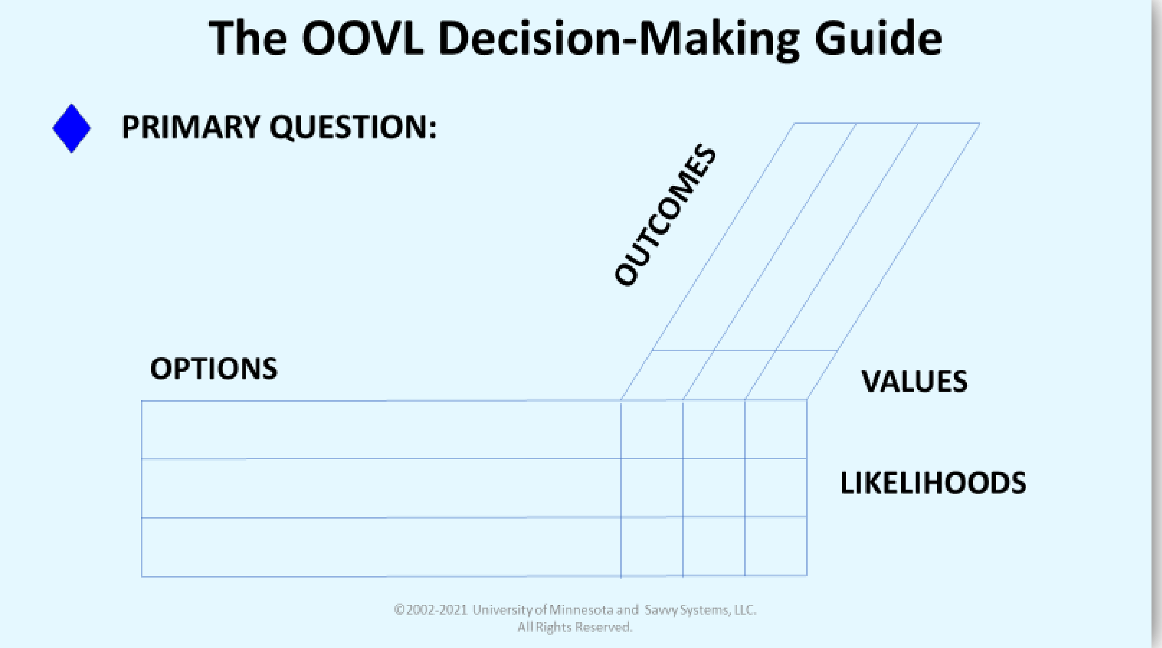
[*] This method was described in an article that appeared in *The Journal of Gerontological Nursing*, authored by Marsha Lewis and others. (See volume *15*(6), November-December 2000, pp. 361–366.)

The Decision-Making Guide: Options, Outcomes, Values, and Likelihoods (OOVL)

The Guide provides caregivers with a structure and process for making choices for themselves and their person. The structure for decision-making is represented by a grid that relates the four elements**: Options, Outcomes, Values, and Likelihoods (OOVL)**. It is pronounced like the word "oval".

The blank OOVL form is pictured below. In each of the following sections, we will fill the form out section by section.



Filling Out the OOVL Decision-Making Form

There are five main sections in the OOVL form.

- **Primary Question** is what you need to make a decision about.

- **Options** are the various actions or choices being considered. It is useful to list up to three options that are different from each other.

What choices do you have? What actions are you considering?

- **Outcomes** are the results or consequences you hope to achieve. These outcomes involve results for both your person and you. Think of immediate outcomes *and* outcomes down the road, and state them in positive terms. (Example: "I want my person to be comfortable," rather than "I don't want her to be uncomfortable.")

  What are the things you would like to have happen? What are the outcomes you are most concerned with in regard to this decision?

- **Values** are defined as the importance assigned by the caregiver to each of the outcomes. Determining what is most important for you and your person will help in making the decision.

  How important is each of these outcomes to you?

- **Likelihoods** are the odds that outcomes will occur. You will use the information you have learned about your person's performance ability to help decide the chance of an option achieving an outcome you want.

  How likely is it that each option will lead to each of the outcomes? What option is most likely to achieve the best outcomes?

Now that you know the structure, let's take a look at each of the elements and the questions you will be asking in the decision-making process.

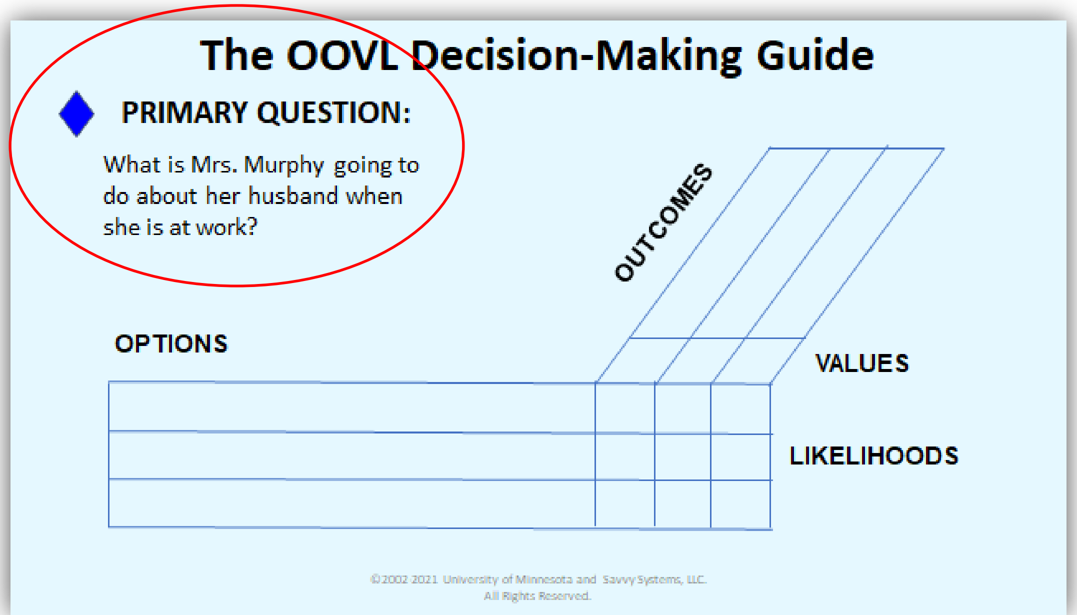
Mrs. Murphy and Her Husband

This example will walk you through making a decision Mrs. Murphy would like to make by answering each of the questions and putting the answers into the grid.

The Situation. Mrs. Murphy works every morning at a florist shop. She enjoys the work and the time away from home. The extra money helps. Mr. Murphy is living with dementia. He has remained at home alone. Mrs. Murphy has become concerned about Mr. Murphy's ability to stay by himself after 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.

Let's walk through each of the five questions.

1. **What does Mrs. Murphy need to make a decision about (Primary Question)?**



The OOVL Decision-Making Guide

◆ PRIMARY QUESTION:

What is Mrs. Murphy going to do about her husband when she is at work?

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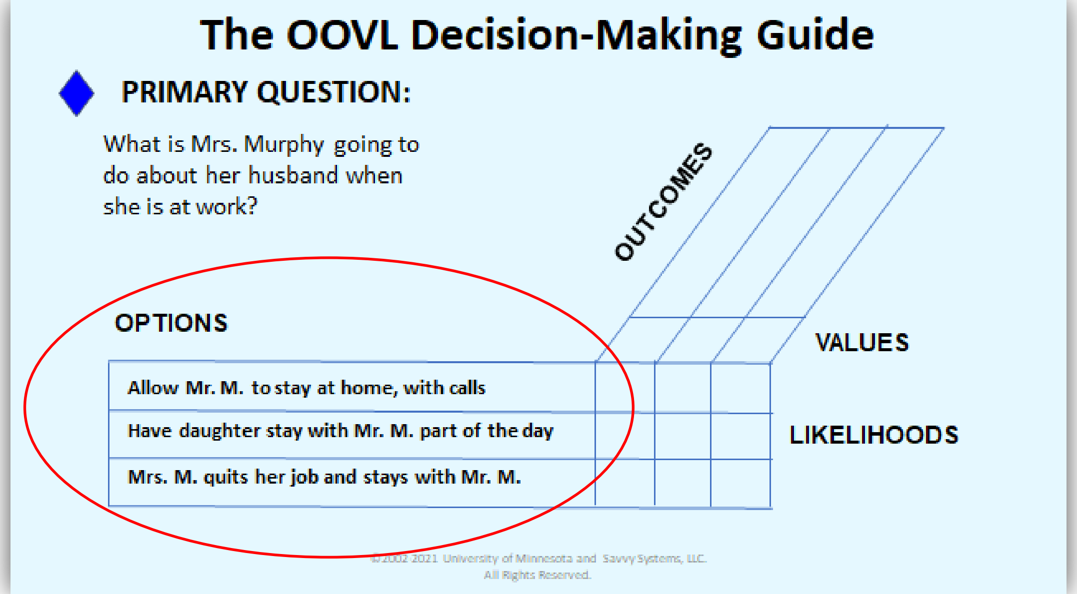
2. What options is Mrs. Murphy considering (Options)?

Mrs. Murphy identifies many options, but then narrows the list down to three:



The OOVL Decision-Making Guide

◆ **PRIMARY QUESTION:**

What is Mrs. Murphy going to do about her husband when she is at work?

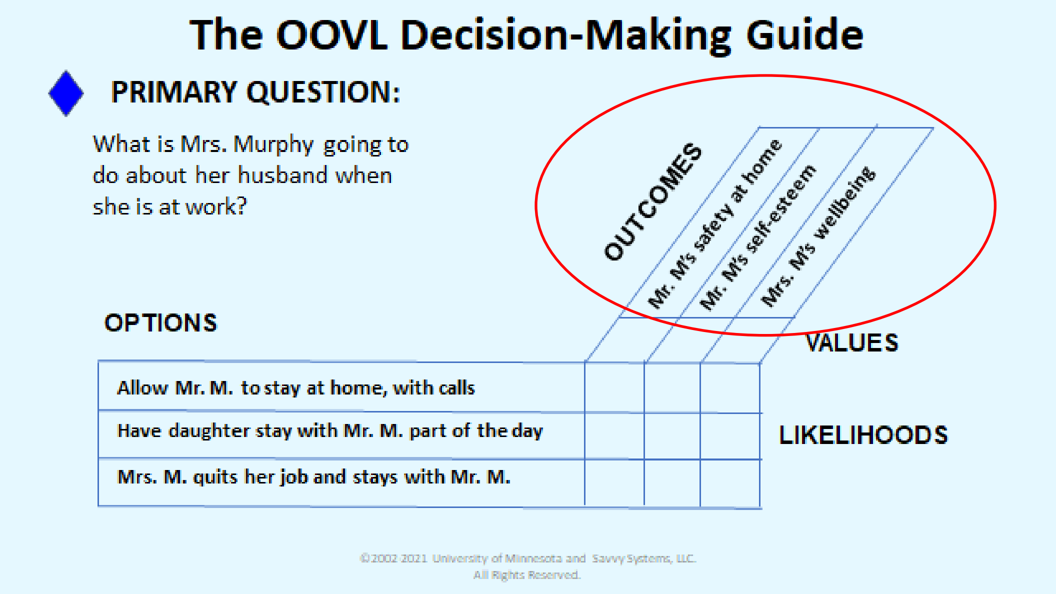
OPTIONS

- 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 outcomes. She needs to think about what she wants to have happen for herself and her husband. She should also think about what she wants to avoid happening. Mrs. Murphy identifies three important results she wants to consider:

- She wants Mr. Murphy to be safe while she is at work.
- She does not want to hurt Mr. Murphy's pride. He says he is fine alone.
- She is also concerned about 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. The work gives her a sense of accomplishment.



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
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.			

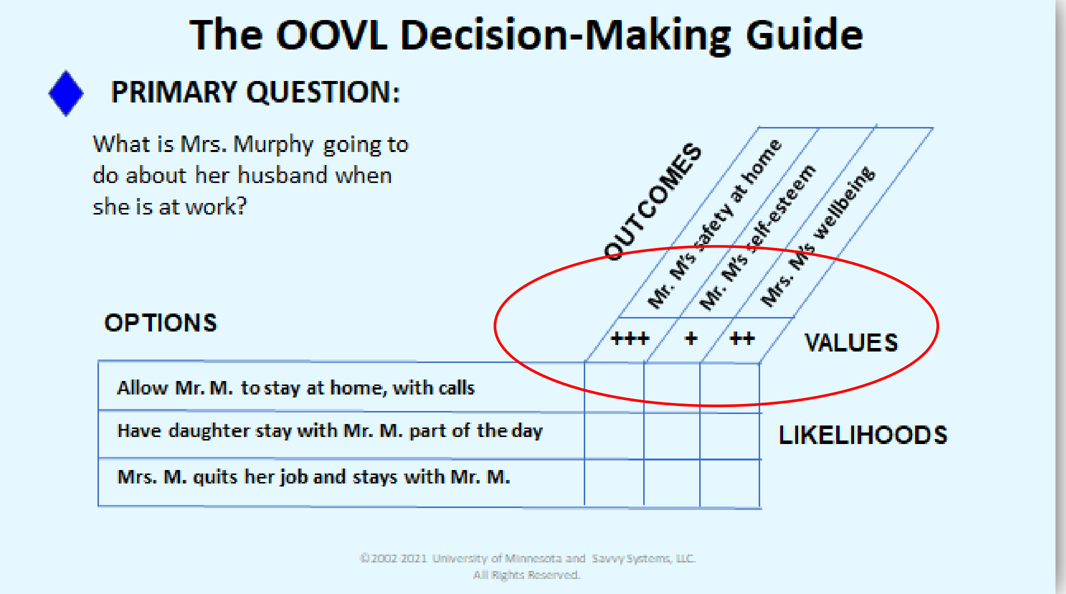
VALUES

LIKELIHOODS

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. These are positive outcomes. A simple way to assign values is to rank them with plus signs. Outcomes can be assigned a value of +++ (most important outcome), ++ (second in importance), or + (third in importance). If two outcomes are of equal importance, they can be given the same value. Mrs. Murphy considers the three outcomes she has listed.

- She ranks Mr. Murphy's safety as the most important outcome. She assigns it +++.
- She ranks her sense of wellbeing as a ++. She knows that if she feels okay about herself, she is better able to take care of her husband.
- Mrs. Murphy considers the outcome of hurting her husband's pride. Mr. Murphy has always been a proud, independent person. Mrs. Murphy has noticed that he allows her to do more for him lately. Sometimes he even asks for help. None of this seems to bother him. Mrs. Murphy is still concerned about his feelings. She 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?

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.			

5. **How likely or possible is it that each option will lead to each of the outcomes (Likelihoods)?**

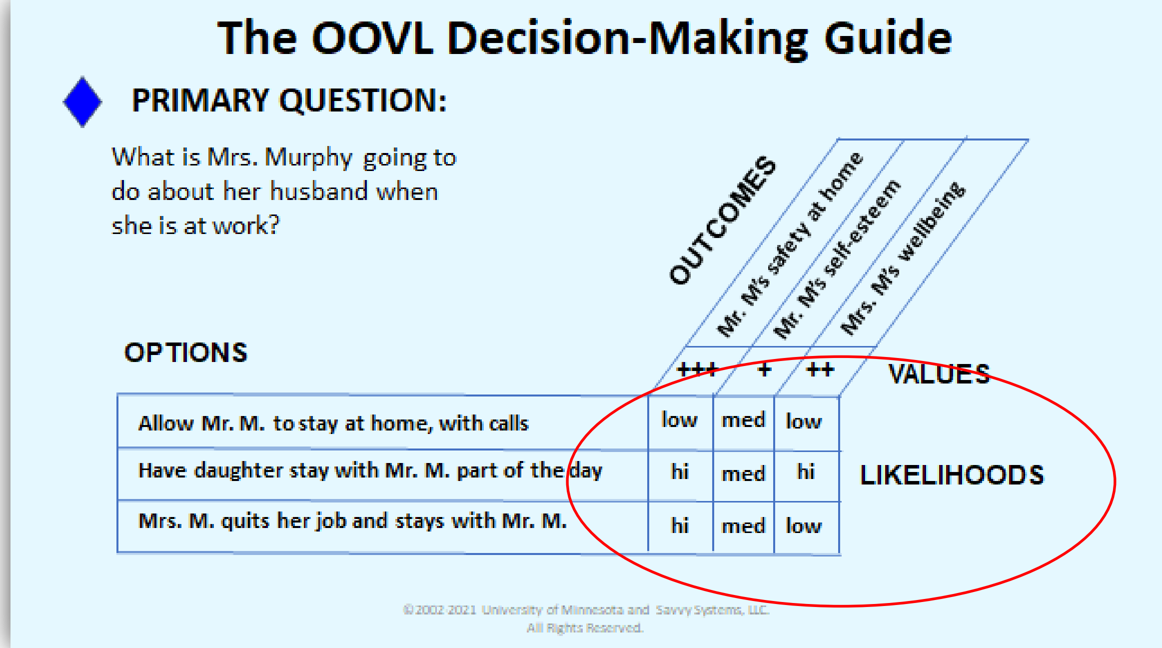
Decision-making involves looking at each option and determining the likelihood that the option will lead to the outcome. Determining likelihoods is based on a number of things: your personal experience as a caregiver; understanding your person's level of thinking; and information you have from resources like healthcare providers and community agencies.

Mrs. Murphy has participated in the Savvy Caregiving Program and has estimated Mr. Murphy as being in the Early-Middle Stage. She knows that means Mr. Murphy is very impaired in memory and thinking, is easily distracted, and needs much assistance.

One way to rate the likelihoods is to use words such as high, medium, or low. Mrs. Murphy thinks about the likelihood of the various outcomes in the following ways:

- She thinks about Mr. Murphy leaving the stove on and the door unlocked when considering the likelihood of him being safe at home alone. She rates the chance of him being safe at home alone as low, even if she calls him. She ranks the likelihood of Mr. Murphy being safe with her or their daughter at home with him as high.
- Mrs. Murphy thinks about the likelihood of her husband's pride being hurt if she quits work. She remembers something she learned about people living with a dementia illness: they become less able to understand the meaning of events happening around them. She guesses that he won't understand that her being around more means that she quit her job to care for him. So, he won't be as upset as he might have been in the past. She rates the chance of his pride being hurt under any option as medium.

- She then thinks about her own wellbeing. Mrs. Murphy realizes that the chances for positive wellbeing are high if her daughter comes over. They are low if she continues to leave Mr. Murphy alone or quits work.



The OOVL Decision-Making Guide

◆ **PRIMARY QUESTION:**

What is Mrs. Murphy going to do about her husband when she is at work?

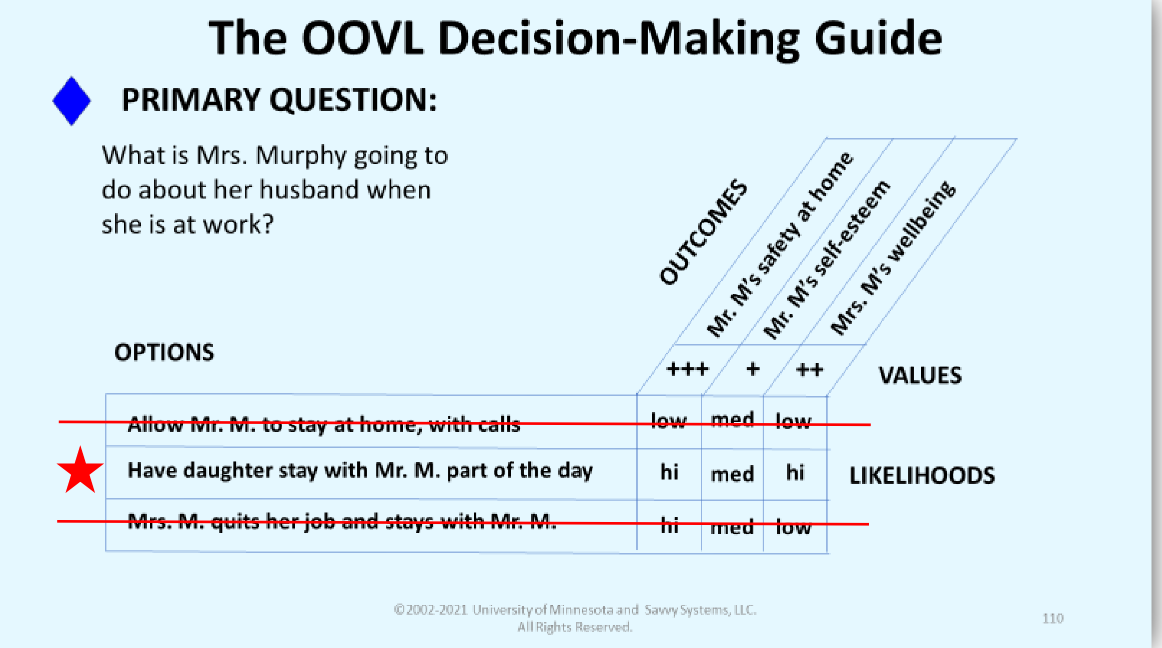
OPTIONS	Mr. M's safety at home	Mr. M's self-esteem	Mrs. M's wellbeing
VALUES	+++	+	++
Allow Mr. M. to stay at home, with calls	low	med	low
Have daughter stay with Mr. M. part of the day	hi	med	hi
Mrs. M. quits her job and stays with Mr. M.	hi	med	low

The Decision Most Likely to Achieve the Best Outcomes

Once the decision grid is complete, the caregiver makes a decision by looking at the information and comparing the options. The grid serves as a guide in the process.

In our example, Mrs. Murphy ponders the grid. His safety is the outcome most important to her. Since the other two options both have a high likelihood of keeping Mr. Murphy safe, she can choose between them by examining their likelihood of achieving the remaining two outcomes. This simplifies the decision.

Mrs. Murphy then relates the two options and the two outcomes based on the values and likelihoods she assigned. She 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. This will help her to provide the best care she can for Mr. Murphy. The option most likely to achieve this is having their daughter stay with Mr. Murphy. She has offered to help in any way she can, so Mrs. Murphy decides to ask her to stay with Mr. Murphy during the morning when she is at work for now.



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

Mrs. Murphy Summary

This simple example was selected to illustrate the structure and procedure of this guide. Mrs. Murphy's situation and values influenced her decision-making. Other people may face more complex decision situations. They may think of different options and outcomes. They may assign different values and likelihoods. Everyone comes from their unique situations and brings their unique perspectives.

Savvy Caregivers are encouraged to think about decisions using all components of this guide as they learn to use it. Be assured that you do not have to fill out the entire grid for each decision you face. Just considering options, outcomes, and values will fuel enough reflection to make the best option clear. Not every decision requires this type of analysis. The kinds of decisions that are best suited to using this tool include serious or complex decisions, recurring decisions, and those that are troublesome, perplexing, or uncomfortable.

Decisions may need to be made more than once. This is often the case as changes occur in the situation or in the condition of your person. For example, a day-to-day management option that worked in the past may no longer be appropriate, or the importance of an outcome might change.

The Guide can be useful in situations where the caregiver and other family members' values or preferences differ. This approach promotes systematic and consistent evaluation of options. Share the decision grid 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, perhaps reaching consensus. Family members may also identify new ways that they can help.

There are two things to consider and remember about this guide:

- The process of answering the questions and filling in the grid is useful for long-range decisions and day-to-day matters that caregivers face in managing their person's life.
- You may not have to go through the formal exercise of using the grid once you have the questions and process clear. Often the process of looking at the available options will make the decision clear. The tool is there. You should feel comfortable using it. You can choose when to use the whole thing.

Example 2: Mr. L. and Day-to-Day Management Issues

You are faced with numerous decisions about what to do in the daily care and management of your person. You can use the decision grid to process care-management decisions in conjunction with the information you are learning about dementia illnesses and Savvy Caregiving.

> **Example**. Mrs. L is caring for her husband who has been assessed to be in the Early-Middle Stage of his disease. He continues to like to be helpful around the house. She feels it is important for him to feel useful. The problem is that he makes mistakes. She then has to clean up after them. He likes to help with the laundry, but gets confused about when the laundry cycle is completely over and often mistakes the brief pause in the washer's operation for a sign that the laundry is done, and moves clothes from the washer to the dryer in the middle of the wash cycle. This causes all kinds of problems. The clothes are usually very wet. The floor gets all wet. The clothes are either not clean or not rinsed fully. The dryer takes on a lot of water. It is a mess.
>
> Mrs. L. is reluctant to stop her husband from helping her because she is afraid it will hurt his self-esteem. She still needs to get the laundry done. She does not

need the extra work that her husband's help is causing her. She is trying to decide how to handle this situation.

Think about the key decision-making questions as a way of thinking through this problem and arriving at an appropriate decision.

1. What does Mrs. L. need to make a decision about?

   She has to decide whether to let Mr. L. continue to help her with the laundry. She has to decide what his help may look like.

2. What would Mrs. L. like to have happen as a result of her choice? (OUTCOMES)

   - Not have Mr. L. lose self-esteem
   - Not have the extra work and mess
   - Get the laundry done

3. How important is each of these outcomes to Mrs. L.? (VALUES)

   - Mr. L.'s self-esteem +++
   - No extra work +++
   - Get laundry done ++

4. What actions might Mrs. L. consider in this situation? (OPTIONS)

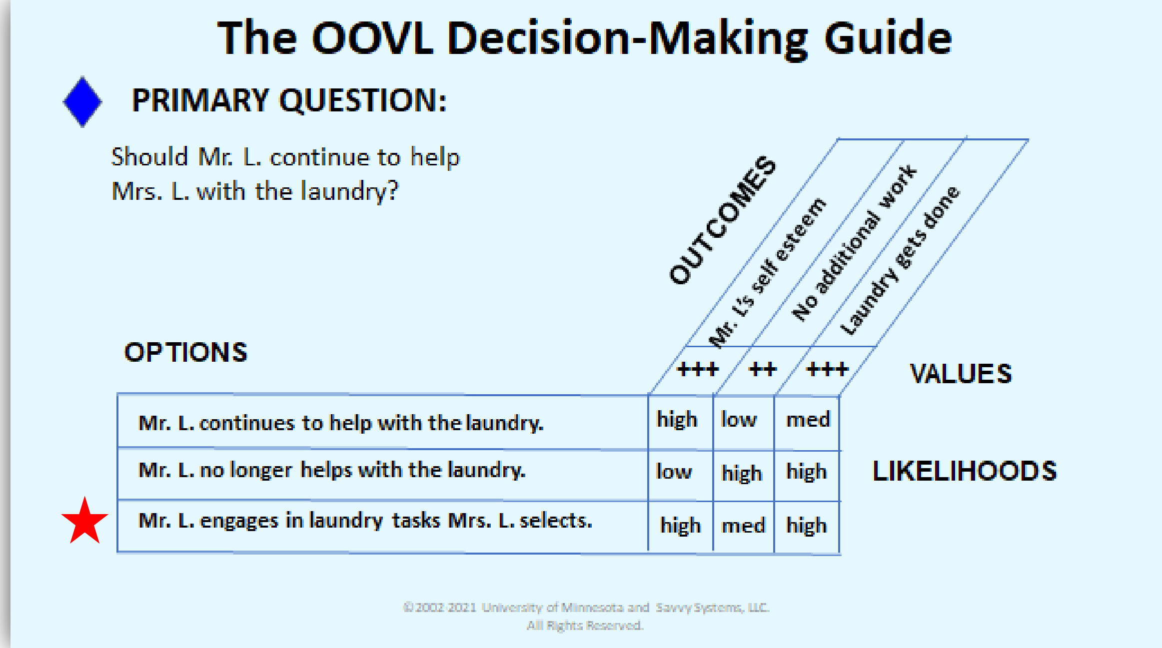
   - Having Mr. L. continue doing what he is doing. Mrs. L will just live with the consequences and the mess.
   - Having Mr. L. not help with the laundry at all.
   - Consider Mr. L.'s Performance Level. Use the Structure and Support guidelines to select portions of the task that he could help with.

5. How likely is it that each option will lead to each of the outcomes? (LIKELIHOODS) Why?

Option	Likelihood per Outcome	Reason
1. Mr. L. continues helping	High for self-esteem	Nothing will change and he will continue to feel as good as he currently does
	Low for no extra work	Mrs. L. will continue to have to clean up
	Medium for getting laundry done	It will continue to take extra time
2. Mr. L. does not help at all	Medium-low for self-esteem	He may well notice that he is no longer involved and this may affect him even though his dementia illness has progressed
	High for no extra work	Mrs. L. will be able to do laundry faster
	High for getting laundry done	Mrs. L. will be able to do laundry faster. There will be no extra work to do
3. Mrs. L. designs tasks for Mr. L. to help.*	High for self-esteem	He will feel he is helping. The progression of this disease makes it unlikely he will realize Mrs. L. has taken back some of the tasks
	Medium for no extra work	It will not be as efficient as if she were doing it herself. It is not as much work as if he were doing it alone
	High for getting it done	It may be slower. There will not be the extra work of cleaning up after him. It will get done.

*She can instruct him to put the clothes in the washer and to start the machine. Later she can instruct him to transfer the completed load of laundry to the dryer and start the dryer. He can help to take things out of the dryer and to fold them. Mrs. L uses her Savvy Caregiver training to realize that Mr. L.'s sense of himself been dulled by the disease. He is no longer acutely aware of self-esteem as an issue. It is not so important to him anymore. It is not nearly as important as feeling close to Mrs. L. He likes feeling he is of some use to her.

When all of this information is put on the decision grid, it looks like this:



The OOVL Decision-Making Guide

◆ **PRIMARY QUESTION:**

Should Mr. L. continue to help
Mrs. L. with the laundry?

OPTIONS	OUTCOMES: Mr. L's self esteem	No additional work	Laundry gets done
VALUES	+++	++	+++
Mr. L. continues to help with the laundry.	high	low	med
Mr. L. no longer helps with the laundry.	low	high	high
★ Mr. L. engages in laundry tasks Mrs. L. selects.	high	med	high

LIKELIHOODS

It was important that Mrs. L remember that the dementia disorder lessens Mr. L.'s awareness of issues like self-esteem. It is the key piece of information Mrs. L. needed. He is probably at a much simpler level in his thoughts and feelings, and is satisfied to be helping. **His decline makes it unlikely that he would remember what he used to be able to do.** He would not compare it with what Mrs. L. is asking him to do now.

This is actually a key point for many caregivers, who assume the person's feelings are unaffected by the disease. There is a great deal of worry about how the person will react to changes (such as taking over the finances). These concerns are often framed in terms the person's self-esteem. Caregivers worry that their person will feel less good about him/herself, or will somehow feel diminished. Remember that the issue of self-esteem fades as the disease progresses. Keep that in mind as you make choices about how much to involve your person and what limits to impose. For example, Mrs. L. realized during the OOVL process that Mr. L. could still remain engaged by helping her with part of the laundry task. This has the highest likelihood for balancing her need to get the work done, minimizes extra work, and attends to her husband's need to stay involved.

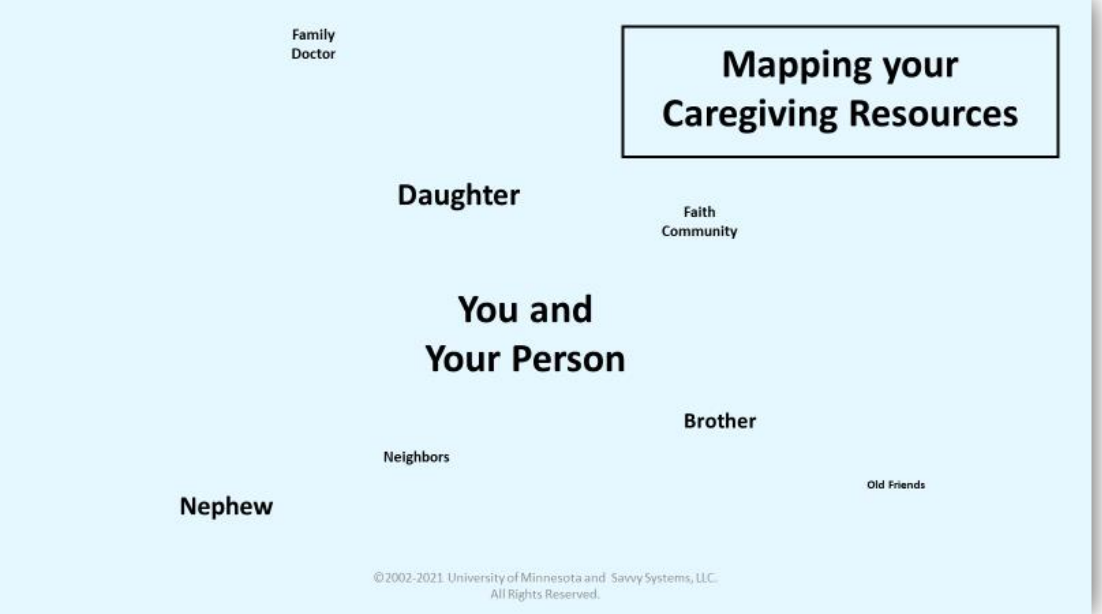
Mapping Your Caregiving Resources

It is likely that the world you and the person living with dementia live in extends beyond just the two of you. There may be family members and friends in the picture. And, there may be a variety of organizations who are or have been part of your life and the life of the person. This section aims to help you examine how and to what extent those other people and groups can serve as resources for your caregiving. It asks you to map out these resources and to name the kinds of help or demands you experience from them. Finally, it asks you to consider if there are ways your resource map could be changed so it would work better for you and your person.

This is an exercise in three parts.

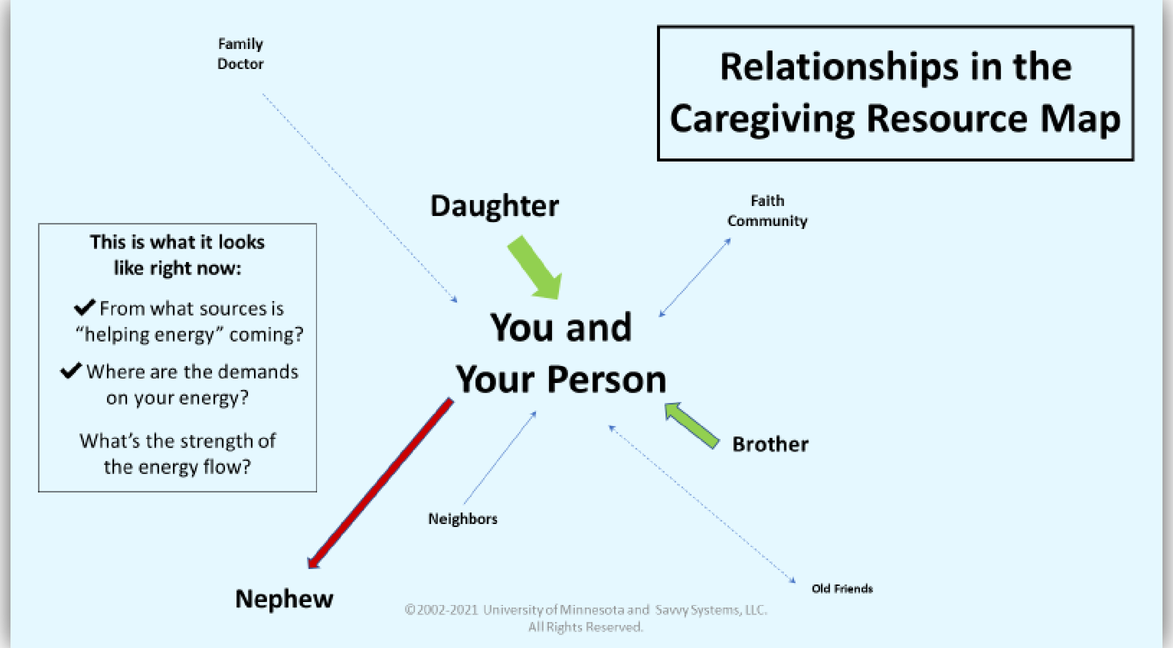
First: Make a list of everyone and every organization you can think of that somehow touches you and your person. List all of the family members, even the distant ones. List all of the friends and neighbors. List all of the groups and organizations (clubs, religious institutions, medical and other service providers, etc.). Be sure to include people and groups that used to be connected with you but no longer seem to be in the picture.

Once you've made the list, make a "map." Below is an example.

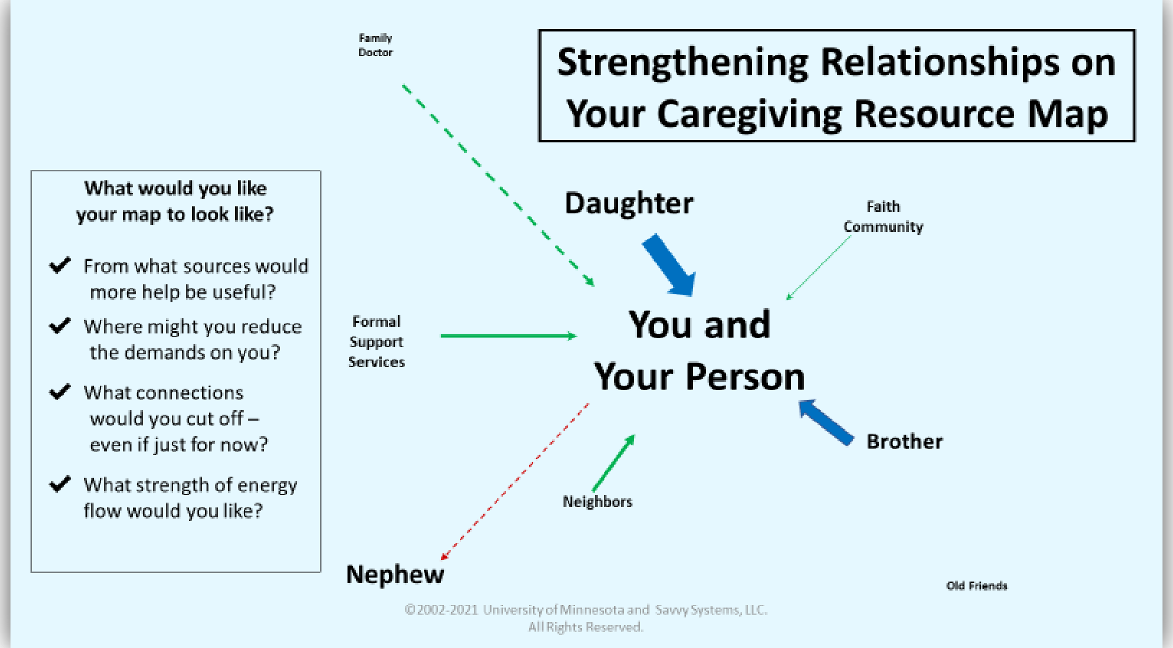


Put yourself and your person in the center of a blank piece of paper, just like in the image below. Then place everyone and every organization or group on the map. Put those with the greatest impact on your lives close to you and those with the least impact at a distance. Make the names bigger or smaller depending on the extent to which they are or are not big and important presences in your lives. It doesn't matter if the presence is a positive or a negative one. Just use the size of the name as a way to represent the amount of impact you feel from the person or group.

Next: Draw arrows between the people and groups and organizations to you and your person. The direction and size of the arrows are important. If you get help from someone, have the arrow point from that person toward you and your person. If that person or group makes demands on you, have the arrow point away from you and toward that person or group. If the help and demands are relatively equal, draw a two-headed arrow. Once the arrows are drawn, describe how strong or weak the connections are. Very narrow, dashed-line arrows represent very weak connections. Broad and bold arrows indicate strong connections. Arrows of various widths represent the differences in intensity of the connections in your caregiving network.



Finally: Step back from the map. Ask yourself, as you look at the arrows: Is this working the way I think it should be? Am I getting the help and support I need? Are there people or organizations that are asking more than I can give right now? Are there people or organizations that are letting me down? Are there people or organizations that aren't on the map that should be there?



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?

When you've studied the map for a while, redraw it in a way that you wish it would look, so that you and your person would get as much help as possible and have as few demands on you as possible.

The final map (above) provides you with information. Are there those from whom you want more help? Are there some with whom you want to cut ties or reduce the amount of contact? Are there those (for example, formal support services) whom you might approach for help?

In the example pictured, the caregiver may have realized that the family doctor could be more helpful. The nephew is demanding too much and draining too much energy; there needs to be more distance. The faith community has been asking too much and helping too little. There are services out there than need to be tapped. The old friends haven't called for a long time and put you off when you call. Maybe it's time to put them out of mind for a while and to stop trying to connect with them. It may be that you are getting good help from a couple of sources. Acknowledging that help is important; you want it to continue.

As the person’s condition progresses, the challenges are likely to grow. As the challenges grow, the resources needed to meet them are likely to change. So, it may be a good idea to repeat this exercise from time to time. See if there are ways to change the map. We will look at some strategies in Session 6.

Weekly Session 5 Notes

Weekly Session 6

“Caregivers can get good at—and feel good about—mastering a basic set of caregiving skills.”

Strengthening Family Caregiving Arrangements

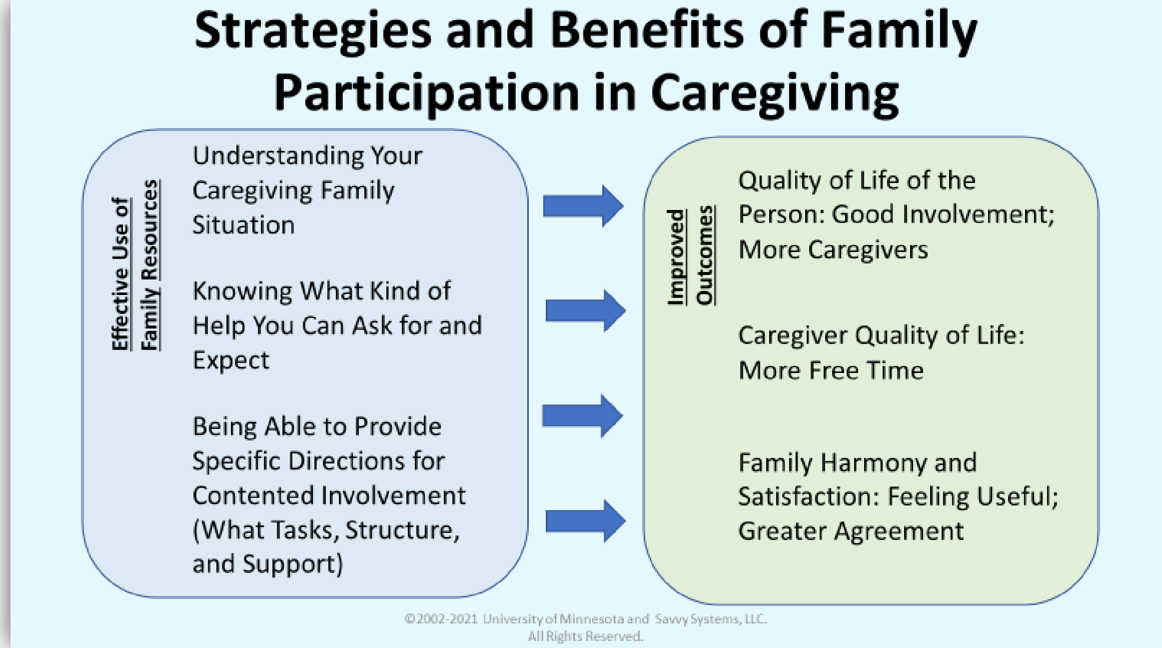
Caregiving for a person living with a dementia illness presents unique demands and challenges for the primary caregiver, but also affects the family as a whole. We define "family" broadly. **The key is how you, the caregiver, define "family" for yourself.** This often includes blood relatives but might include friends or others who are considered to be family for you (your "family of choice").

Family life has changed a lot over the past decades, with more of us living away from relatives, two-parent working families, and high rates of divorce and remarriage. Family roles and responsibilities are shifting and often complicated. There can be added confusion about caregiving roles and responsibilities in stepfamily situations.

In any event, relatives and people who are close to the person with the illness will be directly affected by the changes in the person. These people may provide you with emotional or hands-on assistance. Or not. They may visit you and your person. Or not. **The key here is to recognize the kind of caregiving network you are in and to figure out ways to manage and benefit from it.**

There are several ways to categorize types of caregiving networks. This section describes the main barriers and the key aids to improved caregiving. It is meant to help caregivers link this new knowledge about what kind of caregiving situation they are in with what they have already learned. It should assist you in asking for specific kinds of help from others – like family members or friends – who already share a relationship with the person living with Alzheimer's or a similar illness.

Why is it important to make effective use of other resources? What is involved in doing that? The diagram here suggests that the improved involvement of family members or others as caregiving resources can lead to several positive outcomes. The key to those outcomes is recognizing what kind of help you can reasonably expect or hope to get from others. You also need to know how to ask for that help. This begins with having a basic understanding about the kind of caregiving situation you already have.



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

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The latter part of the manual provides two ways of understanding caregiving alliances. One is a way to describe a broad range of relationships that a caregiver might have with his/her family and community (your Resource Map). The other is a way of describing the kind of dynamic that might exist between the individual caregiver and that family and community. These can help you to see where help is coming from, where drains and disappointments are present, and where weak support might be strengthened.

The section also explores possible reasons why people and organizations who might be helpful in caregiving do not meet expectations. It suggests several strategies you might use to strengthen the support s/he receives from their resource network. It frames the disappointments and drains in terms of decisions you might make to redefine your network.

Why Make Effective Use of Caregiving Resources?

Effective involvement of family members and/or others as caregiving resources can lead to many positive outcomes. The person who is cared for benefits from having more care. This may improve his/her overall quality of life. There are also clear benefits for you as a caregiver that can improve your quality of life. With more support and assistance, you are less isolated in your role. The generous work you do within that role is better understood and appreciated. You may find more time for your own life and for taking care of yourself. Family, friends, and the community can take pride in caring for one of their own and in living up to their own expectations.

Types of Caregiving Arrangements

There are several ways to categorize the dynamics of caregiving arrangements. This manual describes five common caregiving arrangement types: **Solitary** Caregiving, **Observed** Caregiving, **Tag-Team** Caregiving, **"Uneasy"** Caregiving, and **Collaborative** Caregiving. Being able to identify the type of arrangement situation you are currently in may help you decide about strengthening or redefining your caregiving group.

It may help you to understand your current arrangement. You might identify another possible arrangement. You may decide that a different one is going to be better for you. It should assist you in identifying what kind of help you can reasonably expect or hope to get from others.

We also describe some main barriers to effective caregiving networks and provide suggestions for overcoming these barriers. This may assist you in asking for specific kinds of help from others in the network.

Families or care teams usually fit into more than one type of caregiving arrangement. One type is not necessarily better than another, although some do seem to involve more help while others involve more conflict. Caregiving arrangements often change as the dementia illness progresses and caregiving needs change.

Now, let's look at each of the common caregiving arrangement types in detail.

1. **Solitary Caregiving**
   One person does all the work of caregiving in solitary caregiving. Responsibility of care rests almost solely on that caregiver even when other concerned people like family members live in the area. Perhaps social connections have weakened or been cut off. The breaking of connections may be from both sides, and it may not be intentional. Those connected to the caregiver may not understand the situation. They may feel unsure how to help. They might even be frightened by the person's condition. The caregiver may not want to ask for help. The caregiver may be unclear about what or how to ask.

   Example: Tina married Paul six years ago. Paul started showing signs of a dementia condition four years ago. Tina can no longer leave him alone. Her two daughters from her first marriage live in the area. They have offered to be with Paul while Tina goes out. Tina feels that, since Paul is not their father, her daughters should not have to deal with his condition. This leads to Tina not taking them up on their offer. Tina also knows that they have their own families to care for. Paul's two children live out of state. They visit once a year and call weekly. They also have jobs, families, and very busy lives. They do not offer to help. Tina is a solitary caregiver.

Tina had been active in her faith community. She has stopped attending services, and being active in its food bank activities. No one from her faith community has reached out to her. She has not told anyone about the situation. Paul and Tina belonged to a group of friends with whom they went out to dinner monthly. They no longer go out with the group. No one from the group comes around. Tina is feeling cut off. She feels disappointed that her faith community and her friends have not reached out to her and Paul.

2. **Observed Caregiving**
One person does all the work of caregiving in observed caregiving. Others are vocal about how they think care should be given, but they do not offer to help. There is a community of sorts. It appears to be a community of critics, advisors, and commentators. Family members, friends, and others also continue to make demands of the caregiver as if the dementia condition was not happening.

Example: Agnes was diagnosed with Alzheimer's two years ago. Her caregiver husband, Ron, has health problems of his own. Their daughter, Susan, is worried about them both. Susan keeps insisting that Ron and Agnes move into assisted living. Ron does not want to move. The house is paid for. He knows the people in the neighborhood. What he would really like is for Susan to come and clean the house, but he does not feel right asking Susan to help him. Their son, John, is concerned about the parents moving to an assisted living facility and their assets being used up. He and his sister may then need to assume some financial responsibility and might lose their inheritance. John is encouraging his father to "hang in there." He wants his dad to keep taking care of his mom at home. The children are not really helping. They are putting pressure on their dad.

Ron's golfing buddies keep asking him to play in their regular game. They are critical of him for not coming. Ron does not feel that he can leave Agnes alone. He had been active in his precinct political caucus. He is getting pressure to continue at a past level of activity. The golf partners and the community group members keep telling Ron that he is “coddling” Agnes. They think he should get on with his life. Their family doctor tells Ron, “It is dementia. What can you do?” Like the son, the doctor encourages Ron to “hang in there.”

3. Tag-Team Caregiving

The work of caregiving is assumed sequentially in Tag-Team arrangements. The responsibility of caring for the person living with a dementia condition rotates among caregivers. One person at a time is a primary caregiver in tag-team groups. Such arrangements often reflect a high degree of commitment by the caregivers, and communication needs to be deliberate. They also may not take full advantage of the resources that might be available for caregiving.

Example: Benjamin is the father of three children. He is living with Alzheimer’s. He can no longer take care of himself. His wife died two years ago. His children take turns caring for their father. They have arranged it so that Benjaminstays a month at each child’s house. Each child is responsible in turn for getting Randy to his usual day program and taking care of him at night. The other two siblings are not expected to help when it is not their turn unless there is an emergency. Each child functions as a solitary caregiver in each month. The organized arrangement among the children does provide care. It involves backup and support.

There is little coordination and communication among the children. There is no effort to share their observations about their father’s condition. There is no sharing of “what works” in caregiving. may be experiencing highly fluctuating kinds of care in the three environments. There may be no coordinated effort to help him find Contented Involvement in each of the three settings.

Moving in with his children meant that Benjamin left the neighborhood he knew well. None of Benjamin’s anchor institutions is involved with him any longer, and he is isolated from everything in his village except his children even if he does not realize it.

4. “Uneasy” Caregiving Arrangement

More than one person cares for the person living with a dementia condition over a given time period in an “Uneasy” caregiving arrangement. Members share the work but do not necessarily focus on the same goals. They may not have similar styles of providing care. The “unease” between or among the caregivers can get in the way of coordination of care. It may also interfere with other caregiving activities that are being performed by others.

Example: Sara and Martha are both caring for their mother, Margaret, who continues to live in her own apartment. Sara and Martha both have their own families and live across town from their mother. They agree it is good that Margaret remain in her apartment. They disagree on the extent to which the dementia illness has affected her ability to care for herself. Sara believes that Margaret should do as much for herself as possible. She thinks that that this will keep her alive and alert. Sara has Margaret help her make dinner and do small chores around the house when she brings her mother home to visit.

Martha feels Margaret is too frail to leave her apartment. She worries about her mother's safety. Martha is afraid that Margaret will cut herself or burn herself on the stove while helping Sara cook, and has repeatedly asked Sara not to let their mother help . Sara believes that Margaret enjoys helping, and that her mother is not in danger. Martha does everything for her when she is with her mother. Martha considers herself a good daughter and caregiver. Sara thinks Martha is "babysitting" Margaret. She thinks this kind of caregiving will make Margaret worse.

Margaret's neighbor, Bill, used to drop in on Margaret regularly to check on her. He also took her to the store with him. Sara is grateful for this attention. Martha is suspicious of it. She worries that the outings may be dangerous. She is also worried that Bill might be trying to take some advantage of Margaret. Martha has made comments to Bill that let him understand her suspicions. He has stopped visiting.

5. Collaborative Caregiving Arrangement

Several key people take part in caring for the person living with dementia in a Collaborative caregiving arrangement. Group members share a common understanding of what help is needed. They work out a plan for delivering that help. Members perceive the help each provides as supportive of the person living with a dementia condition and of their own efforts to provide care. Everybody pitches in to help. Each person does not necessarily have to do the same amount of caregiving or the same tasks. The common understanding of the situation and care needs paves the way for broader caregiving assistance from others in the group of family, friends, and other community members.

Example: Sharon cares for her husband, Ray, who has had a dementia illness for about 5 years. Sharon gets quite a bit of help from her three children, Ray Jr., Paula, and Fred. Fred takes care of the outside work on the house. He mows the lawn and repairs things around the home. Paula does the shopping. She helps her mother clean the house. Both Fred and Paula visit frequently. Ray Jr. lives 10 hours away. He cannot give the same consistency of help. He does find a way to help his mother manage the family's finances. And, he comes and stays with his father so she can visit her sister in Nebraska one week each year. Ray Jr. also comes home during long holiday weekends to do what he can. All family members want to keep Ray at home as long as they are able.

Paula knows the leader in Ray and Sharon's faith community well. She has let him know of the family situation. Paula has worked with the pastor and a women's group in the community to arrange for regular home social visits. Some community members come every few weeks to allow Sharon to get out for a few hours. The parents of Ray Jr's best childhood friend still live in the neighborhood. Ray Jr. has asked his friend's parents to "check in" from time to time. The friend's father has now asked Ray to take short walks with him.

Where Do You Fit?

Think about how you would categorize your caregiving situation. It would not be surprising if you said a blend of types. Think about where you see yourself, your family, or your group of concerned people fitting.

Now think about what type(s) you would like to be operating in. How would you know when your situation became a different type of caregiving alliance? You might say:

- It would be less of a Solitary Caregiving situation if I would ask my grown children, neighbors, or friends from the bridge club for help more regularly.
- It might look different if I would accept offers of help from my children.
- We would be a Tag-Team family if my sister would take care of Mom every other week, or every other month.
- We would be a Collaborative Team if my sister managed the finances, my neighbor mowed our lawn, and my husband's best friend took him to the barber.
- We would be a Collaborative Team family if my sister would call Dad every week to ask him how he is doing, since she lives out of town.

Hopefully you have identified where you would like to be among the caregiving categories. Hold that thought. The next section will help you to begin to build a strategy for moving closer to where you would like to be in terms of caregiving.

Barriers and Aids to Successful Caregiving Arrangements

Caregivers often feel unable to take time for themselves. They cite specific obstacles or barriers. Caregivers often wonder if others will do as good a job at providing care as they do. Caregivers may be careful not to impose on others by asking for help from grown children or friends who are busy with their own careers or families. Caregivers have been known to turn down help.

Others often *do* want to help but do not know how or what to do. Give relatives and friends information about dementia illnesses. Offer details on how best to interact with the person. Help them to overcome hesitance to be alone with him/her by addressing their lack of confidence or experience. Not knowing what to do if the person gets agitated prevents many people from offering their help. You might share this manual with family and friends who are interested.

Barriers to Forming Effective Caregiving Arrangements

There are three main barriers that get in the way of successfully coping with and providing care for a person living with a dementia condition: denial or lack of recognition, lack of role flexibility, and lack of experience.

- **Denial or Lack of Recognition.** People are sometimes unable or unwilling to acknowledge the presence of a dementia illness. They may also be unable to accept the losses associated with it. This is quite common around the time that someone is seeking or considering a medical evaluation.

  Both the person living with dementia and his/her family members and friends can be in denial. Some people are not ready to confront the reality of how the disease will affect lives, roles, and relationships. Relatives may be struggling with the loss of their relative or friend as the condition progresses, and may not want to face the fact that life will change.

  People cannot cope successfully if they cannot see or admit there is a problem. Denial or lack of recognition is often a cause of friction. Family, friends, or community members who do not admit what is happening are likely to resist the caregiver’s efforts to seek their help. They may not understand and may even criticize a caregiver for wanting to use outside help like a day program, assisted living, or a nursing home. This puts additional pressure on the caregiver. S/he cannot turn for comfort or support to those who do not or will not see the reality of the situation.

Caregivers need to understand that denial or lack of recognition result from fear or lack of information. They are not necessarily signs of being uncaring. Providing information about the disease and the situation, and helping someone to spend time with the person who is living with the dementia illness are both powerful tools for getting someone to accept the facts of the situation.

- **Lack of Role Flexibility.** A second barrier for families, friends, and communities coping with dementia illnesses is the inability to adjust and change roles. Adjustment is often necessary when someone is living with a dementia illness. S/he gradually loses the ability to perform tasks like driving, paying the bills, cooking, and making major decisions, like where is the best place to live when someone develops a dementia condition. The caregiver often finds that doing all the things s/he accomplished before the onset of the disease is more difficult. Taking on new tasks may feel extremely difficult. The person also gradually loses the capacity to engage in usual social interactions and activities. The person’s role in the family, their faith community, community groups, and the neighborhood changes.

  Lack of flexibility can lead to disorganization within a family. It can also lead to responses by family, friends, and community that exclude and isolate the person with the disease and the family caregiver. The family’s transition into caregiving will be smoother and the family will be a resource in caregiving if members of a family are flexible regarding who can perform certain roles.

  Take the example of a mother of a large family who used to prepare elaborate holiday dinners for everyone in the extended family. She is no longer able to because of her condition. Someone else can take over the role of hosting holiday dinners or other members can share the responsibility if roles are flexible within the family. The family may stop having holiday dinners together if they lack role flexibility. They might feel that was always Mom’s job. Nobody else feels willing or able to do it.

The caregiver may foster or support role inflexibility. Parents frequently see their role as providers of assistance rather than recipients of help. They believe their children are too busy with their own lives to assist them. Some caregivers can't or won't ask others for help.

The caregiver has to recognize his/her own need for help. He or she benefits from finding ways to ask the family to reorganize itself or friends to redefine roles around the reality of the situation brought on by the dementia disease.

- **Lack of Experience.** People may not know what to do to care for a person living with a dementia condition. They may have never been in this situation before. They may have no models for how to act or respond.

  Lack of experience may show itself in at least two ways. First, a person may not want to spend time with the person living with Alzheimer's or a similar illness because they do not know what to expect. The disease is a mystery. The behavior of a person living with a dementia condition is puzzling. S/he might fear being unable to "handle" what the person might do. Second, people may not know how much work is involved in caregiving or how to do it. They may feel inadequate about how well they could provide care if they were to be "in charge" of the person. This may make them less likely to offer help and understanding.

  It is also important to recognize that family relationship history may affect how much help the caregiver wants or can expect. The nearly endless kinds of family dynamics that were present before the illness will likely shape reactions to the changes in role and relationships caused by the illness. A caregiving adult child from a family of supportive parents may anticipate more caregiving support from siblings than a caregiver from a home characterized by neglect. A person who returns to care for a divorced spouse (this happens) may expect less support from the rest of the care recipient's family. A spouse caregiver might expect less help from the spouse care recipient's children from an earlier marriage.

Strategies for Enlisting Help with Caregiving

There are three ways to help break through barriers to create successful caregiving alliances and help others cope with caring about someone who is living with a dementia illness. These tools help in everyday life. They are more crucial when an illness invades a family or social circle.

1. **Gain knowledge and skill – and then share it**. It is important to know about dementia conditions and their progression. It is even more important to know how to manage things as the condition progresses. It is also valuable to know about 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 help people organize successfully to aid in caregiving. The person living with a dementia condition and caregiver(s) will benefit if individual members of a care network know the types of losses the person will face, techniques for interaction, and ideas to maximize quality of life.

   Share what you have learned in this program. Ask others to take the Savvy Caregiver course. Let them read this manual. Urge them to go through the exercises to estimate your person's cognitive level. Ask them to see what the disease means for you and your person.

2. **Have a plan**. When people say, as they will: "This is so hard for you. I wish I could help," be ready to say: "You can, and I'll tell you how."

   You know the things your person enjoys doing. You know how to set things up and help the person to get involved in these things. You probably even know the times of the day when the person is at his/her best. You know the warning signs when the plan might be going off the rails. And you have strategies for handling certain problematic reactions or for keeping the person meaningfully occupied.

   Package this knowledge. When someone offers to help, be ready to say: "Here's what you can do, and here's how you can do it." "Would you be able to come over on (say) Saturday afternoon for an hour or so?"

   Be ready to provide directions and guidance so that this small occasion of helping can be successful for your person and for the person who is helping. Building other people's caregiving skills can expand the capacity of your resource network. Consider other ways people could help you too.

3. **Practice good communication.** Caregiving alliances work better when people share common goals and strategies. Communication helps break down the barriers to successful caregiving alliances. Communication also helps with building successful caregiving alliances by allowing for shared knowledge and making a plan. Creating a plan for successful caregiving relies on exchanging information on what individual members need and can provide. You also need to know what goals each person has regarding caregiving and the future of the member with the dementia condition.

   Talking about the disease and how it affects all members of the family and your larger network can help people let go of denial. Communicating about day-to-day caregiving with family members and friends enables them to understand the effect of the condition on the person and you. Communication about what works for you in your interactions with the person helps others feel more comfortable around him/her. Other people will be more able to assist with the tasks that need to be accomplished if you are able and willing to let them know what you need, and what works in day-to-day caregiving.

   Communicating emotions also fosters feelings of support and understanding. Talking helps get over barriers most people face when struggling with a long-term progressive disease like Alzheimer's. Family members and others are more likely to pitch in and offer support when they truly understand.

Try an exercise meant to highlight concrete steps that you could take to improve your resources for caregiving. Think again about the kind of caregiving situation you wished you had. Think about the following:

- Consider each of the barriers in developing caregiving alliances: denial, role inflexibility, and lack of experience. Work through what you see is stopping you and others close to you from more effective caregiving in your situation.
- Consider the aids and strategies in developing caregiving alliances: increasing knowledge and skills, having a plan, and practicing good communication. Indicate what kinds of knowledge and skills you wish members of your caregiving alliance had. Do you have a plan or plans?

Rally resources to compile concrete plans with your new Savvy Caregiver insight and confidence. Work with others to get agreements about specific help they will give. Give them specific directions about how they can be successful in providing that help. Practice what you would like to say to others.

Further Reading:

Sherman, C.W. (2012). Remarriage as context for dementia caregiving: Implications of positive and negative support for caregiver wellbeing. *Research in Human Development, 9,* 165-182.

Cade, E. (2002). *Taking care of parents who didn't take care of you: Making peace with aging parents*. Hazelden, Center City, MN

Weekly Session 6 Notes

Conclusion

The Savvy Caregiver

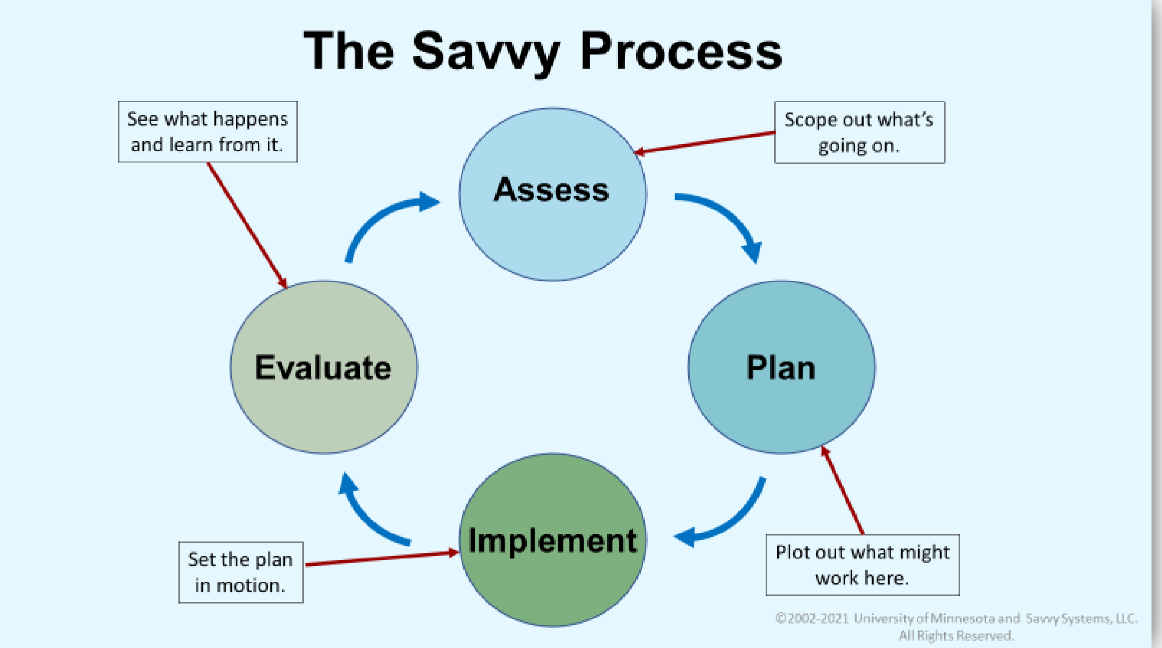
Knowledge, Skills, and Mastery

Going Forward

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 has 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.

Review of the Savvy Process

The Savvy process that you learned will be key, going forward.



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.

Behavior has Meaning

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.

Other Key Savvy Lessons to Keep in Mind

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.

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!

Conclusion Notes