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- PRESENTS -

SAVVY *Caregiver*

A series of classes for relatives or friends
providing unpaid care for a senior

**Professional-Level Training for the Non-Professional
Caring for a Loved One with Dementia**



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UNIVERSITY OF MINNESOTA

The Savvy Caregiver

Caregiver's Manual

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Introduction

The Savvy Caregiver Program (SCP) is a **training program** for caregivers. Caregivers are persons like you who care for family members who have a dementing illness, such as Alzheimer's disease.

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 does for his or her relative. It is work.
- **The caregiving role has a “job description.”** You couldn't hire other people to love the person you care for the way you do. But think about this. You could, *if you had the means*, hire people to do 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 with a dementing illness is specialized work. To do this work successfully, caregivers need special skills and knowledge. They also need an outlook or attitude that helps them to look after themselves.

The Savvy Caregiver Program will give you that training.

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 but 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 the 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 generally 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 program, you will learn about the strategies that a number of researchers and clinicians have developed in their work with persons with Alzheimer’s.** The most important thing, though, will be for you to work out how to make use of these strategies in your own caregiving.

Why Become a Savvy Caregiver?

Family members who take on the caregiving role are often under a lot of stress – usually for a long time. When dementia caregivers are compared with persons like them who are not caregivers, the potential perils of the situation are clear.

Dementia caregivers are:

- Twice as likely to have health and mental health problems
- Two-and-a-half times as likely to be taking medicine for their nerves
- Only 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 pinched financially.

Being savvy about caregiving won’t stop the course of what you are dealing with or make it go away. Savvy caregiving won’t mean there will be no stress in the day-to-day or the long-term situation with which you are dealing.

* We’ll give you references to authors, books, articles and websites, so you can find more information if you want to.

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

What's This Training Program About?

The Savvy Caregiver program is built on the notion that the successful caregiver has three main tasks:

- Manage daily life with the person
- Find and use help with caregiving tasks
- Take care of yourself

Managing Daily Life

This program stresses that the most reasonable goal of caregiving is to keep the person content and involved as much as possible. This program will help you to develop caregiving strategies to do that.

The training to promote contented involvement is built around two ideas:

- People are most content when they are doing things they enjoy and doing things without feeling anxious.
- Confusion is the principal problem in dementia. Confusion is the upsetting feeling of being mixed up and overwhelmed by all that is going on around. It is the root of many of the problems caregivers face, particularly problems related to behavior. And it hinders people from being content and involved.

This gets to the heart of your day-to-day management task. As dementia progresses, your person will lose ground. Your person will:

- Be less able to direct his or her own life.
- Become more confused.
- Have less reliable powers of thought and communication.

As these things happen, the challenge to help the person to be involved and content and to keep confusion at bay also increases.

Dementing diseases and the behaviors of persons with dementia can be puzzling. It is important to recognize that behavior is just what people do, how they act. The word does not mean “good behavior” or “bad behavior.” It only means action – like walking, talking, or sitting.

As the disease goes on, people become more confused and are less in control of what they do – of how they behave. They won’t necessarily know why they are behaving in a certain way. They will almost certainly not be able to tell you why they are doing things. And they will not be able to respond to attempts to use reasoning to change behavior.

This doesn’t mean that behavior is random or meaningless. It is useful to remember that all behaviors have meaning. Behaviors are typically reactions or responses to needs, emotions, wishes or impulses.

Many caregiving strategies have to do with figuring out what their person’s behaviors mean and how to deal with those behaviors. The disease makes this harder to do:

- The old ways don’t work.
- The person won’t or can’t help you understand.
- You have to take control.

Getting Help

The second kind of caregiving work is that of resource management. This work can take two forms:

- Strengthening family (and friends) as resources for caregiving.
- Finding and organizing formal help (like physicians, home health agencies, and the Alzheimer’s Association).

Strengthening resources – family and friends. All caregivers are involved with relationships. There is, of course, the relationship with the relative who has dementia. But there are often other relationships as well:

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

The Savvy Caregiver program offers help for caregivers with two frequent problems:

- **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 in helping the family member with dementia.
- **Help.** Sometimes, family members and friends don't know help is needed. Often they don't know what help to give or how to give it. Savvy Caregivers know the many different tasks involved in caregiving. They are better able to decide which parts others might play and to instruct others in how to perform those tasks.

Using outside resources. There is help for caregivers. You have to be able to find and use 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 number, 1-800-272-3900, for a referral to your local chapter. Seek information from their web page at www.alz.org. No matter where you live, there are regional and national help-lines available. The U.S. Administration on Aging can help you find your local help line. Use the Eldercare Search Line (<http://www.eldercare.gov/Eldercare/Public/Home.asp>) or call toll free 1-800-677-1116 (M – F 9:00 am – 8:00 pm ET). In many places, there are agencies that offer help that can come into the home. Adult day programs or volunteer visitors may be available for your person. The Internet offers access to information and help. A series of caregiver education pamphlets is available at

http://www1.va.gov/minneapolis/services/grecc/serv_grecc_pamphlets.html. Home health care agencies and senior centers can be sources of help.

Caregiver Self-Care

Caregiving is a generous and loving act. It is also taxing. Burden and burnout are real problems. This program emphasizes the need for caregivers to attend to their own needs. It provides a number of strategies that caregivers can use to recognize and deal with their own feelings and to care for themselves.

The program also works on strengthening decision-making skills. Over time, the caregiver becomes the decision-maker for the household. This is true if the caregiver is a spouse, a child, or other relative. For some caregivers, being the one who has to make the decisions may be a new experience. Even for those caregivers 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 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 daycare 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?

Becoming a Clinician.

Being a savvy caregiver is like being a nurse or a doctor – or a detective or scientist. Savvy Caregivers are analysts and problem-solvers and action-takers.

Savvy Caregivers are able to stand back and look at the scene coolly. They recognize they have to exercise control. They know they will have to figure out what's best for the person in any given situation. They see that the person may have less and less to contribute to solutions.

Savvy Caregiving is not business as usual. Usually, when we interact with another person to solve problems, we can rely on that person for critical 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 how much of a crisis it is.
- ✓ give us some idea about what kind of solution s/he wants.
- ✓ cooperate with us in solving the problem.

Caregivers are faced with having only parts of the usual information. The person's behaviors may give the clues about what is happening. Familiarity with the person and knowledge about dementing disorders may help to form hunches about what may be going on and what might help. These hunches will lead to trying things out to attempt to solve the problem. Some solutions may work; others won't. It's possible that some solutions may even make the problem worse for a time. If the first solution doesn't work, you will devise another and try it out. Eventually you will solve the problem.

Through this process, caregivers learn more about how the disease affects the family member and what strategies work – and when they work. They store up information and classify it under “things that don't work and things that do work sometimes.” 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 learn more about themselves as they work with their family member. They learn in what ways they are comfortable and effective. They learn what skills they want to improve. They see where they are confused and need help, advice, or information. Like great nurses or doctors, Savvy Caregivers are constantly looking to get better at what they do.

What Does this Program Teach?

The program unfolds over a series of sessions. Usually there are six sessions, but this may vary. The main focus of the program is on the first task of caregiving, Managing Daily Life. It covers finding help and taking care of yourself as well.

The training program covers a number of topics in a set order, and the manual is set up to follow this order:

It's a Disease

The first part of this manual is a guide to dementia. It is structured with caregiving in mind. It provides general background information about the disease with which you are dealing.

Thinking Through What the Disease Means

This section has two purposes. It focuses on how dementing disorders affect key powers of thought – like memory, reasoning, and judgment. It also begins to introduce you to caregiving strategies. Looking at each of the losses of thought, the section points out how caregivers have to think and work strategically when providing care.

Feeling Through What the Disease Means

It's one thing to think about how dementia works on the person. It's another thing to appreciate how it must feel to experience having this disease. This section of the training helps caregivers understand and feel how powerful a role Confusion plays in the daily reality of the person. It focuses on the emotional needs Confusion creates in the person and what these needs can mean for the caregiver.

Taking Control

The caregiver comes to recognize that s/he's in control. 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 threatens and, eventually, destroys the ability to make choices. Taking control can reduce confusion and provide calm and security. But caregivers have to understand and accept this new part of their role.

The Goal of Care

Caregivers need a goal for the work they're doing. Dementing disorders cannot be cured and, usually, their progress cannot be stopped. So what's left? People with dementia **can** have good quality of life. They **can** have a series of days that are busy with things they enjoy. This section of the training will focus on setting this kind of a goal.

Your Person's Abilities

Because dementing disorders are progressive, your person's abilities decline over time. In this section of the program, the Savvy Caregiver learns a practical way to describe how abilities decline.

Providing Practical Help

The focus of this section is on how to help the person to become and remain involved and content in tasks and activities. This section draws on everyone's natural sense of matching activities to abilities.

Dealing with Daily Care and Complicated Behaviors

This section provides guidance and suggestions about how to look at and change behaviors that are challenging. It also provides information about how to help with other care chores.

The manual includes material on three other topics covered in the Savvy Caregiver program. These topics include:

- **Self-Care**
- **Families and Caregiving**
- **Decision Making**

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. Some people find it easier to take notes on these handouts than to write in their manuals.

Instructional Media

Material for the talks in the training program is all in the manual. You can read the manual like a book even without the training. The program relies on some video materials that are available in a number of ways. The organization may have a video that will be used in the program. You can obtain a CD-ROM entitled "Dementia Caregiving Strategies" that contains much of the material that is in the

Savvy program.* The CD-ROM (and an on-line version of the same material) are available through a group called Healthcare Interactive. Their web address is <http://www.hcinteractive.com>. These are neither necessary nor required. The manual and the CD-ROM go together in many places in this program. The CD-ROM includes information that ties directly into key points of the training.

What Should You Expect During Training?

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

- **Participation.** You already have a great deal of experience and expertise in caring for your loved one. As such, you are one of the experts in the class. We encourage you to contribute to everyone else's learning.
- **Preparation.** We plan to give you "homework." We will ask you to read sections of the manual to prepare for the next session. Most times, 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.

* This CD-ROM was developed by the Veterans Administration Education Service. The producer was Richard Adelson, DDS, and the contributing authors included Ken Hepburn, PhD from the University of Minnesota (UM), Melitta Maddux, RN, MS from the VA Geriatric Research, Education, and Clinical Center (GRECC), and Stan Smith, MD, MPH (UM). The curriculum of the CD ROM and the Savvy Caregiver program derives from research conducted at UM on a family caregiver education program called the Minnesota Family Workshop. Further information on that program and the results of that research can be found in the following articles:

Ostwald S, Hepburn K, Caron W, Burns T, Mantell R. A randomized psychoeducational intervention for caregivers of persons with dementia. *The Gerontologist*, 39(3), 299-309, 1999.

Hepburn K, Tornatore J, Center B, Ostwald SW. Dementia family caregiver training: Affecting beliefs about caregiving and caregiver outcomes. *Journal of the American Geriatrics Society*, 49(4), 450-457, 2001.

What Should You Expect from the Training?

We expect the program will expand your knowledge and skills for caregiving. The most important outcome, though, should be that you will feel more sure of your ability to carry out the caregiving role you have taken on. The word we use to describe this feeling is **Mastery**.

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 family member. We want *you* to appreciate how skillful you are.

Introduction to Dementing Illnesses

This overview section includes:

- ✓ A brief discussion of what normal aging is like
- ✓ A definition of dementia.
- ✓ A description of the main diseases that produce dementia.
- ✓ Information about depression – a disease that can look like dementia.
- ✓ A description of the course of dementing diseases.
- ✓ A discussion of medical evaluation and care.
- ✓ Information about treatment possibilities for dementia.

Normal Aging.

Just about everything we do slows down as we age. Our physical body functions are slower and weaker. It takes longer to do things, and we tire faster. This slowing is only fractional. Researchers can measure the difference, and we might be able to feel the difference. Generally, it's just a gradual and slight slowing down. Physical exercise is beneficial for older people. With exercise, they can, for example, increase the size and power of muscles. The improvement in size and strength is not as great as that experienced by younger people doing the same exercise, but they do gain strength and size.

The same is true for mental ability. There are small – but measurable – slowdowns in thinking. We process information more slowly than when we were young. It takes longer to recall information. And to learn new things. Mental exercise is effective in older people. With mental exercise, older people's processing speed and capacity is increased. Again, when compared with younger people doing the same exercise, older people don't gain as much speed and capacity.

Most people, as they age, notice this physical and mental slowing and loss of capacity. 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 ask someone for it), and come up with the word or a good substitute. . When these things occur with older people, 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 their keys or glasses. They remember these "tricks." People may also realize that, in their case, 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

Dementing illnesses are not normal in aging. About 5.4 million Americans are affected by Alzheimer's and similar diseases. That means about one in seven persons over 65 have this disease. If no cure is found before then, about 15 million Americans will be affected by 2050.

These conditions – Alzheimer's and similar dementias – are not at all the same as the normal decline that occurs with age. They are produced by diseases that are attacking the brain.

Dementia affects memory, thinking, behavior, and the ability to care for oneself or to function safely and independently in the world. In almost all cases, these diseases are progressive and global. This definition contains a number of important parts.

This is a disease. It is an important step in caregiving to acknowledge that what is going on in your family member is due to a disease. 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 will the problem to go away.

It is not a normal part of aging. Even though this was covered in the section above, it is important enough to repeat. Everyone's powers of thought slow with age. However, the losses in dementia are more profound and come from a different source. Dementia is the result of a disease in the brain.

The disease is almost certainly progressive. You are dealing with a moving target. The person's condition changes and gets worse over time. An ability that the person has today will begin to fade, and over time it will be lost. As a caregiver this means that things that work in caregiving today may work for a while. Over time, strategies for managing the daily activities of affected family members will almost certainly have to be changed as your loved one loses more ability because of the disease.

It is global. The disease affects a person's entire range of thinking abilities. Often dementing diseases are thought of as diseases of memory. That's only partly right. Memory is always involved, but it is important to realize that all other areas of thought are also involved.

Dementia interferes with a person's ability to function safely and independently in the world. This goes beyond forgetting other people's names. The person loses the living skills we tend to take for granted. The world becomes foreign. The person doesn't recognize it or know how to get around in it. The person may gradually lose the ability to behave in "normal" 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 or handling tools.

Dementia is a condition. There is no disease called "dementia." The word dementia refers to a condition (sometimes called a syndrome) that can be caused by many diseases. A condition describes the effects, which means the signs and symptoms that result from having a disease. Alzheimer's is one of the diseases that cause a person to be identified as having a dementia. So the main difference between "dementia" and Alzheimer's is that one (dementia) describes what is happening and the other (Alzheimer's) provides the name of the disease that is causing it.

What Are the Main Diseases that Cause Dementing Illnesses?

All dementing illnesses are brain diseases. At least 70 different diseases can cause a dementing condition. Most dementia is caused by Alzheimer's disease or vascular dementia (also called multi-infarct dementia) — or a combination of the two. These diseases act in different ways to cause the brain to lose its ability to absorb, recall, or make use of information.

Alzheimer's disease is the most common form of dementing illness. It produces abnormal deposits of proteins not normally found in the brain (amyloid and tau). These proteins bring about the death of brain cells. They do this either by choking 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 communication channels. As cell loss and chemical imbalance continue, the brain's abilities decline. By the late stage of the disease, few important abilities remain, and people appear unable to function on their own. They seem entirely cut off from the world around.

Typically, the changes produced by Alzheimer's — the plaques and tangles — could only be seen through an examination of the brain at autopsy. New techniques — new kinds of X-rays and new ways to examine fluid from the spine — are becoming better at detecting Alzheimer's. As these techniques get better, it may be possible to make earlier diagnoses and to begin treatment earlier as well.

Vascular dementia results from brain cell death caused by a series of strokes. Strokes are associated with high blood pressure and diabetes. These disorders are very common among African Americans. Strokes are produced either by a blockage of a blood vessel in the brain or by a leakage in a blood vessel. Small — and often unnoticed — strokes are called trans-ischemic accidents: 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 sustenance.]

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, 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.

Alzheimer's and Vascular Dementia Alzheimer's and vascular dementia account for most of the cases of dementia. Alzheimer's is the most common cause of dementia, accounting for half to two-thirds of all cases. Vascular dementia is involved in somewhere between 20-25% of all cases. Alzheimer's disease can be present along with other dementing disorders, such as vascular dementia. In some studies, Alzheimer's disease is present in up to 90% of the cases studied. That includes cases where Alzheimer's is mixed with some other disease. There are several other dementing conditions that account for much of the remaining 10% of the cases of dementia.

Lewy Body Disease.

Lewy bodies are abnormal protein accumulations that are not normally found in the brain. When they enter the brain in great quantities – and we don't know how this happens – they produce a progressive dementia similar to Alzheimer's disease. It is the second most common form of progressive dementia. It can start at an earlier age than Alzheimer's. Many of the symptoms are the same as those in Alzheimer's. Persons with this illness have progressive losses in powers of thought (memory, reasoning, judgment, etc.). The illness can produce greater changes in mood and feeling than are typical in Alzheimer's. So, big mood swings and sudden bursts of temper are sometimes seen. Hallucinations may also be more common and vivid.

Frontotemporal Dementia

Similar to Alzheimer's disease and Lewy Body dementia, Frontotemporal Dementia (FTD) is caused by an injury to the brain produced by deposits of unusual proteins. As the name suggests, this dementia affects the front part of the brain. The frontal cortex of the brain is the part that controls our behavior. FTD is often associated with very erratic behavior. Persons with FTD 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 become very profane or vulgar. They may become sexually disinhibited.

FTD often occurs in relatively younger persons (in their 40's or 50's). In these cases, families with young or teenaged children are involved. Thus, FTD caregiving can take on added dimensions. Active marriages are 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. Many other diseases produce dementia. Among these are Creutzfeldt-Jakob disease, and Wernicke-Korsakoff syndrome. Two diseases in particular, HIV/AIDS and Parkinson's disease, produce dementing conditions in their later stages. Both HIV/AIDS and Parkinson's affect the central nervous system, and, as they progress, the damaging properties of the diseases affect the brain. Nearly one-half of all persons with HIV/AIDS develop a dementing condition in the later stage of the disease. As many as 80% of those who survive to late stage Parkinson's disease develop dementia.

Are There Any Reversible Dementias?

A very few dementing illnesses are reversible. These are disorders that can produce a condition that mimics (looks and acts like) dementia. 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), 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 memory function.

How Does Depression Fit into the Picture of Dementia?

Depression – an illness more common among older persons – fits into the dementia picture in two ways. First, depression is the most common disorder that mimics dementia. Depression can affect 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.

These are signs that are also commonly seen in persons with dementia. So it is not hard to see why it could be confused with dementia.

Be aware that depression is a frequently missed diagnosis in the elderly. Don't assume your doctor will 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 and ask him/her explicitly to assess the person for depression.

There is a second way depression fits into the dementia picture. It is also commonly found along with dementia – especially in the early stages. The two can co-exist, and when they do, the depression makes the dementia worse. It adds to the burden.

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

Who Gets Alzheimer's and Other Dementias.

Most dementing illnesses affect older persons – with some exceptions. Alzheimer's and vascular dementia occur mostly in persons over the age of 65. A few of the dementing illnesses do appear to begin at earlier ages. Frontotemporal dementia and dementia associated with HIV/AIDS are the most prominent of those affecting people at younger ages.

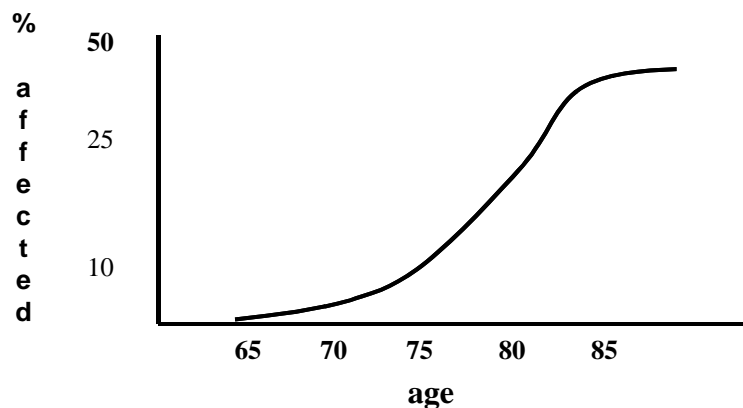
Approximately 10% of all people over the age of 65 are affected with a dementing illness. As many as 50% of all people over the age of 85 may be affected. The risk of becoming affected with a dementing disorder is, in general, not very great at any point in time. For a given individual who is 65 years of age, the risk is approximately 1 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, the risk is approximately 2-3 in 100.

Dementing illnesses are, typically, long-term illnesses. It is generally said that the average course of a disease like Alzheimer's is 8-12 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.

That is why there are so many people over the age of 85 with the disease. It is not that people acquire the illness when they turn 85. It is that it developed in them 5, 10, or 15 years ago, and they have remained alive with the disease. In other words, many of those who came down with the disease at a younger age 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 dementing disease increases with age. Only about 1% of all persons age 65 have a dementing disease. About 10% of persons who are 75 have a dementing disease. Some estimate that nearly half of all persons 85 years or older have a dementing disorder.



Percentage of the Elderly Population Affected by Dementia at Various Age Points

What Causes Alzheimer's Disease?

The cause of Alzheimer's disease is, as yet, unknown. A number of genes have been identified that appear to be associated with Alzheimer's. And so, it is likely that some people are more susceptible to the disease than others because of their genetic makeup. But not everyone who has these genes develops Alzheimer's. We still do not know what it is that activates the disease. Environmental factors, toxins, and previous head trauma have all been linked to Alzheimer's disease, but

not conclusively.

Do Children Inherit Alzheimer's Disease?

Only a very small percentage of cases (2 – 4%) 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 demented. Also, in these cases, the disease often begins very early in life (as early as the 20's or 30's).

Outside these unique families, people whose parents had Alzheimer's do appear to have an 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-fold increased risk. Remember, though, the risk for the disease is not ever very great, so even an increased risk is not a sure thing. A 65-year-old who had both parents with the disease has a 7% risk (compared to the normal 1% risk at that age).

Should a person be tested for the Genes Associated with Alzheimer's?

Virtually all the 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, this information provides rough odds of the likelihood of developing the disease. So it is not information on which to base any certain actions or plans. It is also the case that 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 the information, but the burden of anxiety might well outweigh the sense of being prepared.

Virtually all Alzheimer's research studies will ask those who are taking part to provide samples of blood and spinal fluid that will reveal the presence of key genes. This kind of information is vital for advancing knowledge about Alzheimer's. However, it is almost always the case that the agreement between the researchers and those taking part in the research is that information about the genes will not be given back to participants. This is meant to protect participants from knowing information that might provoke worry but that they can do nothing about.

Dementing Illnesses are not Equal Opportunity Diseases

There is evidence that Alzheimer's disease and other dementing illnesses are more likely to develop among African Americans than among whites and that they are

more likely to develop earlier in persons of Hispanic/Latino descent than in other groups. African Americans are known to be more affected with a variety of cardiovascular diseases, especially high blood pressure. They are also more affected with related metabolic conditions, such as diabetes and obesity. This combination of risk factors is, in turn, associated with a higher risk for dementing conditions. The link, for example, between high blood pressure and stroke is very strong. And stroke is the basic cause of vascular dementia. These relationships likely affect the earlier onset of dementia in Hispanics/Latinos.

Historically, the relationship between disadvantaged groups and the health care system has been uneasy and, frequently enough, less than effective. This has had consequences for dementia family caregivers. Research indicates, for example, that disadvantaged groups such as African Americans who are affected with dementing illnesses are diagnosed later in their illness than are members of other racial/ethnic groups. This means that families from disadvantaged groups or groups that experience disparities in healthcare availability or provision are dealing with these conditions without accurate or useful information for longer periods than other groups. Research also shows that members of such group typically use formal health and social services less than other groups. So these family caregivers are going it alone more. Finally, persons from disadvantaged groups with dementia who are admitted to nursing homes are admitted at later stages of the disease than those from other groups. The reasons for this are unclear. Some research indicates that it is strong family structure and values in these groups that moves families to keep their loved ones at home longer. Distrust of the formal care system may also contribute to this. For whatever reason, this pattern suggests that family caregivers from disadvantaged groups engage in much more difficult care tasks than do other caregiving groups.

There are other group differences in dementia. More women of all races and groups are alive with the disease, but this is because women typically live longer than men do. There are more whites than African-Americans or Hispanic-Americans with the disease, but this, too, has to do with greater longevity among whites (and greater numbers in the population).

How is a Diagnosis of Dementia Made?

One of the most difficult things about dementing disorders 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 – 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. Anyone faced with the possibility of 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.
- ✓ It is important to know the extent and stage of the problem.

It is not an easy evaluation. 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 (physician or nurse practitioner) should be aware of these. You have every right to expect two things:

- The clinician should test the person in a number of ways before giving the diagnosis.
- 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? Certain conditions must be present to make a diagnosis of dementia:

- A noticeable problem with memory, especially recent or short-term memory.
- A 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.
 - impaired judgment.
 - disturbances of other powers of thought.
 - change of 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 demented.

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

- **History.** Usually the most telling piece of information is the history of the person's condition. Often the physician 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 (2-3 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 the clinician determine whether the process is caused by a process of accumulation of substances in the brain (proteins) 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 tests to rule out possible causes of decline in thinking ability. These will include tests of thyroid function and nutritional status. Other tests for chemical balance 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. For example, examination of spinal fluid is showing promise in the diagnosis of Alzheimer's disease.
- **Imaging studies.** Brain scans – magnetic resonance imaging (MRI) and computer assisted tomography (CAT scans) – allow 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) which occurs in Alzheimer's.
- **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 physician pinpoint the diagnosis.

The clinician may, by him or herself, put all this information together to arrive at a diagnosis. Or, there might be a referral to one or more diagnostic specialists.

Neurologists, psychiatrists, neuropsychologists, and occupational therapists can all be called on to contribute input to the diagnosis. Geriatricians – internal medicine physicians or family physicians with special training in the care of older persons – can also be experts in the diagnosis of dementia.

What is life Like: What to Expect as a Caregiver

As noted, dementing illnesses are generally progressive and have a long course. 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:

- The person will slowly disappear. Many of the things you consider to be who the person is will fade. As you will learn in later chapters, things we consider essential gradually weaken and go away almost entirely. Sometimes, personality itself changes and becomes very different.
- The person’s control over his or her life and actions will likewise slowly erode. This can lead to difficult moments. Guiding the person’s actions to keep things calm is a big part of what this program is about. So you will learn a lot more about this in later chapters.

The family caregiver – and there is usually just one primary caregiver – is faced with these changes. As the disease progresses, the work of caregiving generally increases. The caregiver is increasingly in control of what the person does and how the person acts. Care choices also become more difficult. Choices the person might once have made now fall on the caregiver. Whether to call in extra help; whether to pursue aggressive treatment if other illnesses develop; 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 the Medical Care of a Person with Dementia?

Research has made good progress in understanding Alzheimer’s and similar diseases. This knowledge has led to some medications that are used to treat the symptoms – but not the underlying causes – of these illnesses. As a result, there are medications available that, in many cases, seem to slow the progression of the disease. Once such medications are begun – and assuming the person can tolerate them – the condition seems to improve. It is as if the person returns to the state s/he was in 6-12 months before. So the person seems better. However, the disease

is not stopped. It continues to progress. It may be that the progress is slowed some, but it is not stopped.

It is important to realize that dementing illnesses make it more difficult to identify, treat, and manage other medical conditions. Particularly in the middle and later stages of these illnesses, the person may lack the ability to recognize that something is wrong. Or s/he might lack the ability to tell you or a doctor just what is wrong. So pain might not register as pain in a person with a dementing 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 here is another part of the caregiver's role. You become the reader and interpreter of the person's physical signs and symptoms.

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

The brain is weakened by these diseases. Given that, it is important to remember that medications – both prescriptions and over-the-counter – often affect the brain. Therefore, it is very important to have expert advice on the possible effects on the person of combinations of medications. So if the person with the dementing illness is taking medications for other medical conditions, find out how those medications affect the dementia. Likewise, if there are medications being prescribed to deal with problems associated with the dementia, find out about their side effects. Here's where a good health care partner is important.

Agitation and emotional upset can be problems for persons with dementia. So much is out of their control, and so much is confusing to them. It is not hard to understand that they can react to things in ways that are self-protecting. This can 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 this program is focused on teaching you strategies for keeping the person calm and involved throughout the day.

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

- really listen to what you are saying and asking for.
- help you manage day-to-day life with your family member, including with other illnesses need to be managed.
- help you with tough issues – like getting your family member to stop driving or getting you to admit you need more help. Or help you with tough choices involving nursing home placement and advanced 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 who can 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 doctor or nurse practitioner just what you need. If help is not forthcoming, consider shopping for another clinical partner.

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

- Family doctors and gerontological nurse practitioners usually know the person's history. The clinician should be able to detect key changes that signal the need for a complete work-up. A clinician who has kept up with things can usually provide a good evaluation. Internal medicine and family practice doctors and gerontological nurse practitioners are trained to give this kind of care.
- Geriatricians are family physicians or internal medicine physicians who have had additional training in caring for older persons. The assessment and management of dementing disorders is 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 neurologists and psychiatrists have extensive experience with the diagnosis

of dementing disorders.

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

The Internet might be your friend

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 (<http://www.alz.org>) is a good source of current information. The National Institute of Aging sponsors the Alzheimer's Disease Education and Referral Center (ADEAR). The ADEAR website (<http://www.alzheimers.org>) is another excellent source of current information about Alzheimer's disease and treatment. The ADEAR toll-free weekday phone # is: 1-800-438-4380.

At the same time, much of the information on the web is not screened by experts. So you have to be very cautious about what you believe from it. Be cautious of "cures" and "tests" you might read about on line – even if there seems to be a medical person associated with it. The drugs and tests that are currently recommended by reputable clinicians have all come through a careful process of testing. Not all of the cures and treatments on the web have been thoroughly tested.

Dementia 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. These are not bad people, but their claims do not help. Some years ago, for example, Ginko Biloba was all the rage as a memory drug. After very careful study, Ginko was found not to be effective. Nevertheless, it is still available in pharmacies and health food stores. There are also people who use the web to scam people with dementia and their caregivers.

The takeaway message is: have a good health partner. Discuss things you hear from the web or TV with that person.

What Is on the Horizon?

Scientists around the world are working on the problem. Work is taking place in laboratories, and tests are being conducted with animals. Human trials 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.

This work will continue to develop, but right now, two promising lines of work are being carried out:

- **Brain stem cells.** In this therapy cells, called stem cells, are injected directly into the brain. They seem to function as repairing agents. When they find damaged parts, they cause new and healthy cells to grow to replace them. There have been some early encouraging results in treating Parkinson's disease.
- **Amyloid antibodies.** Amyloid proteins cause brain cell death in Alzheimer's. Scientists are trying to find ways to "clean out" these proteins. Work in this area may also be referred to as Alzheimer's vaccines.

Also better methods to accurately diagnose persons affected with Alzheimer's disease in very early stages are being explored. If new therapies are found that can slow or even stop Alzheimer's disease, these methods will be necessary to identify those who would benefit from them. There are, for example, exciting developments in testing of cerebrospinal fluid for tau proteins and amyloid protein build-up and in neuroimaging.

What About Taking Part in Research Studies?

The advances in treatment so far have relied on people to volunteer to be in studies. Allowing your person to be in studies 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. The form is just part of agreeing to take part in research. 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 flipping 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

You can find more information about Alzheimer’s at the websites below:

The Alzheimer’s Association: <http://www.alz.org/index.asp>.

The National Institutes of Health Alzheimer’s Disease Education and Referral Center (ADEAR): <http://www.nia.nih.gov/Alzheimers/>.

You can learn more about vascular dementia at the Alzheimer’s Association website and at the websites below:

Mayo Clinic Health Information: <http://www.mayoclinic.com/health/vascular-dementia/DS00934>.

Wikipedia (on Multi-infarct dementia): http://en.wikipedia.org/wiki/Multi-infarct_dementia.

More information about Lewy Body Disease can be found at the two websites below:

Lewy Body Dementia Association: <http://www.lbda.org/>.

Mayo Clinic Health Information: <http://www.mayoclinic.com/print/lewy-body-dementia/DS00795/DSECTION=all&METHOD=print>

A Caregiving Strategy: Re-Integration. The basic meaning of this chapter is that a disease is causing the person to break apart as a person. All of us, as we grow and become adults go through the process of becoming who we are. This is a process of integration. Parents, family, teachers, friends, others, and the world around teach us. In some ways they shape us. And we shape ourselves, through efforts we take and choices we make. Gradually we become the whole and integrated persons that we are. We become the sum of our likes and dislikes, of what we know and can do.

The dementing diseases gradually dis-integrate the person. Who the person is, what the person can do, how the person operates in the world – all of that is changing, fading, coming apart.

Your work, at its most basic level, is to put some of the pieces back in place some of the time. You won't be able to re-integrate the person. But mostly the caregiving strategies you will learn and develop will involve filling in a gap or substituting for a loss that is brought about by a dementing disease.

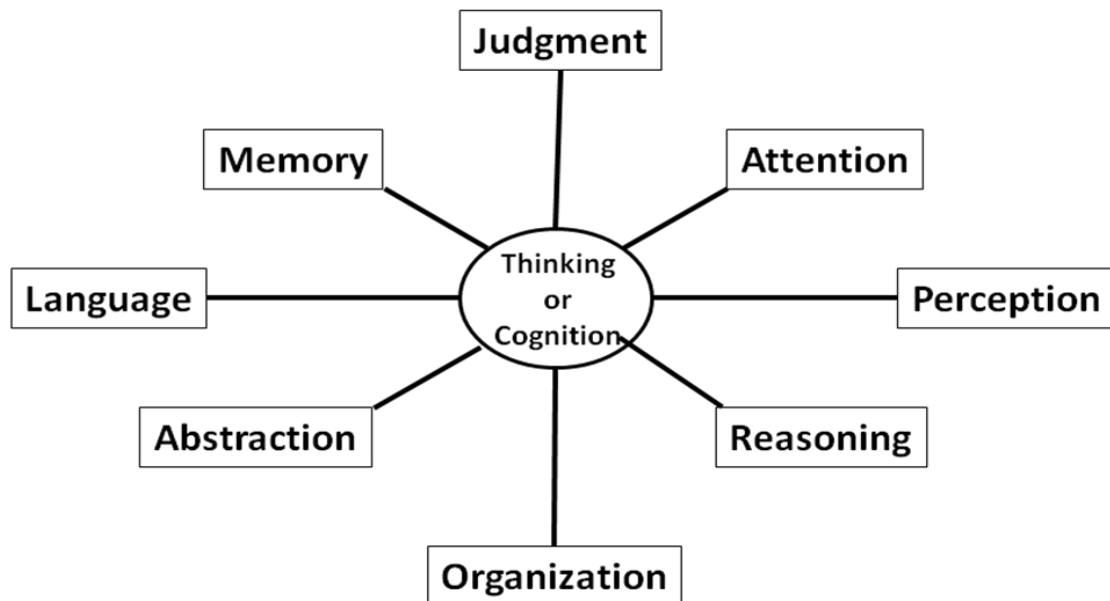
The Effect of Dementia on Thinking

The Brain at the Center

This portion of the manual is about:

- What happens to thought processes when dementia sets in.
- How these losses affect the person with dementia.
- Caregiving strategies to deal with these losses.

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



What Happens to These Powers When Dementia Is Present?

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

- Describe the thinking function and the losses that occur in the disease.
- Discuss the effects of these losses in everyday life – on the person and on you, as a caregiver. Point out how the dementia 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 affects each of these functions. We can talk separately about losses in each function, but the losses are taking place together. That is, the disease is affecting all these powers. However, *the losses take place in different ways and at different rates in each individual. Dementia has a general pattern, but each individual experiences this pattern individually.*

These losses will change the person. All the things the person could do will gradually be lost. How the person experiences and reacts to these losses will vary from person to person. Some will have a sense of losing powers. Others will not. Some will remain the same, temperamentally; others will change, perhaps dramatically. Some will become timid and fearful. Others might become aggressive or defensive. Some may deal with the changes by becoming more compliant. In others, caregivers may have to work through resistance before obtaining cooperation. And these reactions and behaviors may change as the disease progresses.

MEMORY – What's Being Lost?

Memory is the glue that attaches a person to life's continuity. It holds all the webs of relationships together. It keeps us in touch with who's who in our lives and with how we fit into the social fabric. It keeps us plugged into the work and play of our lives – what we do and how to do it. Memory stores the key habits, beliefs, and values that make us unique and vital. When memory begins to fail, our ties to life begin to unravel.

Many families begin to recognize that a problem with dementia exists when memory begins to fade. The first memory problems usually occur with recent memory. The person has difficulty recalling what occurred in the not so distant

past. Immediate recall remains intact for a long time. The person can understand what you say at the time and can respond appropriately. However, a short time later, s/he may not recall the interaction.

Long-term memories seem to last the longest. In some, they remain very far into the disease. The person may be able to remember people, events, and facts from the remote past well into the dementia. Over-learned behaviors are also kept for a long period of time.

The phrase “over-learned behavior” 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, are over-learned. Other acquired skills, like playing a musical instrument, have become over-learned by some people.

There is a general pattern to the memory loss. Early on, a person may keep track of details. S/he may remember where the children live and what they do and what the grandchildren’s names are. Later, these kinds of memories become less reliable. Eventually, almost all is forgotten. In the late stages of the disease, recognition of even the most familiar people fades.

Effect of Memory Changes on Daily Life

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. None has a larger context. This experience of the world could be lonely, confusing, even frightening. It might make a person withdraw. Or it might make the person defensive – even hostile.
- **Learning will not occur.** Persons with memory problems are less able to learn. Memory, especially short-term memory, is important for learning. New skills, facts, or ideas have to be remembered if they are to be learned. People with dementia might be able to follow steps, if instructed. But they won’t remember these steps for any length of time. This does not mean persons with dementia should not be asked to do new things. Like anyone

else, people with dementia will enjoy doing things. And they will be able to do things – with help. The important thing is not to expect people to be able to do something tomorrow. They won't remember. They won't have learned it. But they may well enjoy it again. If they are again helped to do it.

- **People with dementia 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 with dementia 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. For others it is a source of humor. Still others do not even seem to recognize they have a problem. Others may deny the problem, even vehemently.
- **Social skills fail.** Many social skills rely on memory. Manners and other social behaviors are learned. We learn how to behave in public, how to behave at table, and how to interact politely. As these learned behaviors are forgotten, social graces may fall away. Even the most polite 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.

Dealing with Memory Problems

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 spouses remember their first spouse but not their caregiving spouse.

- Don't be frustrated. 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.

Develop caregiving strategies.

- Be ready to supply information that's forgotten without drawing attention to the memory loss.
- Familiarity can substitute for memory. Create or strengthen routines. They can create a feeling of familiarity that is comforting and secure. Use objects – pictures, momentos, 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 reminiscence.
- 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 may be embarrassing.
- Over-learned and well-remembered skills should be part of your bag of tricks as a caregiver. These can be useful diversions when you find yourself in a bind with the person.

LANGUAGE – What's Being Lost?

The ability to communicate is what allows us to connect with others in the world. We rely on communication to express 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 there are other ways, too. We rely on gestures, body language, and facial expression to communicate.

The ability to communicate is gradually lost in dementia. The first problem 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 are known. Later, they may have difficulty expressing ideas. They may know what they want to say, but be unable to find the words. All of this can lead to embarrassment and frustration. It may prompt people to withdraw. It could produce an emotional outburst. Sometimes people might blame caregivers for the problem.

Over time, people's thoughts becomes less complex. They will tend to become 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.

Understanding 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.

Effect of Language Changes on Daily Life

- **The person may feel these losses.** Early in the disorder, 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 dementing disorder has affected them. This can be doubly hard for the caregiver. The person looks so good, looks like his/her former self. But the caregiver knows how great the distance is between looks and reality.
- **Getting through 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 with dementia is using them on purpose or just because they somehow fit the situation.

Dealing with Language Problems

Keep in mind what's happening.

- The connection is breaking. All communication is becoming more difficult and less reliable.

Adjust your expectations.

- Don't expect communication to be two-way and equal. You will be doing most of the work.
- Be delighted with retained verbal skills. However, don't let yourself think that these mean the person is getting better or that the progress of the disease is stopped.

Develop caregiving strategies.

- Help the person. Give the person the 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.
- Don't worry about correcting the person or trying to get him/her to be more effective.
- Try to match your communication strategy to the person's strengths and abilities. For example, try using shorter sentences or emphasize just one or two key words. As the disease progresses, too many words can 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 and tactile communication (sight and touch) techniques will become more necessary as the disease progresses.

REASONING – What’s Being Lost?

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 progresses and reason declines, people are less able to make sense of the world. They lose the ability to control their lives. With reasoning reduced, people are trapped in the present moment. They also become very self-centered.

Effect of Reasoning Changes on Daily Life

- **People with dementia can’t be reasonable.** Most of us expect others to be reasonable. We assume this when we interact with them. We regularly appeal to reason. We use 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 carry the day. Dementia turns these expectations upside down. Increasingly, normal forms of interaction – like persuasion – won’t work. Logic will fail and may backfire. Asking the person to think ahead through a series of steps may cause confusion, withdrawal, or impetuous behavior. One outcome of the loss of reasoning power is that the caregiver needs to take more control.

- **The relative weight of things becomes unclear.** Reason helps us to understand what things are more important than others. The ability to see the relative importance of things allows us to set priorities and plan things out. With dementia, people lose this ability. So sometimes things we consider unimportant become very important to the person. Talking about this, 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? Normal life and normal 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 disease progresses, this natural impulse – one that springs from respect and affection – can produce real discomfort. The person with the disease may feel confusion. The caregiver who repeatedly provides choices may become frustrated.

Dealing with Reasoning Problems

Keep in mind what's happening.

- Using traditional respectful 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. We expect adults to enjoy being fully involved in things. As the disease progresses, being involved in the moment is enough.

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,” “here's your lunch,” “it's time for your shower”).
- Figure out how to get the person to do things. Typically, people do things because they see some form of self-benefit. As the dementia 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 s/he may respond positively when you ask for help with something (“it would help me if you’d put this shirt on”).

- Listen for phrases that assume the ability to reason (“Don’t you understand that...” “Can’t you see that...”). These phrases may not hurt the person’s feelings. They might suggest that you haven’t thought all the way through the losses that are occurring. You may think more reasoning is present in your family member than is actually there.

ABSTRACTION – What’s Being Lost?

We rely on abstract thought to deal with everything in our lives that is not concrete. A lot of things we take for granted are abstract. Time is abstract. The past and the future are held in order by the power of abstraction. Possibilities are abstract. Being able to think about the “What If’s” 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 – are abstract.

Like the other powers of thought, abstraction declines with the progress of the dementing disease. This ability is lost fairly early in the disease. This means that many of the concepts we rely on to live in this world no longer have meaning for the person.

Effect of Abstraction Changes on Daily Life

- **All is present. Time and order are lost.** Very early in the disease, notions like tomorrow, next week, yesterday, or this evening begin to lose meaning. Without a sense for time, it is difficult to order and prioritize activities. At a certain stage of the disease, persons with dementia cannot make, follow, or appreciate plans. They become rooted in the here and now and may be confused by ideas of past and future.
- **Connections are lost.** Words may remain, but their felt meaning will fade. Their exact use will deteriorate. A person with dementia might call an adult son “son” one day and “father” the next. The person might feel a general connection, but may not know or understand what it is.

- **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 with dementia 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. Getting and feeling lost is easy. Feeling unsure and confused about where they are is common.

Dealing with Abstraction Problems

Keep in mind what’s happening.

- The person is living more and more in a very concrete present and a very immediate space – the here-and-now.

Adjust your expectations.

- You can’t rely on the person to understand or relate to anything outside of what’s happening right now. That includes a sense of time.
- Be prepared for confusion about who you and other members of the family are.

Develop caregiving strategies.

- You have to think about the future and about plans for both of you.
- People with dementia likely will not benefit from directions that use 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?” may not motivate them. They may become confused by such statements. They may not understand what “this afternoon” or “next week” mean. They may take this to mean “now” and ask you repeatedly about when the event is to happen.

ATTENTION – What’s Being Lost

Attention is the ability to remain focused. Attention includes the ability to initiate, maintain and stop a task. We rely on attention to get things done. Attention enables us to stay on track with a task or activity even when we are faced with numerous distractions. Under normal circumstances, even when a lot is going on around us:

- We are able to make almost instantaneous decisions not to be diverted from something we are doing.
- We are able to 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 dementia relates to how easily the person can be diverted or distracted.

Effect of Attention Changes on Daily Life

The main effect of losses in the power of attention is that people don't stay 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.

Dealing with Attention Problems

Keep in mind what's happening.

- Increasingly, the person will need your help to stay focused on a task.
- There is a relation between attention and ability. Tasks that fit the person's ability are more likely to capture and hold attention than those that are too complex or too simple.

Adjust your expectations.

- Helping the person to get and stay happily doing things is a big part of success for the Savvy Caregiver.
- Quality is unimportant. Doing things is important.

Develop caregiving strategies.

- Keep in mind the kinds of things that used to hold the person's attention and try them out.
- Set-up: task design matters. The caregiver has to figure out the kind of activities the person can successfully perform. They may need someone to get the supplies, define and set up the task, and get them going. Problems with attention in tasks and activities typically relate to matters of fit and distraction.
 - ✓ If a task or activity is too hard or too easy for the person, s/he may lose interest.
 - ✓ 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 will be distracted even more easily.
- Support: cueing and direction help. Persons with dementia need help starting and staying with activities. Many persons appear unable to start a task, but when someone gets them started, they're fine. They may need reminders and cues at each step in order to keep going. The situation worsens as the disease progresses. By the middle stage, the person may only be able to do very repetitive, one or two step activities such as sweeping, dusting, wiping, folding or stacking. Near the late stage the person will be seen repeating the same motion over and over, as in shaving the same spot until reminded and directed to move to another spot.

JUDGMENT – What's Being Lost?

Judgment is the ability we use when we ask the question "What if?" Asking ourselves this question allows us to judge the safety or benefit of a situation.

The ability to imagine the possible outcomes of a situation is very important for personal safety. A person may be drawn to the loveliness of a fire. However, being able to consider the bad consequences of getting too close to the fire prevents us from doing so and getting burned. This is the same ability that keeps us from wandering across busy streets or getting into other harmful situations.

Judgment enters into 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 dispose of property.

This capacity is lost relatively early in dementia. Because of distorted thinking, judgment may be poor or faulty and very different from the person's previous decision-making and behaviors. The person's own insight into his/her thinking problems varies greatly from person to person and changes as the disease advances. All of this makes it hard to know whether and how much to involve the person in critical life choices.

Effect of Judgment Changes on Daily Life

- **Safety first.** Safety is a major issue when judgment becomes impaired. As the disease progresses, caregivers have to take more control. Driving has to be stopped. The use of kitchen appliances has to be supervised and controlled. Access to the outside world has to be limited. Identification items (bracelets, name tags on chains, cards in purses or wallets) are important.
- **Caregivers must take control.** Some individuals 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. People may resist attempts at all rational discussions and be a danger to themselves. They may want to continue activities that are too complicated. Such activities include driving, using power tools, or attempting to manage business affairs or jobs. The person may be vulnerable to sales pitches or "get rich quick" schemes in the mail or on TV. If the person still has a checking account or credit card, look for unusual spending patterns.

- **Behavior may change.** The gradual loss of judgment can contribute to insensitivity towards others. This is somewhat common in individuals with dementia. These persons gradually lose the ability to imagine how their behaviors affect others. Sensitivity to others' feelings is a learned social behavior. We learn to respect other people. We learn that being self-centered is not acceptable. But these learned manners can be forgotten as the disease progresses. If 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.) Also, we've learned it is impolite. However, due to the loss of judgment and memory, a person with dementia may blurt out something that could be hurtful or offensive.

Dealing with Judgment Problems

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), or other objects that pose a safety hazard. The person may be capable of using such objects or machines under normal conditions. But the person may lack the judgment to respond effectively in a situation where the unusual occurs. You have to determine whether, if the situation suddenly turns confusing, the person has the ability to handle the sudden changes safely.

Adjust your expectations.

- It's not personal or deliberate. Often, persons with dementia say things without regard to manners or concern for other's feelings. They may say hurtful things. Frequently demented individuals will accuse their spouse of being a stranger. Charges of infidelity and of stealing are not uncommon.
- The person cannot watch out for his/her own safety. Expect to be watchful all the time.
- Persons with dementia might use words that are crude or offensive. Caregivers should realize that if these things are said or done, they are coming from the disease and not the person. These behaviors are not personal, and the person would almost certainly never have done or said this in his or her normal state.

Develop caregiving strategies.

- Get clear about values. The person's safety is at stake. Dementia has taken away a lot of the person's ability to make judgments. Values like autonomy and an individual's right to choose no longer apply.
- Be prepared to take control. Remember that reasoning won't work. You have to decide: now is the time to stop driving; now is the time to stop using the stove.
- 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. Use guile and trickery if necessary. Disable the car; put a hidden control switch on the stove.

PERCEPTION – What's Being Lost?

Normal perception involves two things. First, our senses allow us to take in the world around us. Through sight and hearing, but also through touch, smell, and taste we take note of things outside of ourselves. Then, our brain makes sense out of what we 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.

Either way, perception is a key ability that lets us size up and prepare for things as they happen. It helps us not be surprised – and 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.

Effect of Perception Changes on Daily Life

- **Mistakes are made.** As the disease progresses, people more often make mistakes in sensing and interpreting things. For example, s/he may interpret images on television as being real. They may start talking back to the

television. Reflections, including a person's own reflection, 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 uncrossable. Such misperceptions are sometimes called pseudo-hallucinations. It is 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.

- **Suspicion and paranoia can occur.** Problems with memory and 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, the impaired person may notice they are missing and think they have been stolen. Some caregivers report that their persons accuse them of terrible things (like cheating, infidelity, or abandonment).
- **Overload and Confusion.** As the disease progresses, the person 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 physical contact, and asks questions all at the same time. Crowded and noisy places (like shopping malls) might be overwhelming.

Dealing with Perception Problems

Keep in mind what's happening.

- 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.

- You and the person do not share experience. You and the person do not share the same world. What you and s/he understand about what you both see may be very different. So, don't assume you and the person are operating from the same base of perception and interpretation.

Develop caregiving strategies.

- Reassure rather than reason. 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've misplaced. Don't try to correct the mistake. Rather, try to offer reassurance. Offer to check outside and to stay with the person. Offer to help find the checkbook.

- Periodically check the environment. Look around to see whether there are things that may confuse the person. Remember that the capacity for 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.
- In dementia, problems of perception can go along with problems of judgment. Perceptual problems further contribute to the danger of allowing a person to continue to drive.
- 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.

ORGANIZATION – What's Being Lost?

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.

Effect of Organization Changes on Daily Life

- **Goals may be lost, but patterns can remain.** Even early in the disease people may not remember the goal of actions. Or they may be distracted and forget the goals. When goals are lost, people usually do not complete a task. 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 put the clothes in the washing machine and turn it on, but not put in the detergent. Or, s/he may take wet clothes out because she forgot that the machine has to go through several steps before the laundry is done. Mistakes like these are very likely to occur. The person may not be able to complete a whole task on his own. But the person may still be able to do parts of tasks.

Over-learned skills and routines are good. Persons with dementia 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.

Dealing with Organization Problems

Keep in mind what's happening.

- Organization, the executive or controlling capacity that enables goal setting and plan following, 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 not unusual. 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 in exchange for a relief of pressures.

Develop caregiving strategies.

- Let the person 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.
- 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, and, if needed, direct the person in their use.

The Effect of Dementia on Feelings

Confusion

This section of the manual continues the focus on the caregiver's main task – managing daily life. This section about confusion focuses on two things:

- What happens when confusion sets in?
- What confusion means for you as a caregiver.

Why Focus on Confusion?

Confusion, a central problem in dementia, links losses in thinking ability to behavior. The main idea of the section is illustrated in the diagram below.

This diagram is meant to indicate a three-step process that is at the heart of the problems caregivers face.



The Role of Confusion in Behavior

The process described in the diagram goes like this:

1. Confusion. The mind of the person with dementia is weakened. It 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 last section.

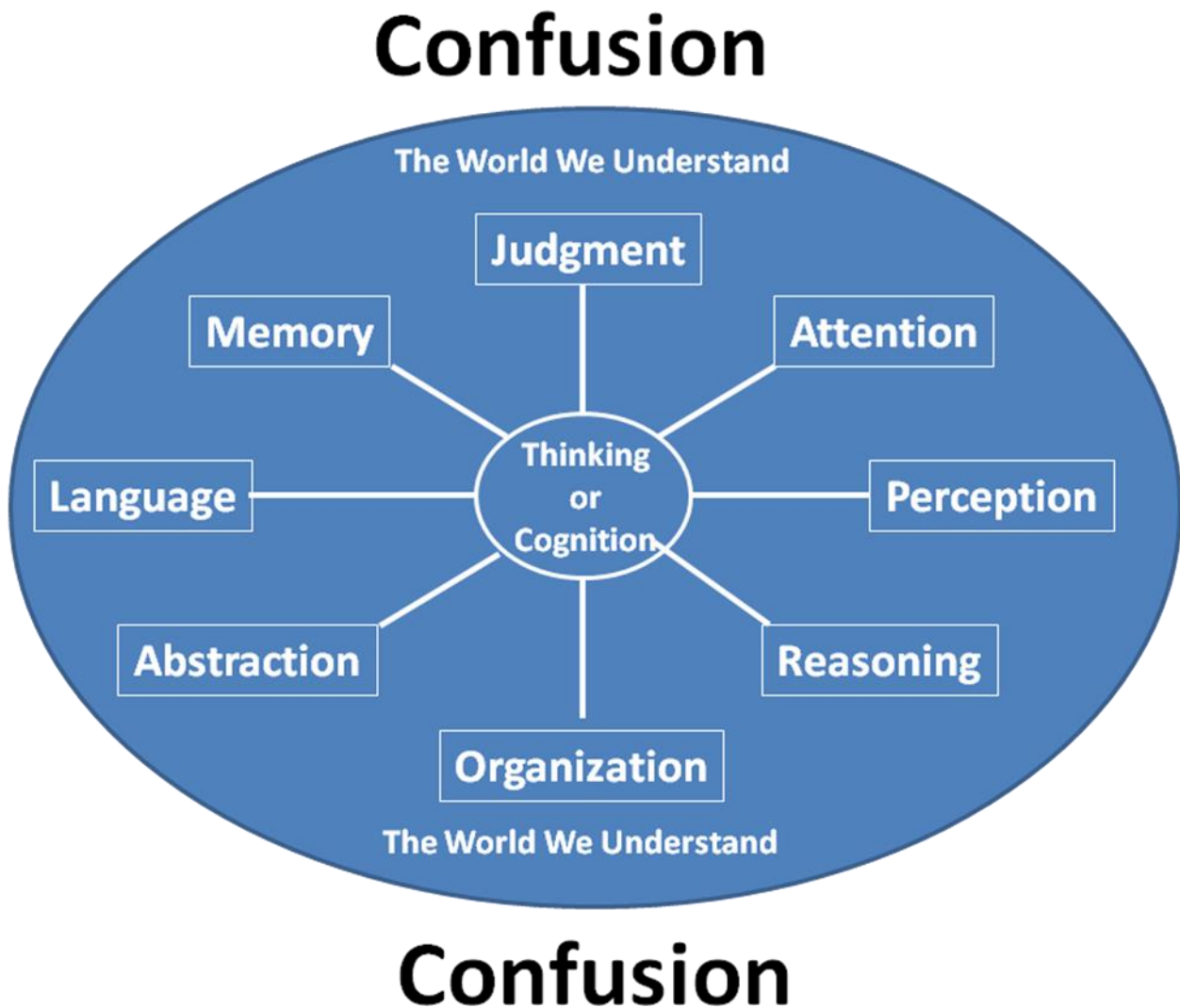
2. Discomfort. Confusion produces discomfort. It is unsettling not to understand what's going on. It is uncomfortable to feel as though the universe is swirling around. This part of confusion has to do with feelings; it produces an

emotional response.

3. Behavior. People who are uncomfortable generally react in some way. They do something. These actions 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 normal? The diagram below represents a normal 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

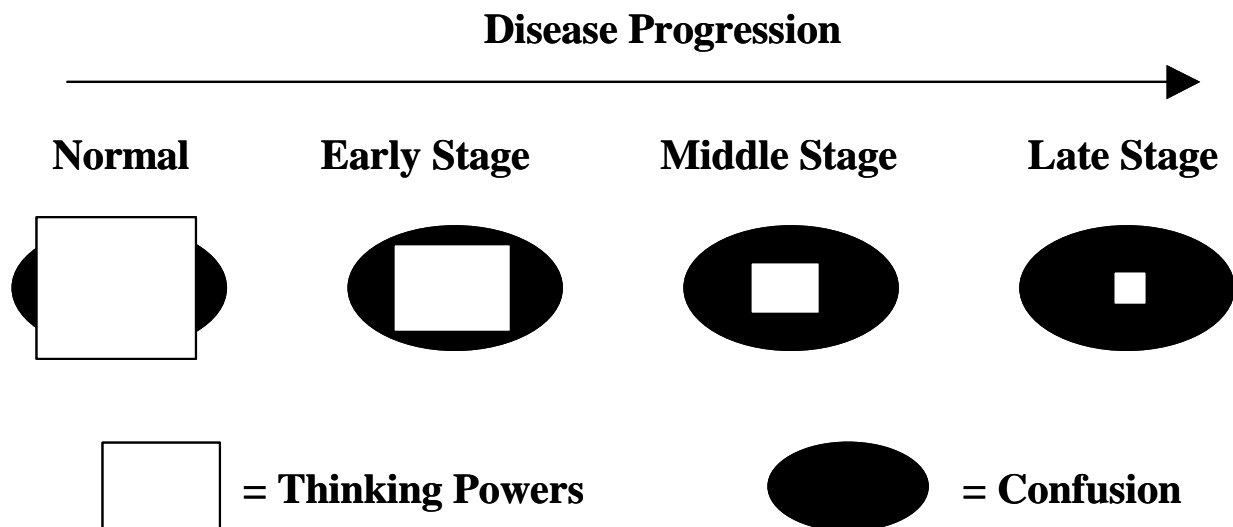
Normal comfort and control. Usually, people’s thinking ability allows them to understand enough of what’s going on to feel in control. There are limits to the world in which people feel comfortable. Most people experience confusion when situations and events push them to go beyond the limits of their thinking ability.

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 brains working normally, serious confusion is not a frequent event. The mind stays on guard. It tests situations and events to see if they may be threats. 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 These Changes Affect Daily Life for a Person with Dementia

Dementia profoundly changes people’s abilities to keep the world ordered. These changes affect the way people with dementia live in the world and how they get along 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 below is meant to show what happens to people as dementia 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 is a larger part of the person's reality. As the disease progresses, the mind's ability to keep confusion at arm's length declines. The person with dementia faces the universe without the normal filters and protections. All the feelings that go along with confusion are more present.

The feeling of confusion. There is a powerful emotional part to this. Being confused like this can be terrifying. The world outside the person is very 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 with 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
- 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?

Confusion Produces Strong Feelings. 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 represents what the confused world of the person with dementia is like. And just like you in the exercise, we can imagine that the person with dementia has a strong need for:

- Calm
- Control
- Security

Like you in the exercise, people with dementia 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. As the disease gets worse, the world seems to be closing in and becoming more confusing, threatening, and frightening to the person. When persons with dementing disorders 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. S/he may, for example, yell or call out. The person might engage in some kind of defensive action. By verbal or physical means, s/he 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.

Fewer Ways to Express or Control Feelings. Normal thinking abilities provide many ways to handle emotions, and these strategies are gradually lost in dementia. The ways that are left are less measured and more direct and explosive. Among the skills that are lost are the ability to:

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

Results of Confusion. 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 very likely a scary experience. And for the person with dementia, it is the ordinary 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. Understimulation or boredom can also produce confusion. Unoccupied people are open to inputs they cannot absorb 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 alters people. Thinking about confusion provides caregivers with a way to understand the differences they see. People with dementia may be:

- **Changed.** Often people with dementia 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 very different from how they behaved before the disease.
- **Self-absorbed.** Persons affected with dementia 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 – 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 with dementia 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 be keeping in contact with you.

It is important to recognize this central role you are playing in the person's emotional well-being. Two things to keep in mind about the 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 with memory-affecting disorders have very sensitive emotional radar. They very 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 very 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 family member 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. 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 will 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 affected with dementia 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 situation.** 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 the activity in a way that makes the person comfortable with it.

- ✓ 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 sees you as you approach and sees what you plan to do.
- ✓ Approach slowly and calmly, rather than quickly and efficiently.
- ✓ 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.
- ✓ Be calm. Your attitude should provide reassurance throughout the activity.

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.
- A slowing down in what the person is doing.
- A certain gesture or look.
- A turning away.
- Picking up a familiar object.
- Pacing.

Response. There are two 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. 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, listening to favorite music).

The Caregiver in Control

People often believe that persons with dementing illnesses like Alzheimer's frequently exhibit difficult or troubling behaviors. As these diseases progress, they produce an increasing amount of confusion. They also affect the person's understanding of the world and of how to act. Confusion and failing understanding can show themselves in how the person acts. Sometimes how the person acts *can* be hard to figure out or manage.

Here are some key ideas to keep in mind when thinking about the behavior of a person with dementia:

- Dementia affects all aspects of thinking. The disease impairs and eventually destroys the brain's ability to act effectively in the world.
- The confusion that is possible is uncomfortable. The losses have a feeling-level impact on the person. Feelings of insecurity, anxiety, and fearfulness are not uncommon. Nor is the sense of being out of control.
- Confusion and losses can spark difficult behaviors. The person may withdraw or react in many ways that are problematic.

This section of the manual deals with an important aspect of your role as caregiver – being in control of the person's behavior. The section is in two parts:

- Thinking about behavior, in general.
- Developing caregiving strategies to deal with behavior.

The section should leave you with two messages:

- As the disease worsens, the person is less responsible for his/her actions.
- Over time, it falls increasingly on you, the caregiver, to control the person's actions.

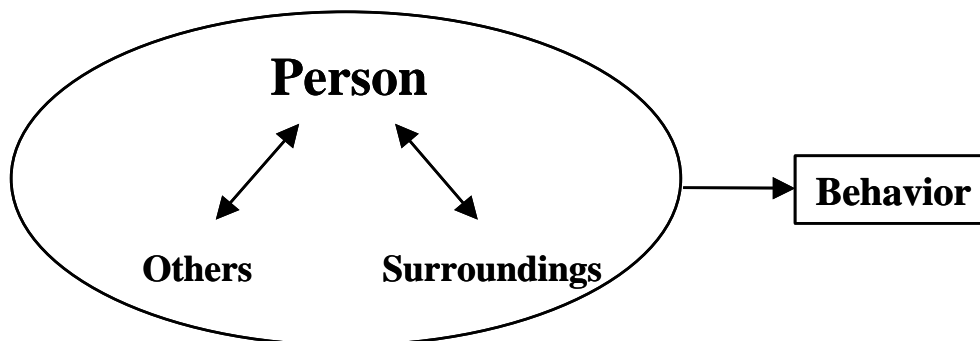
How Does Behavior Happen?

Everything we **do** is behavior. When we eat, read, ask questions, walk up and down – all of those are behaviors. They are actions we take in the world.

All behavior has meaning. When we are dealing with people whose thinking is unimpaired, we can usually figure out what their behavior means. We can usually see what produced a particular behavior and what the person meant by it. For example, when we see parents crying at their child's wedding we can be pretty sure that the tears relate to the wedding. We know that they are crying partly out of joy for their child and partly out of a sense of loss they may be feeling.

As the diagram below portrays, three things influence a person to behave in a certain way:

- **Person:** The person him/herself is usually the main source of behavior. In the example above, how the parent feels about the child's wedding is probably the single biggest factor in the weeping.
- **Others:** Others who interact with the person serve to stimulate or reinforce behavior. For example, friends commenting on the bride or groom in the reception line might intensify the parent's feelings – and reinforce the tears.
- **Surroundings:** The place or environment in which the action takes place may have strong associations for behavior. Thus, seeing the child coming down the aisle during the wedding ceremony provides a compelling context for tears.



A Model of How Behavior Occurs

Normally, an unimpaired person holds the key to his/her own behavior.

- The person considers choices and possible outcomes.
- S/he is swayed by personal likes and dislikes.
- S/he takes personal safety and comfort into account
- Ethical concerns and personal values affect behavior.

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

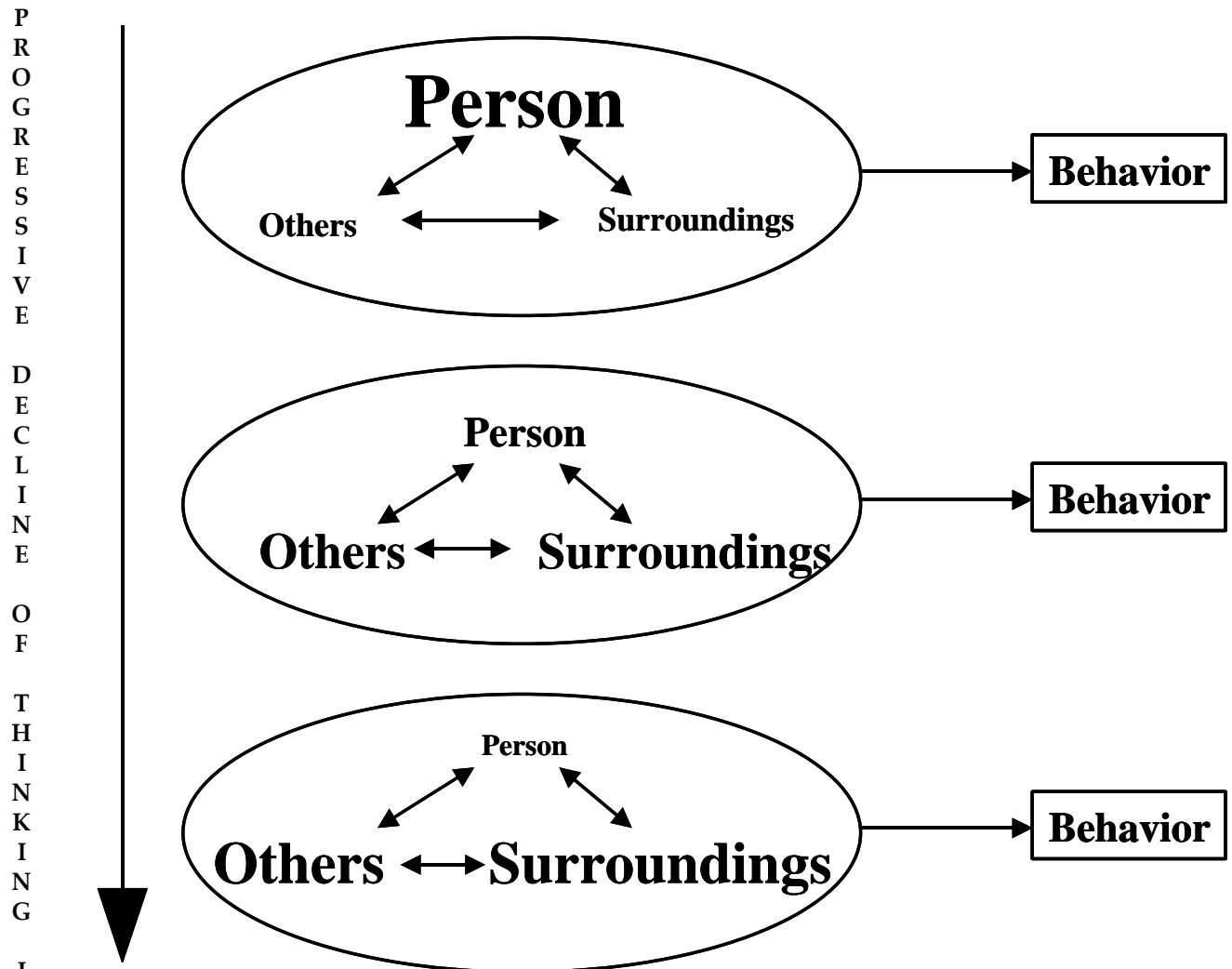
Other people's influence can be strong. The influence of others can be exerted in a number of ways

- Persuasion, suggestion, or force can affect how someone acts.
- Others may influence a person to keep on behaving in a certain way by rewarding the behavior (this is called reinforcement).
- It can be through direct communication – what we say in words. It can be through what we indirectly communicate – through tone of voice or body language.
- It can even be through direct physical contact — for example, steering someone away from a curb.

Surroundings can be powerful. Surroundings can present compelling choices – think of a kid in a candy store. They can make certain kinds of choices undesirable or uncomfortable. A walk outside is less attractive when it is very hot or very cold. Similarly, a person is more likely to read than watch TV if there is no TV around.

How Should the Savvy Caregiver Think about Behavior?

The diagram below may help you think about how behavior and dementia mix. As you've learned, dementia affects the powers that let a person control behavior.



This diagram is meant to show that, as the disease goes on, the person loses control of behavior. Other people and the world around are stronger influences. Eventually, behavior is not a choice, it is a reaction.

**Progressive Effect of Dementia on Behavior:
The Person Is Less in Control**

What Does This Mean for the Caregiver?

The caregiver is called on to play an ever-increasing role in the behavior of a person with dementia. In effect, the caregiver has to take control. As the person has less control over what s/he does, the caregiver has to take steps to shape and direct the person's behavior.

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

- **Judge.** The caregiver has to gauge just how much real choice the person is able to make in given situations. 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. So they may seem – on the surface – able to make choices. You have to decide just how authentic the choices are.

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

- **Support.** If the person can comfortably choose, encourage this. If the person can make limited choices, help this to happen. Depending on where the person is in the disease, s/he may be confused by having too many options. S/he may, however, be able to focus on choosing between two acceptable options. You can limit the choices and let the person select between them. For example, s/he can choose between the blue sweater or the brown – or between chicken or fish.
- **Control.** Don't force choices that the person cannot make. If you already know the person will have trouble making these choices, don't offer them. Make them for the person and present them:

“Let's put this sweater on.”

“It's time for dinner.”

“Let me help you with washing up.”

Let the person know what you're doing, but be directive.

Try to control the surroundings so they don't present the person with too many possibilities. As the disease progresses, things in the environment will draw the person's attention. The person may not be able to keep on track with a task or activity and may be distracted.

- Look around. Simplify the area if it seems distracting.
- Choose settings that help the person stay focused.

Doesn't Control Go Against the Grain?

Normal adult interactions are built on values like respect and independence. We expect to be treated as competent persons. We expect to be allowed to make our own choices, even if they aren't the best. Adults make their own mistakes.

So taking control as a caregiver may feel awkward. Here are some suggestions that may help you feel more comfortable with this idea.

- **Avoid harm.** A person with dementia is vulnerable. As the disease goes on, the ability to judge the safety of a choice weakens. You have to protect the person from injury.
- **Avoid confusion.** At any point in the disease, choices can be difficult. Helping the person choose what to do can prevent confusion. This, in turn, can prevent the discomfort confusion produces in the person. It may also ward off difficult behavior resulting from confusion.
- **Give pleasure.** Try basing the directions you provide on your knowledge of the person. If you guide the person to things you know s/he likes, it increases the chance s/he will be busy and content.
- **Benefit yourself.** You are part of this picture, and the day has to work for you as well as for the person. You are doing the person a kindness by substituting your judgment for his/hers. But you are also doing yourself a kindness as well. You can watch the person be comfortable – a reward in itself. But you can also save yourself a hassle.

Self-Care Skills

Caregiving can bring enormous rewards as well as great demands and challenges. Being available and responsive to any other person requires a patient acceptance and willingness to adapt. This is more so with a person with increasing needs and decreasing abilities. Caregivers who take the time to take good care of themselves – physically, emotionally, socially, and even spiritually – are often better able to face the challenges of caregiving and experience the greatest rewards.

Still, it is often very hard for caregivers to take time for themselves. They may feel that “finding time” is almost impossible given the demand of day-to-day caregiving. Some caregivers feel guilty or sad if they take time for themselves. Others feel trapped in the situation and have a hard time admitting to feeling this way. Sometimes the person can’t safely be left alone. Some caregivers feel they don’t have any help to rely on in the home. Others have their own physical or medical challenges. Getting enough sleep, proper exercise and nutrition, and good positive social support and interaction are essential to managing the long-term demands of caregiving for a person with dementia.

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

This section of the manual briefly introduces methods you can use to take care of yourself. The section covers issues related to:

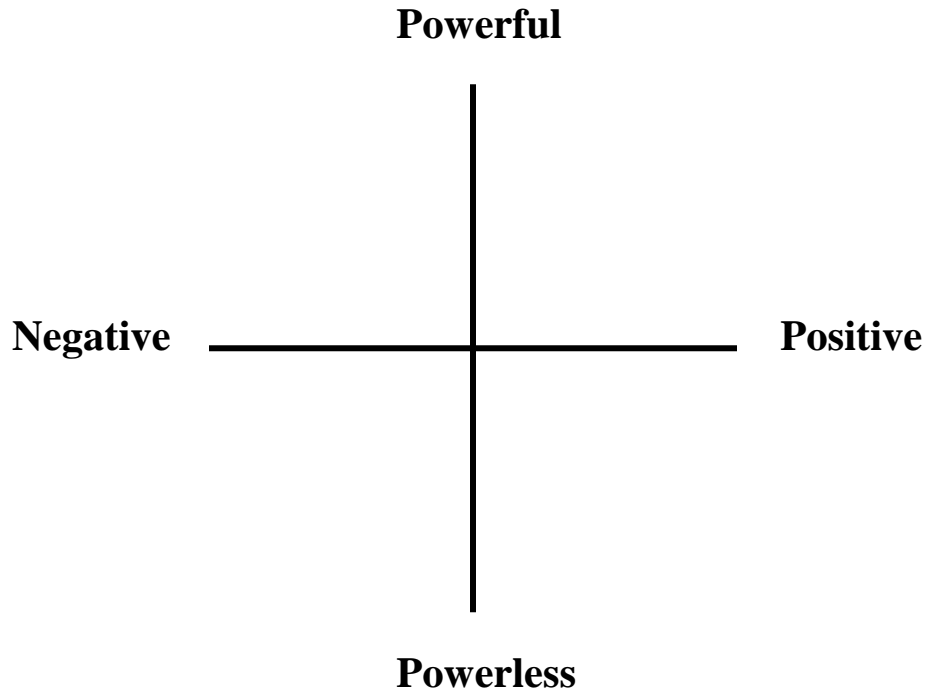
- Identifying and dealing with feelings.
- Taking time for yourself.
- Involving the rest of your family in caregiving.
- Making decisions.

Dealing with Feelings

As you did in class, spend some time reflecting on your experience as a caregiver. Think about - and let yourself experience - the feelings that have been and are a part of caregiving. Think, for example:

- What you felt when you first admitted to yourself that something was wrong with your family member.
- What you felt when you first heard the diagnosis.
- How you feel at the end of a particularly hard day.
- What you feel when you think about the future.
- How you feel when your family member smiles and says thank you.

The Savvy Caregiver program uses a diagram we call the “Four Quadrants of Feelings” as a way of understanding and labeling feelings caregivers are having regarding caregiving. The diagram helps them to organize how they are feeling. More importantly, it offers a way to move to more positive or pleasant feeling states. The diagram is portrayed on the next page. It was adapted from the work of a psychologist at the University of Minnesota, Auke Telligan. Dr. Telligan had thousands of college students record their feelings at random times of the day and night. When he analyzed the feelings, he discovered that he could categorize the feelings using two simple dimensions. One dimension was whether the feeling was a good feeling or a bad feeling (positive or negative). The second dimension had to do with how in control the person felt with the feeling. Did s/he feel in charge or controlled by something larger than him/herself? Dr. Telligan’s breakthrough was to see that, if the two dimensions were arranged perpendicular to each other, any of the students’ emotions could be fit into one of the resulting four quadrants.

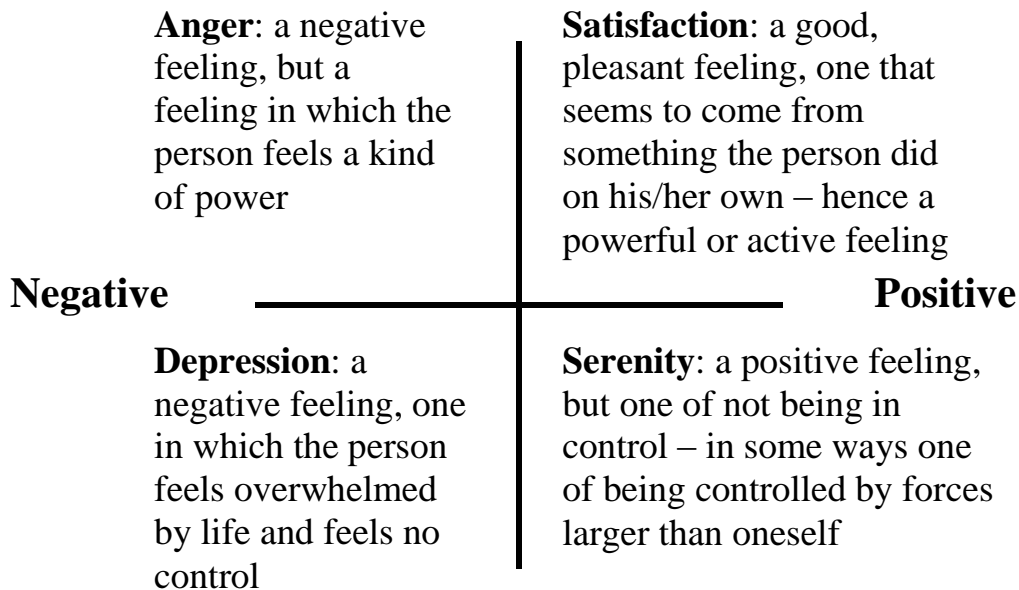


Suppose, for example, that four students reported four different feelings:

- Depression - the student hadn't studied and had failed a test
- Anger - a student was mad at her former boyfriend because he had broken off with her
- Satisfaction - another student had just finished a long project and felt good about it
- Serenity - the term was over and this student was just coasting pleasantly, knowing she had no school work for a month

The way the quadrant of feelings 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. And each can be described in terms of the name that can be given to the quadrant. Thus depression is a negative powerless feeling while satisfaction is a positive powerful feeling.

Powerful



Powerless

Now, following that example, assign these feelings to the quadrants. Consider your own feelings as a caregiver. Typically, caregivers identify many feelings – sadness, devastation, loss, grief, acceptance, being pleased (that s/he can give something to the person “in return”), frustration, exhaustion, rage (at the disease, the person, the system, etc.), just to name a few. On this list, sadness, devastation, loss, grief, frustration, and exhaustion are all lower left quadrant feelings (negative, powerless). Rage is upper left (negative but powerful). Satisfaction – being pleased – is upper right (positive powerful) and acceptance is lower right (positive but not in their control).

Negative powerless feelings are normal in caregiving. You may well find that you place many of your feelings in the lower left (negative powerless) quadrant. It is likely that very few will be on the right hand (positive) side of the figure (either powerful or powerless). Consider three things in this regard:

- Your feelings are common and expected among caregivers. Don't feel guilty about these perfectly normal feelings.
- If you placed many of your feelings in the lower left quadrant, this should reinforce a point made early in the workshop: caregiving is a taxing role.

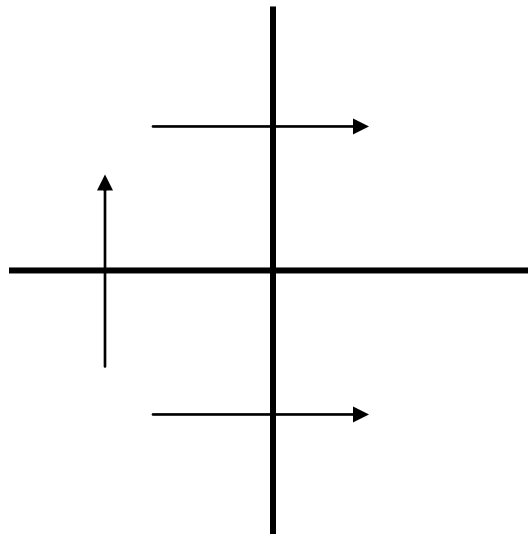
Consistently experiencing predominantly negative powerless feelings can be punishing.

- No matter how many of your feelings are in the negative quadrants, you need ways to get out of this state and to move to more positive feeling states.

Strategies for Changing Quadrants. Briefly, Dr. Telligan states that people's feelings can shift among the quadrants up, down, or sideways, but not diagonally - at least not in one move. Once you become familiar with this way of categorizing your feelings, you will begin to make the determination that you'd much rather be in another quadrant. For example, you feel overwhelmed, so your feelings are in the lower left quadrant. You may want, instead, to feel a sense of satisfaction or reward. To accomplish this, you cannot simply jump diagonally in a single move. Instead, you may have to make a series of moves to get to where you want to be.

3. Do something (and keep at it). Put the plan to work successfully.

2. Plan to do something: use knowledge and skill to form a plan.



1. Let go: recognize the effects of the disease.

1. Let go. Accept the situation as it is. Recognize that the disease is progressing and irreversible and 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, and then building a response based on that acceptance. The material in the first three sessions of the Savvy Caregiver program and in the CD-ROM can help you to better understand the disease and its effects on the person.
2. Plan for action based on your knowledge, skills, and experience. Much of the Savvy Caregiver Workshop 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’m going to do something about this.” Sometimes this phase can be characterized by your feeling angry – and then using the energy of that anger to focus your attention on the problem and to create a plan to do something about it. This step gets you from lower left to upper left. Things are still not good, but the control has shifted from the situation to you.

3. Put the plan into effect. Act. Do something that might have an impact on the situation. If this step isn’t taken, the energy will evaporate. Your feelings may slip back into the lower left, possibly even more profoundly so. There are at least three possible outcomes to putting the plan into action.
 - The strategy (plan) works perfectly, the situation gets better, and you feel good because this represents a real accomplishment.
 - The strategy doesn’t work or works imperfectly, so the situation doesn’t really change. Nevertheless, you recognize that you have done something powerful just by trying the strategy. That makes you feel good. Furthermore, this outcome (as well as the outcome above) reinforces one of the central points of the workshop. As a Savvy Caregiver, you have to be “experimental” and “clinical” in your approach. This creates or reinforces an attitude to try to develop and implement other strategies in the future.

- The strategy doesn't work and you don't appreciate that even trying it was a good thing, so you slip back to the lower left quadrant. As above, the basic savvy caregiver strategy has to be to meet disappointment with a spirit of experimentation. Not all experiments work, but you can learn something from almost all of them. Even in the face of discouragement, try to see if there was something you learned.

Time and Activities for Yourself

A second important element of self-care involves taking steps to develop a repertoire of activities that you can do, should free time become available. Many caregivers become so immersed in caregiving that they lose the sense of what it is that delights and refreshes them. As a result, they don't actively seek time for themselves. Or if they find themselves with time, they are unsure what to do with it.

This portion of the manual is built around an exercise you can do in five-ten minutes. This exercise stresses to caregivers that it is crucial for them to take time to rejuvenate themselves. If they wait until everything is done and they feel caught up, they will never take the time for themselves.

Imagine you have a fairy godmother who has granted you five wishes. Unlike other fairy godmothers, yours decided those five wishes are different amounts of free time. You can choose to do whatever you want during your free time. There's one exception – you can't choose "doing chores" as an activity. The exercise purposefully excludes chores because, even though the caregivers may feel behind in their household tasks, they likely will always feel behind in their chores.

So now imagine:

1. You have 15 minutes of free time.
2. You have one hour of free time.
3. You have three hours of free time.
4. You have one entire day of free time.
5. You have a weekend free of any 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 habit of thinking about themselves and their own well being. They may consider thinking about themselves to be selfish, and may even feel guilty about doing so. If you have found ways to make time for yourself, good for you. Keep it up!

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

People do activities to feel more:

- Energized
- Calm
- Centered
- In touch with themselves
- Connected with their family member with dementia
- Connected with the rest of their family
- Connected with their community
- Connected with friends

Other 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 family member they care for

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

The object of this exercise is for you to generate a personal list of activities you could do if and when you are able to make time for yourself. Write them down here so you don't have to spend free time recreating the list. When time becomes available, pick something from the list and do it.

The Goal of Caregiving

What are you hoping to accomplish in your caregiving?

Take a moment and briefly review what you now know about dementia and its effect on the person:

- The person has an incurable disease.
- The person's condition will continue to get worse.
- Living with the confusion of this disease must be troubling and frightening for the person.
- Losses and confusion can lead to difficult behaviors.
- The person is becoming less able to arrange things for him/herself.

Now think about what people typically hope to accomplish when they take care of someone who is ill. And think about whether these care goals fit in dementia.

Possible Goal 1: See the person through the illness and back to health.

This is probably the most common goal of caregiving – nursing someone back to health. Most people's experience of giving care to someone fits this mode. People are used to it when a family member “comes down with something.”

- There's a period when you think something is wrong. This is when you find yourself paying extra attention for little signs.
- There's 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 seems to abate. There are still caregiving chores, but the worst is over. And, best of all, the person seems him/herself again.

It doesn't work this way with dementia. “Nursing the person back to health” isn't a reasonable goal in dementia caregiving. It is important to recognize that caregiving

cannot bring the person back. There can be no expectation that the person will get better. There are no tricks for jolting the brain back to health once a dementing illness starts. No amount of caregiving can help the person return to where s/he was before the disease struck.

Possible Goal 2: Stop or slow the progress of the disease.

This goal is common in many chronic illnesses. Although irreversible damage is done and an irreversible process is at work, efforts to stop or slow the progress of the disease can be effective. Some ability may be lost permanently and other losses will follow, but 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. In progressive diseases, like Alzheimer's, there is nothing we can do to prevent the condition from worsening. The person's powers will wane.

Possible Goal 3: 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 and spiritual concerns are important.

Attention to the person's Quality of Life provides a reasonable goal for the work of the Savvy Caregiver.

Keeping the Person Involved and Content: How a Quality of Life Goal Translates into Everyday Caregiving

At this point, we want to emphasize a key term in the Savvy Caregiver's training. The term, "Involved and Content," is one we've used before in the manual. It is meant to represent the caregiver's day-to-day goal in caregiving. Successful caregiving boils down to trying to keep the person comfortable and as involved and happy as possible.

The idea of keeping the person involved and content is fairly concrete. It is what you see when a person is busy with something s/he likes and that fully engages him/her.

It is important to keep in mind that, even though a person is affected with a dementing disorder, s/he can still:

- Zero in on a task or activity.
- Stay with it for some time.
- Have a pleasant time doing it.

Keeping the person involved and content may help keep confusion at bay and reduce the chances of distress and difficult behaviors. The phrase only means to suggest that the tone of the day and of events in it is pleasant and satisfying. It isn't meant to suggest that the person should be busy doing things non-stop, from morning till night. Nor is it meant to suggest a big emotion – like feeling overjoyed. A caregiver wants to keep the person's emotions as steady and positive as possible all day long.

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

- Getting necessary things done (dressing, eating, bathing, etc.).
- Having the person do things that seem to give him/her pleasure.
- Keeping things on an even keel.

Consider the application of the phrase Involved and Content to such daily tasks as helping the person to bathe or get dressed. These are seldom activities that produce intense focus or grand emotions. Nor do they require a very broad range of talents. They are, however, activities which can – and, by caregivers' many reports, do – lead to frustration, angry outbursts, and resistance. These daily events – which are part of the backbone of the day – can become unpleasant. For such daily tasks and events, the idea of contented involvement means, simply, that the task you present to the person:

- Fits what s/he can do
- Somehow draws him/her into it

- Proceeds without conflict or distress
- Gives him/her some sense of satisfaction or accomplishment.

In other words, a very ordinary event transpires successfully and uneventfully, and the rhythm of the day remains pleasant and unbroken.

These ideas hold true over the course of the disease. Throughout the disease, it falls on the caregiver to shape the person's daily tasks so they fit what the person seems able to do. And the caregiver also has to help the person begin and stick with these activities. Part of shaping activities comes from knowing the person. Different people find different activities enjoyable. For some people it's nature or sports. For others it's an artistic activity (e.g., playing or listening to music). For still others it's work of one sort or another. The common thread is that these activities reflect the person's preferences and use his/her talents.

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

An Exercise in 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'd 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 you gave and the way you gave them for each kid.
- You would supervise and provide help differently to each kid.

- You'd have different expectations for the "quality" of the work each kid would do.

The next section of the manual gives information about shaping activities for a person with dementia and helping the person get through them. But we all have an intuitive ability to fit task to talent.

How Much Contented Involvement?

Be realistic. Your goal isn't to have the person involved and content every moment of the day. Nobody's day looks like that, and you can't provide it for the person. So give yourself a break. And take full credit.

Think back on your day of caregiving. Can you think of:

- A time or two when the person was really zeroed in on something and seemed happy?
- 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 that got the person back on track?
- An instant when you felt the person was really connected with you?
- A moment when the person beamed with delight at something – and that something was something you brought about?

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

Estimating A Person's Abilities

When you take on the care goal of having a person as happily involved as possible, the first question you probably ask yourself is, “How do I do that?” Behind that question is another question: “What can the person do?” To meet the Savvy Caregiving goal of getting someone involved and happy, you need to know what the person is capable of.

It seems to be part of our nature to “read” what other people are like and what they are capable of. And we tend to adjust how we interact with others based on this reading. Think about the exercise in the last section of having kids bake cookies. Your “reading” of the children’s abilities affected what you would ask each child to do and how you imagined speaking to and directing the child in the activity.

This section of the manual is meant to help you get a “read” on what your person can do, given the present stage of the disorder.

Dementia Affects Doing Things.

As you saw in the first sections of this manual, dementing disorders affect all parts of a person’s life. They affect a person’s cognitive or thinking abilities and they can lead to confusion and loss of focus. The most general effect of dementia is that it hampers a person’s ability to do things in everyday life.

Dementing diseases break up the ability to do things. They affect a person’s ability to grasp and handle tasks or activities. As dementia advances, the ability to do things declines.

How Does Dementia Affect Doing Things?

Think about almost any common task. It could be shopping for groceries, balancing the checkbook, or driving to and from a friend’s house. Doing any of these common tasks involves three main things:

- **Purpose.** Practically everything we do is aimed at some purpose. We want to accomplish something. Identifying and keeping a purpose in mind is a complex thinking task. It draws on the brain’s higher executive ability. The purpose of an activity usually helps us to create some kind of plan or road map for getting to that endpoint. We use this plan to guide the steps to reach

the goal, to check our progress in reaching the goal, and to refocus our activity, should we be interrupted or distracted. For example, the purpose in making a sandwich is to put it together the way we want and then eat it or share it with someone.

- **Order.** Practically any task involves an ordered set of actions. Many tasks involve a set of sets. 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 (e.g., ham and cheese). The person may want mayonnaise or mustard. Lettuce and tomato might be good, too. And the person might want to cut the sandwich after it's made. The purpose isn't achieved if key steps are left out. Nor is it achieved if the order of the steps is switched – putting mustard on the outside of the bread doesn't make for a good sandwich. The order of steps of many activities is deeply engrained. People do repeated actions seemingly without thinking. Many daily tasks – like getting dressed – rely on following an order of steps learned long ago and practiced over a lifetime.
- **Proper use.** Knowing what things are and how to use them is one of the brain's most primitive jobs. If this function is lost, not much meaningful activity is possible. Each of the steps in the order puts a person in contact with some object. It might be a jar or a hammer or a broom. It might be a checkbook or a computer. In order to get through that step, the person has to be able to use that object properly. If the person doesn't recognize a thing for what it is or can't make use of it, the step won't be taken. And then the purpose won't be achieved.

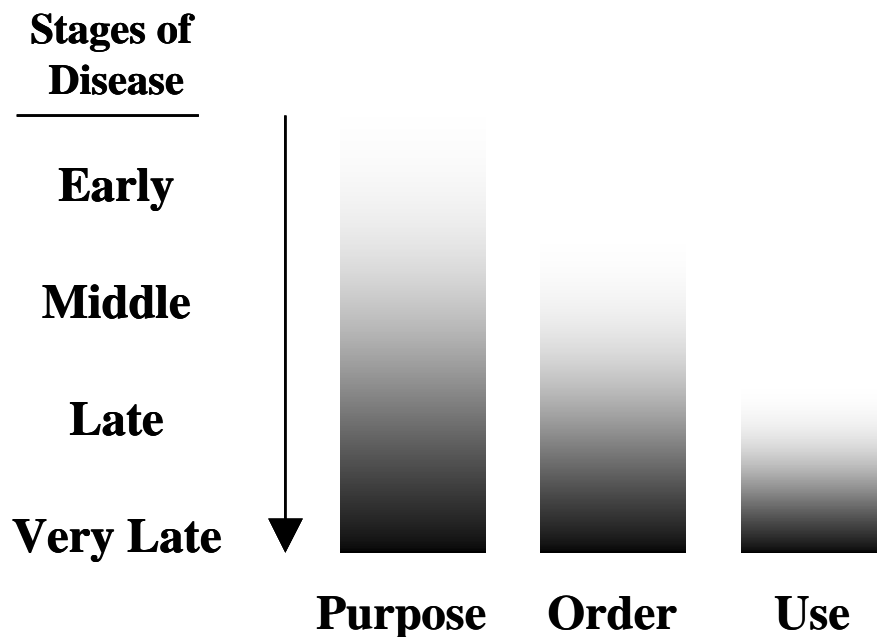
Roughly speaking, the elements of performance are lost in order in dementia.

- First, the sense of **purpose** is compromised and is then lost. Early in the disease, complex tasks become more difficult for the person to grasp and organize independently. As the disease progresses, 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. What the person does is the result direction by others or impulses suggested by the environment.
- Next, the person loses the ability to keep the **order** of doing things straight in an activity. The person can do things, but will lose track of what comes next. For example, s/he might begin to button a shirt, become distracted, and not be able to pick up the activity without a reminder.

- Finally, in the very late stages of the disease, the person will not be able to relate meaningfully to objects. Things don't have any meaning, and s/he will not know what they're for or how to **use** them.

These losses occur gradually. The realization that your family member has lost the ability to relate to the purpose of an activity will begin as a hint – a dim suspicion. This will be confirmed only over time. The losses are seldom dramatic, and they blend into each other. So a person may retain some ability to keep the goal of an action in mind even as he or she is starting to have trouble with the order of steps needed to complete the activity.

The diagram below is meant to illustrate how the ability to do things declines in dementia.



How Key Elements of Doing Things Are Lost in Dementia

The arrow at the left identifies the broad stages of dementia. The three columns represent the three key elements of doing things. In each column, the area that is white indicates that a person is able to carry out that part of doing things with most activities without much difficulty. The area that is black 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 ability. As the disease progresses, the shaded areas get darker and finally become black.

As described above, problems are noted first in keeping a clear sense of purpose. This shows especially with complicated tasks and activities. This ability continues to decline and 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 middle stage of the disease. The same thing happens with the capacity to follow an order or sequence and to use objects appropriately. Losses in each of these are seen later in the disease than those related to purpose.

Keep several things in mind when thinking about the loss of ability to do things.

- It's not sudden. It isn't that, one day, the person isn't able to keep the purpose of an activity in mind. Instead, you will find you'll be less able to rely on the person's sense that what s/he is doing has a purpose.
- There is overlap. Decline in one element begins while decline in another becomes more advanced. You may notice the person is having problems with the order of a task as well as with keeping its purpose in mind. Later, you may see that the person is confused about the object as well as the order of things.
- 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 the simplest task when you have the flu.
- The nature of the task will affect performance. For example, a person who is early on in dementia might have problems keeping the purpose of a complex task in mind. However, that same person might be able to keep the sense of purpose with simpler or over-learned tasks.

Introducing a Staging System for Dementia

This section of the manual outlines a framework for describing the stages of dementia in terms of the effect of the disease on the person's ability to do things. Later in the manual, the framework is linked to strategies for designing activities and choosing communication methods that fit with the person's abilities. Having a

sense of the person's strengths and needs helps you to design or select an activity that fits these capacities.

Four suggestions apply to Savvy Caregiving at all stages.

- **Be positive.** Frustration – yours and that of the person with dementia – is always just around the corner. Once it hits, it changes the mood of a task or activity. It takes the fun out of it and can set both caregiver and care receiver on edge.
 - People with dementia 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. These caregivers adjust their own expectations about performance. This can help prevent frustration in the caregiver – and perhaps in the person.
 - When caregivers' expectations are realistic, they can see the success the person is having in the task. This success can and should be encouraged and recognized. Praise and a pat on the back reassure the person and raise the person's mood.
- **Avoid pressure.** Everything will take longer. If you feel under pressure to get a task done, the person will probably feel it too. Pressure can make the person anxious, defensive, irritated, or any number of other emotional responses. None of these emotions promotes contented involvement.

Plan to do and accomplish less. A basic caregiving strategy involves simplifying the day (or visit). Put less pressure on yourself and the person by removing things from the schedule.

- **Use humor.** There is nothing funny about dementia, but humor is not lost. Persons with dementia can still laugh, and laughter still has a positive effect. Sharing a laugh is something a caregiver can do with the person, even late in the disease. Humor can still provide a point of connection, even when a person has dementia.

Dementia causes people to make mistakes. Sometimes mistakes can be funny. Don't be afraid to laugh at these mistakes. Laugh with the person. This may help relieve any embarrassment the person might feel. But it also

is a way to let the person know you are right there and are sharing and connecting with him/her.

- **Adjust expectations.** Relax your standards with regard to performance. When contented involvement is the goal, it is the doing and being involved that is key. 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.

Don't 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. And it can be frustrating to see how poorly they perform. At these times, it is helpful to keep the care goal in mind. If the person is content to be involved in something, it is the doing, not the product, that is important.

A Staging System for Dementia

There are a number of frameworks that people use to describe the effect of dementing diseases. The frameworks use different ways of describing these effects. Some use words or phrases; some use numbers. But they all have the same intention. They try to portray the losses people experience as a result of dementing diseases.

The Savvy Caregiver program combines two frameworks. One is the framework the Alzheimer's Association uses. This framework uses a timeline image (early-middle-late) to portray the progression of the disease. The other framework is one that comes from occupational therapy, a field with special expertise in understanding how people do things (function and perform). This is a numerical framework originally developed by Claudia Allen. In this system, people who function normally are described with a "score" of 6.0. As their ability declines, the scores assigned to their functioning also decline. A person whose dementia is in the last stage and who is bed-bound and not responding would be assigned the lowest score, 1.0.*

* You can find more information about the Allen levels at (<http://www.allen-cognitive-levels.com>), Claudia Allen's website.

We use a combined system because we have found that caregivers benefit from being able to choose a framework that works best for them. Some relate better to words; others relate better to numbers. Use whichever makes sense to you. The chart below shows how the two frameworks relate to each other. Note that the Middle stage is divided into two parts:

<u>Time-Based</u>	<u>Performance-Based (Allen Levels)</u>
Normal	6.0
Early	5.0
Early Middle	4.5-4.0
Late Middle	3.5-3.0
Late	2.0-1.0

Two Frameworks for Describing the Losses in Dementing Illnesses

The material that follows in this and the next chapter of the manual will use both frameworks together. Much of the material is drawn from and linked to an educational CD-ROM entitled “Dementia Caregiving Strategies.” This CD-ROM was produced by the Department of Veterans Affairs in collaboration with the Geriatric Research, Education, and Clinical Center (GRECC) at the Minneapolis VA and with the University of Minnesota. The “Dementia Caregiving Strategies” is sometimes used with the Savvy Caregiver program. Or you can find out more about it by going to this website: <http://www.hcinteractive.com>.

Normal Performance (Allen Level 6.0)

Normal Performance refers to the ability of people without dementia to perform tasks that are within their scope of 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, create a plan for doing the task, choose tools or objects that relate to the task and set aside those that don’t, and 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 don't enjoy as much.
- When they are starting to lose it – to be over-stimulated.
- How to keep calm and keep the situation enough under control so they don't fly off the handle.
- 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 dementing disease. Imagine a common daily activity, such as getting a household off to school and work or preparing an evening meal. There are many things going on and many demands being made by many people. The tasks are not, in themselves, very hard – when you take them one at a time. When they're all wound together, however, things can get confusing. But people performing normally can usually pull things together and get the job done without getting too rattled. And they may enjoy it, too.

So people functioning normally can get the family out the door every day. They balance all the intertwined tasks and keep their goal clearly in mind. They can get right back on track after a phone call interrupts them. They can direct others and ask for help. They know when things feel too close to the edge of their stress threshold. And they have ways to back away from losing it. They even know how to steal a few moments for themselves. Throughout, they are zeroed in on their tasks, and accomplishing them gives them satisfaction.

Early Stage Dementia (Allen Level 5.0): Signs Begin to Show

Dementing disorders are said to have an “insidious onset.” They seem to sneak up slowly. The clues that these diseases are present are usually subtle and vague. Some times, some things seem a little “off” or out-of-kilter with the person. Most of the time, it's only when the family looks back over the few years before a

diagnosis was given that the signs and clues become clear and a pattern emerges. The early stage of the disease can extend for several years. But it is a stage of the disease, and the effect of the disease on the person is progressing.

Early in the disease, people are still relatively able to do things independently. These persons will have difficulties with short-term memory and will show other early signs of the impact of the disease. They will probably be able to do routine daily tasks without help. They will mainly have difficulties when faced with 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 Level:

- People may show have trouble with the more executive cognitive functions, such as planning and judgment.
- They may have difficulties in problem solving. They may also have problems planning ahead to prevent problems.
- They will begin to show signs of having trouble with abstract thought, and may begin to have difficulty grasping the big picture.

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

- **Encourage independent activity.** People at this level perform basic everyday tasks with little or no difficulty or assistance. It might only be necessary to simplify tasks and schedules for people and to help them to plan ahead.

People at this level can work with others and may even be able to help others whose performance is more severely limited by the disease. Some caregivers report being able to get persons at this level to attend adult day programs by convincing them 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. Or they might get bogged down in a detail.

Watch how people handle new situations and tasks – or tasks that are complicated. For example, people in this early stage may seem fine in routine settings but they might become confused if they were to travel to an unfamiliar location. Even when families have vacationed somewhere for

several years, the onset of a dementing disorder may produce confusion in the person when s/he travels to that location.

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

- **Provide directions when needed.** This can be done subtly and in the background. Persons who are showing the early signs of dementing disorders will generally listen to and be able to 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 can have serious consequences. Start now to supervise this activity. Also, the process of getting the person to give up driving should begin as soon as the dementia diagnosis is received. A person at this level will still be able to drive. However, this person's ability to react effectively in a crisis is already compromised.
- **Watch the person's feelings.** Watch for signs of anxiety or depression. About one of every three persons with dementia 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 be treated effectively.

People may also vigorously deny the condition. Denial may be an effort to mask something they recognize. It may also really be that they don't recognize a problem. Don't argue with or try to convince people they are ill. Provide emotional support by showing concern and giving reassurance.

- **Encourage discussion.** Many people at this level are aware something is wrong. Talk about what's 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, members of your family, a member of the clergy, or a professional (a nurse, 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 and 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:

- **Advanced care planning.** Talk about what the person wants as s/he becomes more ill. Who does the person want to make health care decisions for him/her? What about reviving the person if the heart stops? If s/he develops an infection or pneumonia when s/he is very demented, should s/he go to a hospital or be treated? Does s/he want to be given food or water by tube, should it come 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 that document “official.”
- **Living arrangements.** Where you live can affect caregiving. If you think you might want to move to a different place, this is a good time to talk about it. Moving early in the disease might help the person establish routines in the new place.
- **Care help.** As the disease progresses, you will need help. You might want some time for yourself. Adult day programs or in-home help can give you a break. Later, when every part of care has to be provided, one-on-one caregiving can be overwhelming. Institutional care – in an assisted living or a nursing home – becomes an important option. Opening up these topics now, while the person is still able to reason about them, may make the choices easier for you later on.

Early Middle Stage Dementia (Allen Levels 4.5 – 4.0): Problems and Impairment Increase

In this Early Middle stage of the disease, caregivers see that problems are apparent. People have clear difficulties doing things, although some independent activities continue. They lose track of what they started to do. They get distracted easily. And they need help, even with regular tasks.

As with all stages of the disease, the Early Middle stage extends over a long period of time and the person’s ability to do things declines within the stage. In the section that follows, we use the occupational therapy numerical framework to describe decline in this Early Middle stage.

Level 4.5: A Time of Increasing Problems. Persons at this level still usually look good. They appear to be performing rather normally. However, the higher thinking powers (reasoning, abstraction, planning, etc.) are more affected by the disease, so performance is more affected. The person is becoming less clear about the larger

purpose of the action. Errors show up more regularly. Things aren't done as well or as smoothly.

You may see that people at this level look to caregivers for direction or help. They may do things hastily, without considering results. They may work in trial-and-error fashion. Or they may just freeze, not knowing where to start or what to do. Distraction and frustration may occur, especially with tasks that are complicated.

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

Level 4.0: Impairments are More Noticeable. As the disease moves further into the Early Middle stage, confusion and errors are now seen regularly. People can do little on their own, and their thinking powers are very weak. They need help with even routine daily activities – like getting dressed. (This help often takes the form of prompting and reminding. But that means you're keeping tabs on the person.) They have limited attention and may be easily distracted.

People at this level may keep a goal in mind, but usually only in activities that are simple and familiar. Difficulties in doing things become more pronounced. People may become more hasty or more hesitant. They will likely turn to caregivers more for help or direction. It may be that you will see more unpredictable behaviors. People might retreat, become sad, or lash out for reasons that are not immediately clear.

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

- **Establish routines.** For a person at this stage of the disease, routines are a good means to promote contented involvement. Simple well-structured tasks are most helpful. The person won't strictly remember the tasks or the steps, from day to day. However, repetition may foster familiarity. This can provide a sense of safety, comfort, and control. If you can find a few activities the person enjoys, you can do them repeatedly.

- **Start taking over.** Simplify and organize tasks and activities. If you want the person to do something, set it up and tell the person exactly the steps you want him/her to do. This frees the person from the planning but lets him/her be involved in the larger activity. Let the person make choices that won't confuse him/her, but don't involve the person in choices that will be confusing or distracting. Even as this stage progresses, the kinds of choices a person can make will change. They will be less able to make complicated choices. As the disease progresses, even at this stage, you may have to take full control. You will have to design each task and set up the items needed. Plan which parts you want the person to do.
- **Think about the setting.** The person may be more easily distracted at this stage. Decide where you want the person to do the activity and remove as many distractions as possible. The environment should be as simple as possible. Put everything the person needs for the task nearby.
- **Provide support.** The person will need prompting. You might have to help the person start a task. It is very likely you will have to help the person stay on track. The person may need to be reassured while doing the task.
- **Give directions that work.** Adjust the way you direct the person to fit what works with them. At this stage, a combination of verbal and visual directions may prove effective. Verbal directions should be simple, short, and concrete. Simple written notes or labels may help early in this stage, but don't rely on them. The person may get them or not. It's worth a try. Eventually, written instructions will not work. Visual cues become more and more important as this stage progresses. Point to the things you want the person to focus on.
- **Keep watch.** Observation and as-needed guidance are needed and will help. If you have to correct or redirect the person, try to do so in a way that is supportive and that does not call attention to the person's inability or mistakes. Or, if it's not important, let errors go. A person at this level is not likely to learn from errors. S/he might remember, but it's unlikely. It's more likely s/he'll just feel badly for being corrected, so let it go.

At this level, you may be able to leave the person for a while, but it's important to check back regularly. Also, safety checks are important. The person's judgment is no longer strong. You'll have to watch carefully to be sure the person isn't using things or going places that could be dangerous.

For example, by this stage, a person who used to walk to a nearby store should not be allowed to do so alone anymore. The person's abilities to cross streets safely, to find his/her way back home, and to manage money are all compromised by now.

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

The Issue of Driving. People at this level have very poor judgment and will respond poorly in a crisis. People should no longer be permitted to drive. If you cannot convince the person to stop driving, use all the help you can get.

- Inform your local department of motor vehicles and/or police department of the person's condition.
- Ask your physician to help get the person to stop.
- Bring in other members of the family and get their support and help in getting the person to stop driving.
- Make the car less accessible – take away the keys, disable the car.

This is a serious situation. The person is at risk, but so are others who are on the road.

Late Middle Stage Dementia (Allen Levels 3.5 – 3.0): Dependent and Confused

People at this stage of the disease need help doing most things. They need direct help to begin and get through most tasks. Safety is a big concern. Their growing confusion may lead to unpredictable reactions. The work of caregiving does increase, and caregivers benefit from help from others.

The Late Middle stage extends over a long period of time and the person's ability to do things declines within the stage. Below we again use the occupational therapy numerical framework to describe decline in this Late Middle stage.

Level 3.5: Becoming Dependent in Daily Basic Tasks. Persons at this stage can do very little independently. There are few actions they will begin themselves. They

will need help throughout. They may need help even with basic routine daily tasks. They may, for example, need help getting out of bed or to the toilet. They may need help getting dressed or feeding themselves.

Increasingly, people at this stage do things without a sense that there is a purpose to the action. They do not act with a plan in mind, but 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 and then get stuck or distracted. People can use objects, but may need reminders about what they are supposed to be doing with the object.

For example, you might direct a person at this level to brush his/her hair as part of morning grooming. After you hand the brush and give a direction, the person will likely begin to brush. Then any number of things may happen:

- The person might get stuck in one spot and brush it over and over.
- The person might begin to use the brush in some other way – for example to scrub the wash basin.
- The person might become distracted, put down the brush, and move toward something else.

For people at this level, the world around is confusing and may be threatening. Their powers of thought are so weakened that they are of little help. They cannot sort things out. Increasingly, people are likely not to know where they are or who others are in the environment. They may even no longer recognize family members. People have an increasingly difficult time making words work. They have trouble finding them, using them to communicate meaningfully, or putting them together in a patterned way.

Emotionally, people at this stage will be sensitive to the feelings of others and will pick up impatience, frustration, or annoyance coming from another. S/he is likely to be very sensitive to negative feelings from another – for example, to feelings of being rushed.

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

- **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 parts of the world that is in front of them. They may recognize 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.
- **Striking out.** This may be verbal or physical. People may misunderstand something and take it as a threat. They might feel overwhelmed and become defensive. Even frustration can produce a violent reaction.

Level 3.0: The Person Experiences General Confusion. Expect persons at this stage of Late Middle dementia 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 be able to maintain one or two steps in the order of a task only with help and prompting. Their sense of what objects are and how to use them is slipping markedly. They benefit from short, concrete directions without explanations. Communication should emphasize visual and tactile (touch) cues.

Persons at the stage need to be watched and helped with almost everything they do. They will need help with all daily care tasks and with any activities. At this stage, caregiving is a full-time job. A person trying to provide care on his or her own will be very busy. Because care at this stage is full-time, this is a point when many persons with dementia are placed in institutional settings.

Because they are so confused, persons at this level can be easily upset. Inability to handle a complex world can produce any number of reactions. They may, for example:

- Seem anxious or restless.
- Become agitated.
- Have trouble sleeping or getting back to sleep once awakened.
- React to things they misperceive (hallucinate).

- Behave as though people are stealing from or threatening them.

Many things can upset a person at this level. 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.

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 dementia.

- **Take full control.** The basic design of the day is up to you. Make sure the routine of the day is set. Because the person is so dependent, the day should be simple. Keep as undemanding a schedule as possible. For each part of the day, have a clear plan for what you will want the person to do.
- **Keep things simple.** For each task you want to involve the person in, decide what you want the person to do. The tasks you ask the person to do should be one or two step tasks. In some cases, passive involvement may represent a caregiving success.
- **Keep routines.** The person will do best with simple well-structured tasks. If you have already begun routines, stick to them. If you haven't, look at what you have been doing. It may be that you have established routines but not named them.
- **Lower your expectations.** Be prepared to scale down your plan for the day. Expect less from the day.
- **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. Because the person cannot attend to safety issues, remove all potential dangers.
- **Manage all tasks.** Expect to help. There is little the person will be able to do without help and direction. By gesture or word, you will have to help the person to begin a task. Watch the person throughout. Provide cues and visual demonstrations for each step. Keep your family member on track with simple directions (“keep going;” “that’s all;” “put it down now.”). Be

prepared to draw the person back to the task when s/he becomes distracted or disinterested. It is very likely you will have to bring the task to an end.

- **Use appropriate cues.** Get the person's attention. Verbal directions should be simple – one or two words – and accompanied by more visual cues. Hand objects to the person and show him/her what to do with it (demonstrate). Guiding by touch may be helpful too.
- **Assist directly.** If something has to get done – like dressing – let the person try doing it with your help. But if the person is not cooperating in the task or if it's taking longer than you can bear, jump in. Sometimes the best thing is just to do the job yourself.
- **Refocus.** If your family member's attention wanders, divert him/her back to the activity at hand.
- **Watch over everything.** Safety and well-being will have to be watched carefully. Dangerous object should be kept out of reach, and all daily activities have to be monitored. This includes basic activities like eating, bathing, using the bathroom, etc.
- **Judge when it's over.** Errors, completion, and quality are unimportant. A task or activity is good and useful only as long as the person is happily occupied with it. If the person becomes bored with a task or is clearly not interested, don't push. End the task and move on to something else.
- **End it.** Signal the person the task is done – and praise the person for whatever part of the task s/he did.

As in every stage, there should be no pressure. The person shouldn't feel it matters that an activity is finished within a certain time frame. Nor should it matter how well something is done. Reassurance and rest breaks may also be useful. As people reach the end of the Late Middle stage of dementia, they may benefit from passive participation – just watching.

Late Stage Dementia (Allen Levels 2.0 – 1.0): Minimally Able and Unresponsive

The late stage of the disease is a time when people cannot care for themselves and lose their connections with the world. Even though they require help in all parts of their daily life, it is still reasonable to consider that they can be drawn to things and

take pleasure in them. Typically, they should be expected to take part passively. But even in passive participation, caregivers can observe that the person is expressing pleasure or contentment. Comfort and keeping confusing and frightening things away from the person are important care concerns at this stage of the disease.

The Late stage of the disease may be the most variable of all, in terms of how long it lasts. In the section that follows, we use the occupational therapy numerical framework to describe what to expect in the Late Stage of dementia.

Level 2: Functioning with Minimal Abilities. At this stage in the disease, 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, outside of occasional words and sounds, is gone. There is little left of attention. Movements or touch may draw the person's attention briefly. The person may resist care – may even strike out.

By the time people with dementing disorders reach this stage, they will need more or less total care. Typically, by this level, the family has placed the person in a structured environment – assisted living or a nursing home – where care staff and a range of care services are available.

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

Level 1.0: In bed and unresponsive. This is the end stage of the condition. Persons at this stage of the disease require total care. They are usually quiet, sleep a lot, and 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. The senses are the best way to continue to occupy and provide happy moments for persons in this stage.

- For many people, music remains a pleasure.
- Some people like the presence of companion animals.
- Comfort objects – dolls, blankets, etc. – can be pleasurable.

- Good smells may please the person.
- Soft comfort foods – like shakes – might be pleasurable. Persons at this stage may have a hard time eating even finger foods.
- Non-threatening stimuli — like colorful moving objects — may be enjoyable for the person.

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. At the feeling level, a calm, quiet environment is helpful.

A Word of Caution About Using Staging Frameworks

This presentation on the named stages of dementia and the numerical levels of performance is meant mainly to alert caregivers to a pattern of decline in dementia. The frameworks provide a *rough* guide to the declines. Overall, they provide a general way of thinking about the decline that is brought about by a dementing disorder.

However, the stages and levels should be viewed with some caution:

- These are not absolute states. A person doesn't move from one to the next overnight. The change is gradual over a relatively long period of time.
- People who are described as being at one stage or level do not remain fixed or static until they pass to the next stage or level. There is continuous and gradual change across them.
- People have good days and bad days. Someone who is estimated to be in the Early Middle stage (e.g., at level 4.0 will), one day, seem to act with clear purpose and so look more like he or she is in the Early Stage (level 5.0). On another day the person might seem more confused and so appear to be more like a person at Late Middle stage (e.g., level 3.5).

As we will discuss in the next section, activities affect performance. The size and complexity of a task or activity affects performance – both its quality and how long it takes. A person in the Late Middle stage (e.g., level 3.5-3.0) may, for instance, be able to perform one or two simple, over-learned sequences. For example, the

person may put clothes on in correct order when they are laid out by someone else. This same person may be unable to perform more complicated sequences. A person in the Early Stage of dementia (Level 5.0) might become frustrated when dealing with a complex task – for example balancing a checking account. That same person may well be able to stay focused on a simpler or more familiar task – for example helping to make a cake.

- Many other factors can affect performance. If a person is sick (has the flu, for example, or hasn't slept or eaten well), those factors will contribute to a decline in performance. If there is more noise or confusion than usual in the environment, there might be a decline in performance.

It is important to remember that these stages and levels are starting points for you. Your family member is a unique individual, and the more you can understand her/his pattern of performing, the more you can help out where needed.

What Stage of the Disease is Your Person in and 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 reading on the progress of the disease. Understand the stages gives you a “feel” for the spectrum of the disease. It is simply a good thing to know where your family member is in the progress of the disease. You can look ahead from where you are now and plan for the care tasks facing you. You can begin to enlist more help. You can think about alternatives to the present situation.
- It can be a guide for Savvy Caregiving. On a day-to-day basis, knowing, in general terms, your person's disease stage and level of performance gives you a practical starting point for reaching your caregiving goal. The next section of the manual will provide a practical guide for helping persons with dementia become and remain involved and content while doing things. The guide is linked to the staging frameworks 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. To arrive at an initial estimate, you will be asked to do three things:

- View the videotape in class that shows persons at various stages in the disease performing two everyday tasks. This viewing will be accompanied by a talk by your instructor.
- Re-read the material in this section.
- View Section 4 of the Dementia Caregiving Strategies CD-ROM. This section concludes by asking you to estimate, based on viewing the video clips in the section, your person's level.

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.

That is, you will likely be able to say s/he's either this stage and level or the next one up or down from it. For now, that's all you'll need. The surest way to get at the right level will be to apply the principles you'll learn in the next section. Once you start working with them, you'll be able to judge from the results whether to move your estimate up or down or to stay where you are. 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 an Occupational Therapist (OT) who knows dementia and the performance levels (sometimes called Allen levels) and seek a professional evaluation. An OT should be able to help with the evaluation but also by giving advice and guidance on design of tasks and activities.

Providing Practical Help – the Anchors of Caregiving

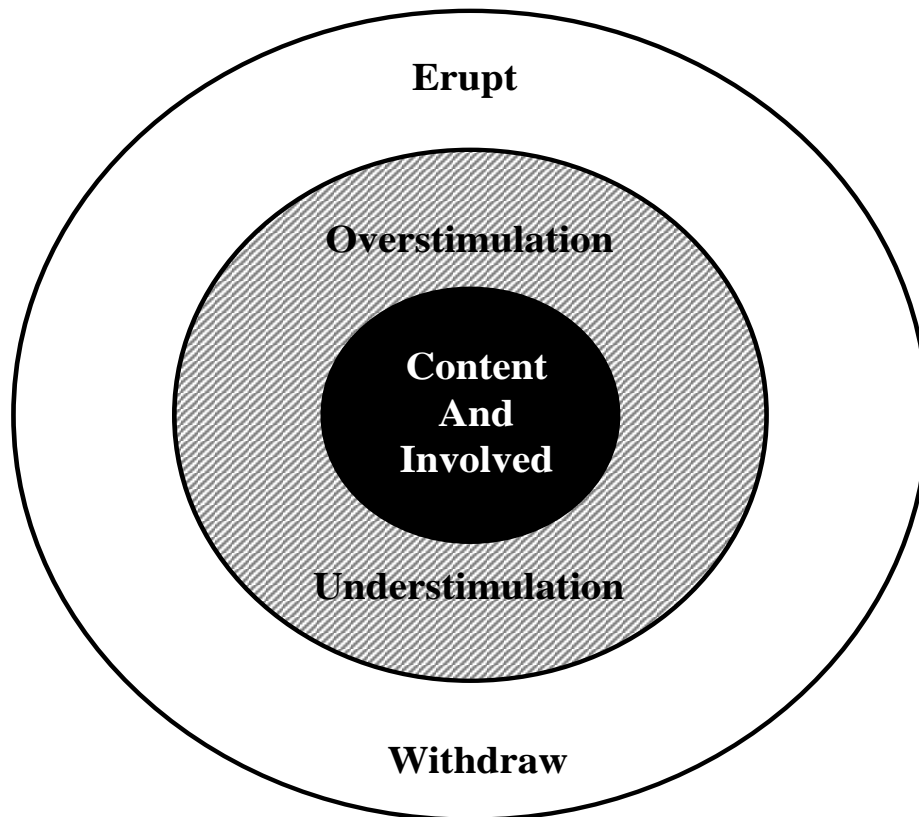
What Is the Savvy Caregiver Trying to Do, Day-to-Day?

As you saw in Section 4, taking control – being in charge – is a key part of the caregiver's role. As the dementia deprives the person of abilities, the caregiver steps in more and more to make things happen. In very practical terms, you become increasingly in charge of what happens in daily life. You are the one who decides what the person will do during the day. And you are the one who helps the person become and stay involved in the activities you choose. This section is about how to accomplish that.

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. If the stimulation is too great, the person can become rattled and erupt and fly off the handle. If the task is too easy, the person can become bored and withdraw. The diagram below displays the possibilities.

Your caregiving goal is to help your person to remain in the zone where s/he is happy and involved as much as possible. In negative terms, you want to keep the person from withdrawing or erupting.

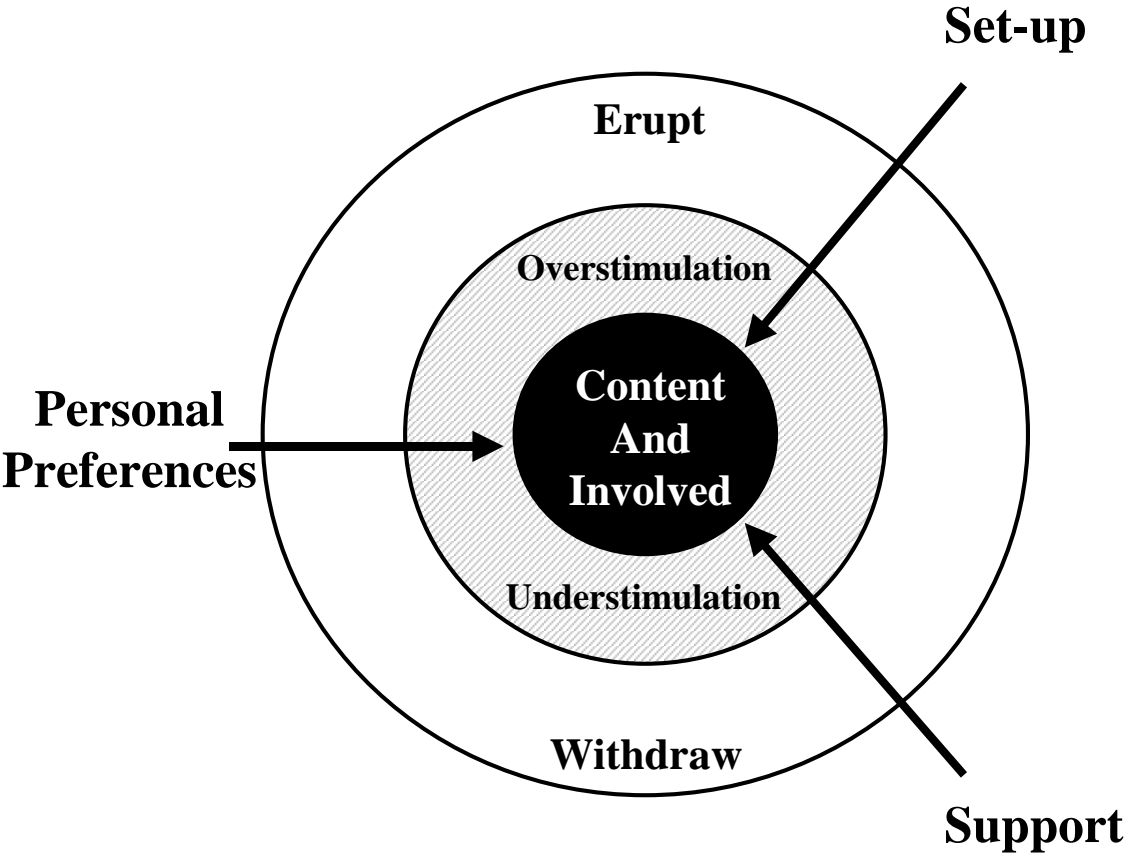
How Does the Savvy Caregiver Keep the Person in the Zone?



There are three basic elements that help anchor a person in the happy and involved zone:

- **Set-up** of task or activity.
- **Support** provided to help the person begin and keep at the task.
- **Person-based** factors, such as preference and habit.

The diagram below represents how these three elements anchor the person in the zone of happy involvement. This diagram shows the three elements working together in a balance. When they are in balance, the person is helped to get to and remain content and involved in a task or activity.



The three anchors are strongly linked to where the person is in the stages of the disease and the level of the person's ability to do things. A good working estimate of your person's ability to do things is a key to helping the person be involved and happy. It can help you decide which activities might be enjoyable. The stage gives you a good clue about the person's remaining strengths. It alerts you to the kinds of problems s/he might have in doing things. It will provide information that will help you to make appropriate caregiving choices.

A Closer Look at the Anchors

Personal Preferences

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 the person likes to do.

People have preferences. They like to do some things and don't like to do – or have never done – other things. You know – from experience and from trial and error – 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 the person who is being cared for. But this is a little tricky. The onset and progress of a dementing disease can alter people's preferences.

- They may continue to enjoy doing things they enjoyed doing before the disease – or 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 (e.g., linking cooking with women and tinkering with tools with men). Just because people never did something but, instead, left it up to their spouses shouldn't eliminate trying those tasks and activities with them.

- Sometimes interests change. People might be no longer interested in things they previously enjoyed.

People seem to like to do things that are not so complicated and demanding that they leave them feeling frustrated and defeated. At the same time, they don't want

to be bored. Usually a caregiver knows what the family member used to be able to do – what kinds of tasks and activities the person enjoyed and could do – before the disease.

The problem is that the dementing disease 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.

Set-up

Set-up concerns the design and layout of tasks. In terms of the model of behavior covered in section 4 of this manual, Set-up relates to the nature of the task and the influence of the environment.

Set-up involves controlling all aspects of the task presented to the person. Tasks and activities are seldom as simple as they seem. Typically, they 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.

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

- **Size.** This is a simple idea. There are big jobs and little jobs, easy tasks and hard ones. There are tasks that exceed a person's mental capacities and 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 family member's abilities (level of performance) into account in giving him/her tasks or activities.

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

- ✓ Sort the laundry into white and dark clothes
- ✓ Match the wash cycle to the clothes
- ✓ Load the washer
- ✓ Put in detergent
- ✓ Start the wash
- ✓ Wait for the wash to run the full cycle
- ✓ Unload the washer
- ✓ Put clothes into the dryer (except those that can't be dried)
- ✓ Start the dryer
- ✓ Unload the dryer
- ✓ Fold and put away the clothes.

To a person in the Early Stage of the disease (level 5.0), “doing the laundry” might be a task of the right size. To a person in the Early Middle stage (level 4.0), the right size task might be unloading the washed clothes into the dryer and then starting the dryer (which the caregiver had pre-set). For a person in the Late Middle Stage (level 3.0), perhaps the right sized job would be sitting and folding the towels. A person in Late Stage (2.0) might enjoy being 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. Complexity relates to how much planning and organizing a task requires. Concreteness relates to the immediacy of the task.
 - ✓ 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 what's 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’ve folded 50 flyers and put them in envelopes, take them to the post office and mail them. But only do that if it’s 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?
- ✓ 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 may need a person to travel outside the home to complete (for example, picking up groceries). Other tasks involve moving from room to room within the home (like doing the laundry). Still other tasks take place right in front of the person within the circle of his or her reach (like stuffing or sealing envelopes).

As always, 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 a very important part of the environment. It helps if you can judge how long it will take your family member 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.

As the disease progresses through the stages, people’s ability to deal with size, complexity and environment declines. Complex tasks get harder. Finally, they are simply out of the person’s reach. Tasks spread over large spaces become difficult,

then impossible. People need tasks that are right in front of them – and 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 below provides some general guidelines for deciding on how to set up tasks in which you might want to involve your family member. The particular suggestions in the table are of less importance than 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 level of the person’s abilities. Performance and the size, complexity, and environment of a task the person can handle.

Stage	Level	Size	Complexity	Environment
Early	(5.0)	4-6 steps	Can involve some abstracts	Can travel outside
Early Middle	(4.5)	3-5 steps	Should be simpler	Might travel
	(4.0)	2-4 steps	More concrete	In one area, reduce inputs
Late Middle	(3.5)	1-2 steps	Only concrete	At a table, no distracts
	(3.0)	1 step or passive	Concrete or passive	Table facing the wall
Late	(2.0 – 1.0)	Passive	Passive	Watching

Set-up Issues at Various Performance Levels

A few examples might help.

- **People in the Early Stage of Dementia (Allen level 5.0).** For most daily tasks (dressing, eating, getting about), people’s ability to relate to the set-up of activities will be fine. They 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 or environment of the activity. If they were asked to do something very complex, they might lose track of the overall purpose while following one or more of the related tasks. For example, driving to a place they have never been to before and having to find their own way could be beyond their abilities.

- **People in the Early Middle Stage of Dementia (4.0).** These people may still understand that actions have purpose. They might sometimes forget the purpose, but they will sense there is a purpose. 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 isn't too complex. And they will have no difficulty using familiar objects properly.

People in this stage might be able to select clothes and put them on by themselves. However, 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 quite tolerable. So you might not intervene but 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 (3.5).** People at this stage may feel that actions have purpose, though this feeling is fading. When reminded of a task, they will focus back in, but 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 and then have to be reminded of the next steps. For example, they may not be able to keep in mind all the steps of “getting dressed.” But they may be able to take the steps for part of that activity. They may, for instance, be able to “put on the shirt” – where this involves putting the shirt on and buttoning it. They won't have trouble using most familiar objects properly. It is likely they will take longer to do something – say, washing up – than people in the Early Middle Stages (4.5).
- **People whose performance is estimated at Level 3.0.** Purpose is no longer there for these people. They act from moment to moment. They may be able to perform two or three steps in a row of over-learned activities. Mostly, their activities will have to be guided, step by step. Their sense of what things are and what to do with them is weakening.

Select tasks that involve very few steps. Tasks that are familiar are best. Also, seek to reduce distraction. Tasks that do not require the person to move about and tasks that are right in front of the person are suitable. People

at this stage can no longer prepare a meal, but they might be able to help with meal preparation. They might, for example, be able to sit at a table in the kitchen and shell peas, peel carrots or potatoes, or tear washed lettuce into a bowl. They might be able to stir pre-mixed things together or to roll cookie dough into balls. But they won't be able to read and follow a recipe or to measure ingredients out – at least not reliably.

- **People in the Late Stage of the Disease (Allen levels 2.0 – 1.0).** By this stage, people don't act with any sense of actions having goals. It is very unlikely they will be able to do any of the steps of an activity. And they will not likely have a sense of objects or their use. So, passive enjoyment is the appropriate caregiving goal. 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 tasks are: 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 (e.g., 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 (doll, blanket).
- Watching while others do thing.

Support

Support is the third anchor of contented involvement. Support means helping through communication, guidance, encouragement, and redirection. As always, there is 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 something you do more or less automatically. Let's look at the main things that Support involves.

- **Focusing.** One of the first concerns in getting people with dementia 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 and/or add to confusion. So before trying to get family members involved in something, make sure that they know you are there and that they are focused or zeroed in on you.
- **Informing.** Tell family members what you want them to do. They may not understand, but the telling is important. Your voice will draw the person's attention.
- **Instructing and Demonstrating.** Give people usable information about how to do what you want them to do. If their performance is not yet seriously affected by dementia, you may just be able to give directions verbally. However, soon into the disease people need more than words. They may, for example, need you to physically demonstrate a task so they can see how it's done. They may need you to demonstrate it a few times. At some point, they may need you to physically lead them through the task. Take the person's hand and guide it in the motions.
- **Initiating.** You may have to tell or show your family member that it is time to begin the task. Particularly after people get to the Early Middle stage (4.0), giving help with getting started is an important part of Support.
- **Prompting and Cueing.** In many cases, particularly after entering the Early Middle stage, you will have to help your family member follow the steps in a task.
- **Monitoring.** For most persons with dementing disorders – and certainly for those from Early Middle stage forward – you will have to check to see how they are doing with the task.
- **Ending.** In some cases, particularly once a person is in the Late Middle stage (level 3.5), you may have to provide cues that the task is done.
- **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 – either in words

or through your reaction to something – should be avoided at all cost.

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

Re-Focus: Dealing with Distraction

Should people become distracted, try to call them back to the task. This should be done in a manner that fits their abilities – using communication techniques appropriate to the level (this will be discussed in a few pages). Try to identify the source of distraction and to remove and eliminate it, if possible.

- This may be something external – 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. Perhaps there are too many steps for the person. Possibly there is something about the task that is too difficult or causes the person to get stuck on it. If you see this, alter the task to better fit the person’s abilities and then draw him/her back into it.
- The distraction may be internal. The person may be ill or feeling pain or discomfort. However, the person may not be self-aware enough to recognize the source of distress. Check the person for signs of physical problems. Check with your doctor.

Re-Focus: Dealing with Disturbance

If people become disturbed in any way, they will have a hard time being involved and happy in a task or activity. When people become less absorbed by an activity, they are more likely to be affected by confusion. In turn, they are more likely to become upset or disturbed by this feeling of confusion and of being lost or out of control.

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

- The signals a person gives off may change. Because people’s verbal skills are declining, they will almost certainly be less able to say they are

disturbed. 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. Instead of a sequence of signals of increasing disturbance, ending with an outburst, the sequence might be short-circuited. You might get only one or two clues something is bothering your family member before an outburst or catastrophic reaction occurs.

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

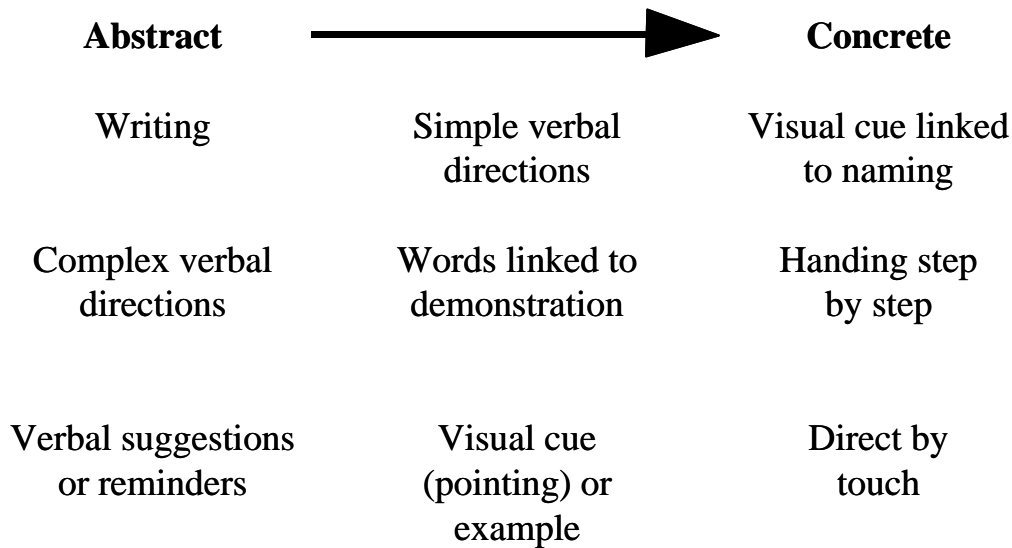
- Looking at a photo album
- Having some tea
- Sitting in a chair and watching the outdoors
- Holding a familiar object
- Listening to music
- Taking a walk
- Holding your hand.

Try, too, to discover the cause of the distress and attend to it. If your family member is uncomfortable, take care of that. If there's something frustrating about the task, make appropriate changes. Once you've helped your family member restore calm, you can help him/her refocus on the task.

Types of Support and Stages of Dementia

By itself, knowing that it's important to provide support to help a person with a dementing illness isn't very helpful. What is helpful is to know how to provide support appropriately. Here it is especially useful to link stages with the choice of Support strategies. Again, the idea of doing so is fairly natural. As a dementing disorder progresses, the person's capacities decline. The Savvy Caregiver tries to match the method of Support with the person's Level of Thinking. As the diagram

below suggests, Support can be thought of as proceeding from abstract to concrete strategies.



The Order of Support Strategies

As dementia progresses, it is important to use increasingly concrete forms of Support. The more abstract forms of communication are the ones we most normally use. Most of our typical interaction involves either writing or complex verbalizations. If these are used with someone who functions normally and is not affected with a dementing illness, we would have every right to expect to be understood. If, however, these same strategies are used with someone already far along in a dementing illness, the “message” is unlikely to get through. This attempt may result in confusion and frustration.

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) strategies to the various performance levels. The table was compiled from information in section 5 of the Dementia Caregiving Strategies CD-ROM. In that section of the CD-ROM advice is provided about set-up and support for persons at various levels of dementia. The advice targets a number of everyday caregiving activities.

Stage (Allen level)	Set-up (Structuring a Task or Activity)	Support (Communication and Help)	Steps
Early Stage Dementia (level 5.0)	<ul style="list-style-type: none"> ▪ Can do many things independently ▪ Consider removing the complex parts (planning or computing) ▪ Think about breaking tasks apart and assigning parts ▪ Check this, but should be able to move from place to place 	<ul style="list-style-type: none"> ▪ Use fairly normal directions ▪ Give help verbally; notes or labels might be useful ▪ Be ready to help – what’s the next step or the missing word ▪ Watch for frustration and be positive and supportive. 	4-6 steps depends how complex
Early Middle Stage Dementia (levels 4.5-4.0)	<ul style="list-style-type: none"> ▪ Take over: do the planning for tasks; establish a routine ▪ Simplify: break larger and more complicated tasks into parts ▪ Structure: get things ready and set them up ▪ By the end of this stage, do activity in one room ▪ Make the environment work for the person – remove distractions 	<ul style="list-style-type: none"> ▪ Begin to be more directive – reason and explanation may not work well any more ▪ Verbal help still works, but simplify and begin to use visual cues. ▪ Fill in – next steps, words ▪ Watch and be ready to help and redirect; frustration and irritation are very possible 	2-5 steps reduce as disease gets worse
Late Middle Stage Dementia (levels 3.5-3.0)	<ul style="list-style-type: none"> ▪ You are in control; you are making the decisions ▪ Continue to simplify: break tasks into fewer and fewer steps ▪ Set everything up ▪ Only show the things needed for the steps you want done ▪ Do task at one place ▪ Remove distractions ▪ Be prepared to do the task for the person (e.g., button the blouse if she cannot) 	<ul style="list-style-type: none"> ▪ Expect to help the person to start and with each step ▪ Use short verbal directions – don’t reason; tell the person what to do ▪ Rely more on showing and physically guiding the person ▪ Show (demonstrate) the step ▪ Expect frustration and end the task and move on if you sense frustration ▪ Don’t force a step ▪ Be positive and reassuring 	1-2 or passive
Late Stage Dementia (levels 2.0-1.0)	<ul style="list-style-type: none"> ▪ You are fully in control ▪ Very simple one-step activities may be possible ▪ Focus mainly on comfort and calm environment ▪ Think about the senses. What might the person like to watch, hear, feel, taste or smell? 	<ul style="list-style-type: none"> ▪ The tone of your voice will convey more than the words ▪ Your emotional tone is also likely to be picked up. ▪ Physically guiding the person and using visual cues may offer the best support. 	1 step or passive

The columns in the table summarize material already covered in this section of the manual.

- **Set-up.** This column relates to the way in which tasks can be organized to take advantage of the abilities your family member 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 family member 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. So, too, should an absence of pressure about time or quality.
- **Steps.** This column provides a rough guideline for the size (number of steps) of tasks appropriate for the various levels.

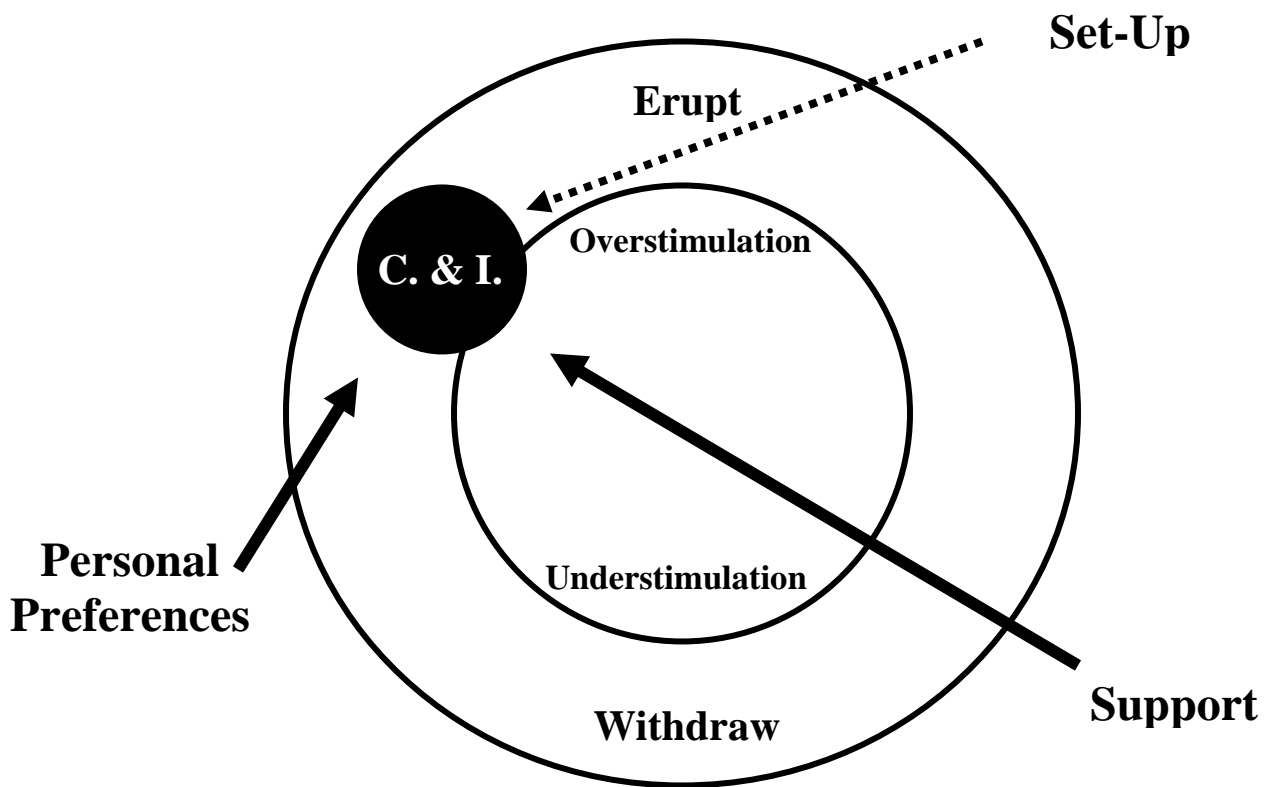
As you read and use the table, you will see that as performance declines, your person will need more and more support and set-up assistance.

- The need for set-up increases as performance declines.
- The attention you need to pay to the person's emotional state – to maintaining it and watching for changes in it – also increases as performance declines.
- Communication strategies become more concrete and specific as performance declines. At the more advanced stages, for example, only physically directing the person – accompanied with very simple words – might work to communicate an intention.
- The size of the task has to shrink as performance declines.

Keeping in the Zone

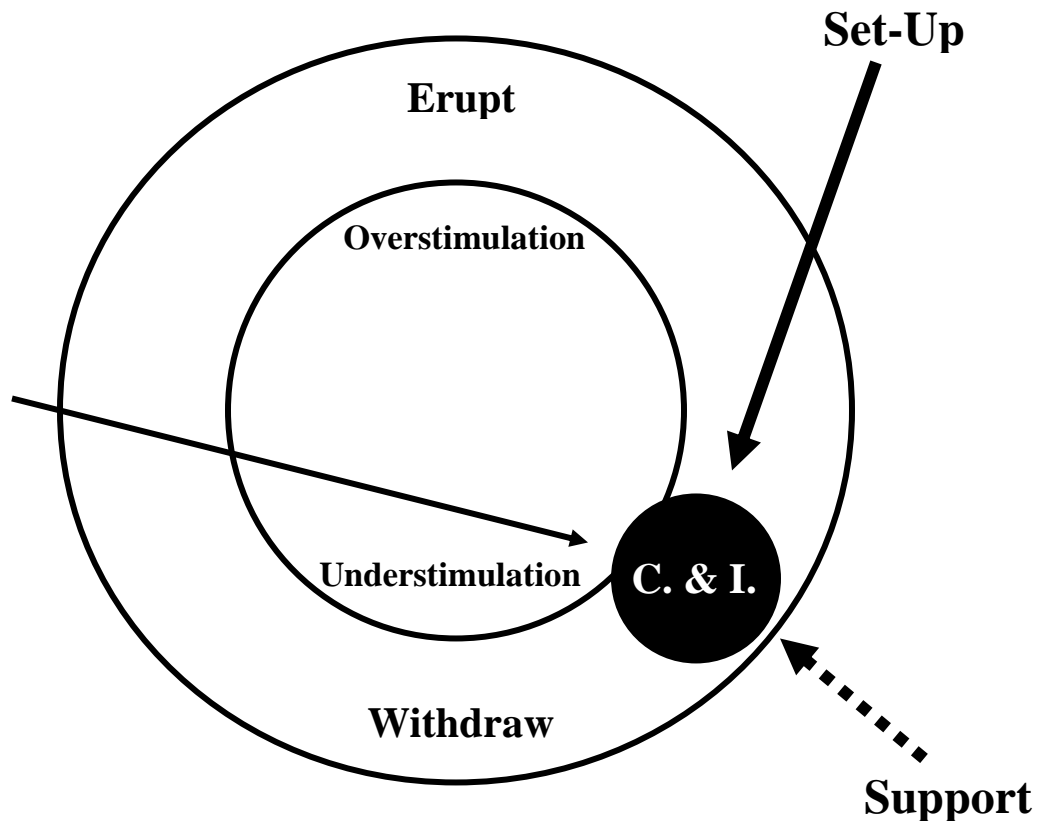
At the beginning of this section, a diagram showed an ideal situation. The three anchors – Personal Preferences and Performance Levels, Set-up, and Support – are working in balance to keep the person in a condition of being content and involved.

Sometimes it makes things clearer when you see what it looks like when things aren't quite ideal. Look at the diagram below.



Here you can see that the person is drifting away from being content and involved (C.I.). S/he is overstimulated and is heading toward an eruption. The task appears to be one the person should enjoy. It fits the person's history of favorite pastimes. However, in this case, the person designing the task misestimated the person's ability. The person is less able than the caregiver thought. As a result, too little support was provided and the task was not sufficiently structured or controlled. 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 diagram shows a different kind of problem developing.



Here the caregiver has chosen an activity that does not fit well with what the person likes to do. In addition, the support and set-up strategies aren't well thought through. Too much structure and control is being applied. Also the help and guidance are too simple. The task is being presented at a level that is lower than the person's ability, and s/he is getting bored. Soon s/he will withdraw.

There are some lessons in these diagrams.

- The person's behavior will let you know how well balanced the anchors are. If the person is involved and happy, the task fits. The way you helped the person begin and stay with it are just right. If the person is becoming agitated or seems to be withdrawing, take a step back.

- ✓ Does the task fit the person?
- ✓ Is it the right size?
- ✓ Is the set-up right?
- ✓ Are these the proper support strategies?
- ✓ Check the balance of the anchors.
- Dementia makes fit a moving target. You know, intuitively, that it's important to fit tasks to what the family member likes and can do. You also know that you have to be flexible enough to try various tasks and activities to see whether they capture the person's interests.

As a Savvy Caregiver, you constantly have to tinker. You are always trying new schemes.

- ✓ Change the size of the task. Add or drop a step.
- ✓ Change the amount of control you have. Apply more or less.
- ✓ Change the way you give help. Use words more or less. Monitor more or less. Demonstrate more or less.
- ✓ Tinker with the environment. Use a bigger space. Or try reducing the stimuli in the area, so that the person is less distracted.

The main thing is trying things out to see if some strategy is more effective than another. The other important thing is to recognize that the strategy that works today may not work tomorrow.

The Savvy Caregiver is willing and able – day-to-day – to try new things.

Managing Daily Care and Complicated Behaviors

Section 4 of the manual has already discussed behavior and how, increasingly, you have to assume control of it. This section discusses how to do that. As a caregiver, you will spend a lot of time doing two things:

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

As you have seen, a good deal 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, this means ordinary, day-to-day things.

You shouldn't have to wrack your brain to come up with activities that will capture the person's fancy. If people are zeroed in, using their abilities, and somehow feeling as though they are really doing something well, common tasks provide contented involvement. Drying dishes, getting dressed, folding the laundry, helping with housework, walking around the block – any of these (and all the many daily things like them) can be the source of enjoyment.

The manual doesn't provide a list of possible activities. That list already exists. It exists in three places:

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

So make up your own list. And keep revising it as you go.

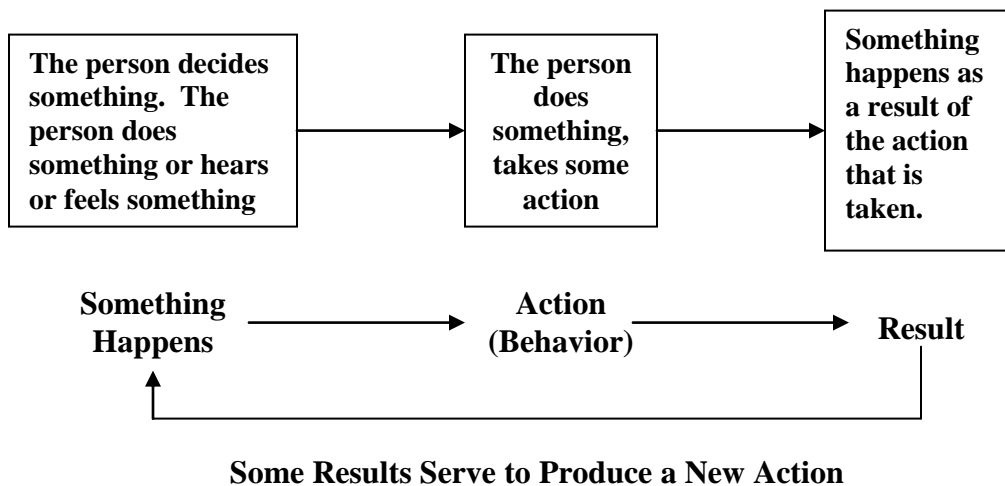
The previous section on the Anchors of Caregiving provided tips and guidelines for how to help your person get involved in activities at different stages of the disease. That section was meant to help you think about

- 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 information in this section is meant to help you put those tips into action.

A Simple Model of Behavior Management: If You Want the Bull to Charge, Wave the Red Cape.

The diagram below portrays a way to think about behavior. This looks different from the diagram in Section 4. But you'll see that the idea is the same. This one just provides more detail. Professor Linda Teri from the University of Washington has done a lot of work describing an A-B-C (Antecedent-Behavior-Consequence) model of behavior and showing how it works in people with dementia.* The model below draws on her work.



* Dr Teri is part of the Alzheimer's Disease Research Center at the University of Washington. The Center's website (<http://depts.washington.edu/adrcweb/>) contains a great deal of helpful information about dementia and behavior.

Something Happens. Remember: All behavior has meaning. Every action a person takes can be traced to some cause. So when you see the person do something, you know something caused that act.

- This may be an internal cause. Nothing someone else did and nothing in the environment caused the action. A person may be thinking about something and take action as a result. A person may feel something and similarly take action. For instance, a person may have a headache and so take pain medication – or do breathing exercises or meditate. The action has its beginning in something internal – the felt pain.

- 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. Whatever the case, someone creates a strong motive for the person to behave in a certain way. Some examples.
 - The cat scratches at the door and you let him out.
 - Your friend asks you for coffee, and you go.
 - The dog growls and you back away.

- Similarly, there may be something in the environment that causes the person to act. The world around often gives cues for behavior. It rains and we put up an umbrella. The light turns red and we stop. You lay out the clothes for the day and the person you're caring for gets dressed.

- In dementia, these external causes may be real, or they may be how the person with dementia perceives or experiences them.
 - The person may be focused on something and not see someone approaching. The person may be startled and feel threatened and then do something to defend against this perceived threat.

- People may misunderstand what others are doing. You may be trying to help wash the person’s face, but he or she may feel fright, perceiving that you are trying to do harm.

Action. 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 family member can be thought of in these terms. Any activity of daily living, for example, involves such a sequence. Consider brushing teeth. From start to finish, this minimally involves

- Getting to an appropriate spot.
- Using tools (opening tube, squeezing out an appropriate amount of paste, closing tube).
- Performing correctly (brushing all surfaces, rinsing).

This is important because, as dementia progresses, each of these actions can be affected by what happens in the next part of the model, the Result.

Result. Actions provide information. In dementia, they provide information to the person – does this feel good or not. From your perspective as a caregiver, the actions and the person’s reactions to them provide important caregiving information. You can read the result of people’s actions in two ways, and what you read should guide you in what to do next:

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

If yes to any of these, then what the person is doing is a good thing, and your task is to:

- Figure out what might have helped the person to get to this state.
- Figure out how to help the person to continue what he or she is doing.
- And figure out how to get the person to do it again.

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

If yes to any of these, then what the person is doing is not a good thing, and your task is to:

- Figure out what might have provoked the person to do this action.
- Figure out how to help the person to stop what he or she is doing.
- And figure out how to keep the person from doing it again.

The section below describes how to use this model – how to accomplish the tasks you will take on with regard to your person’s behavior.

How do you use this model?

This model works with persons with dementing disorders. It can be used to deal with difficult behaviors in which they might engage. In order to make use of it, you have to back away from the person a bit and look carefully and in detail at what s/he is doing. You also have to recognize that “solving” a behavior problem involves a lot of trial and error.

Although the model flows from left to right, from beginning to result, the place to start when dealing with behavior is with the behavior itself. Here are some tips to help you first understand what you are seeing

- **Give the problem time.** Usually, behaviors that you think of as difficult or problematic occur more than once. They happen over and over before you come to think of them as problems. So when a problem arises, don’t treat it as a crisis that has to be solved right away. Give yourself enough time to study it, think about it, and come up with and try different ways to respond to it.
- **Study the behavior carefully.** As problem behaviors surface, we tend to give them names – wandering, rummaging, acting out, etc. Names like these often don’t describe what the person is actually doing. Often they

just identify a broad category of actions into which the person's behavior falls.

Before trying to "do something about" a problem, work at understanding it in detail. Really study the behavior carefully so you can describe in detail just what is taking place. As we did before with "Brushing Teeth," name the steps 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 proceed directly from 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?
- 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 retreat or continue forward toward the person whom s/he is trying to hit?

Observing carefully 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 – for instance your doctor.

- Look for the source of the person's discomfort. Try to determine the meaning of the person's behavior, especially if it is troubling or unusual. Dementia itself is not a cause of a behavior. People with Alzheimer's sometimes wander, but this is typically because they are confused. They may be looking for something that they can't name. They may feel restless and don't have any better way to work that out.

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

If you find some clues, perhaps you can make something happen that will trigger a different and more contented behavior. If you think the person is looking for something, maybe you can help him or her find it. If she or he seems restless, maybe you can suggest an activity that will be engaging.

- If your family member has hit you, for example, what the person does after the first blow may suggest whether s/he is acting defensively or aggressively.
- If s/he, strikes and moves away, it is more likely s/he is reacting to a perceived threat than acting in anger (in anger s/he may continue to hit and might move forward – to drive the person away).

So, in this example, if you think the person is feeling threatened, look for what happened just before the hitting. Was there something that might have been happening in the environment? For example, if the lighting was poor and the person didn't see you coming, he or she might have been startled. Perhaps something else startled the person? Something on a television program or a loud noise in the street? Or perhaps it was the way you did something? Maybe too many things were happening at once? Perhaps you were talking and moving quickly and coming very close all at once. Think back on the scene. If you can come up with a "suspect," try to remove it from the scene and see if the behavior happens again. Try turning off the TV or turning up the lights or approaching more slowly and 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 near.

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; or there is too much happening in the environment and s/he feels lost about what is happening or what to do.
- The discomfort may also have a physical cause. The person may be in real pain, but be 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 doesn't feel good.
- The discomfort might be from fear. Something may be threatening the person.
- Other sources of discomfort could be fatigue, hunger, the need to void, a fever or infection, or some particular something in the environment that the person reacts to.

Any of these discomforts could produce agitation of some kind in the person. Finding the source of the discomfort and attending to it is an important step in preventing agitation or in calming it, should it occur.

Look for patterns in the behavior. If your family member does have some behaviors that are difficult or troubling, look for patterns.

- 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're 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-founded plan for what you'll try to attempt to alter a behavior.

After a long enough period of examining the person's behavior, you may be able to come up with four kinds of ideas:

- **Cause.** It is likely that you will be able to offer one or more possible reasons why the behavior starts – what triggers it.
- **Meaning.** Close examination may also produce speculation about what the behavior means – why the person is doing it.
- **Pattern.** Examination may lead to a discovery of patterns in the behavior – when it occurs and what happens just before it occurs.
- **Effective response.** Study may enable you to pinpoint times during the behavior when it is more possible than other times to stop the behavior.

All of these conclusions – even though they are tentative – allow you to devise a plan to deal with the problem. The plan may be focused on cause, meaning, pattern, or any or all of them. Thus, for example, you might do any of the following:

- **Develop caregiving strategies to prevent troubling behaviors.** If you can predict what might cause your family member to become agitated or even combative, you might be able to prevent this from happening. If the causes are known or suspected, try to avoid those situations. If, for example, the person becomes upset and shouts when you try to get her/him washed up before breakfast, be prepared to try other things. Try, for instance, waiting until after breakfast. Or try other methods for helping him/ her to wash. It may be the manner of approach that is the beginning point for the action. In that case, work on changing the way you approach the person – especially during more intimate tasks that involve activities of daily living (ADLs) such as 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 (these could be quite small – like a change in facial expression) that are signals that the problem behavior is about to occur. If you can become adept at seeing this sign, you may be able to back off or divert the person before the behavior takes place.

- **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.

In addition to knowing what the first signs of discomfort look like in your family member, 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 for the person and into some kind of outburst. Keep in mind that the task or activity at hand is not the point. It is almost always the case that that activity doesn’t have to get done. If the tone of a particular moment is in a direction opposite to contented involvement, stop the activity.
- Divert/distract. It is important to restore calm and a feeling of safety to the person. Over time, try to learn what works to divert or distract the person from a situation that is turning sour. You should keep several such strategies in mind. Some ideas about distractions include: a particular topic the person likes to talk or hear about, a drink or snack the person might enjoy, an activity the person likes (walking with you; listening to music), 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. If the idea and the proposed solution work the first time out, congratulations are in order. If they don’t, don’t be discouraged. Patience, tolerance, and humor are some of your best tools.

Be Savvy. You won’t succeed all the time – and certainly not often on the first try. Managing behavior presents a difficult problem. Reexamine the information you have, and look at it particularly in light of the new information you may have learned from trying the solution that didn’t work. It is important that you remember – while the mystery remains unsolved – that the person isn’t doing something to intentionally hurt or upset you.

Common Behavioral Issues

People with dementia might do things that others find difficult. You will want to find ways to manage these behaviors in a way that is considerate, understanding, and effective. Below, we discuss a number of issues you might face – and how to face them.

We use the behavioral approach discussed above to analyze the problems. We approach most of the problems as being the result of confusion. In each case, there are suggestions you might find helpful for observing the issues and for trying to change the behaviors.

Repetitive questioning

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

Go through the steps outlined above.

Cause? Where are these questions coming from? Repetitive questioning is often a sign of confusion. It may be that the person doesn't know where he or she is. The questioning may be a sign that the person is distressed, feels unsafe or insecure, or feels threatened by something (possibly just by the confusion itself). It may also be that the person just wants to interact with you but may not remember how to do so. And all that comes out is the same question over and over.

Response? Consider the kind of thinking capacity this person is able to exercise. Will any kind of explanation or use of abstract thought be helpful? For example, can you reason with the person 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 or to provide some kind of explanation? Or is the person's thinking at a level where it is more effective to be directive.

What can you do to deal with this behavior? Can you divert or distract the person? Does the topic of the questioning offer you some way to engage with the person. Can you use the topic of the question and try to get the person to talk about or reflect on it. For example, if the person is asking about a relative, perhaps looking at pictures of that relative would be engaging. If the person is

asking when the next meal is, it might be possible to get him or her a snack – or to ask about favorite foods. If the person repeatedly asks what time it is, it might be useful to put a large-faced clock on the wall. This will likely not stop the questioning, but it will give you an easy answer (“Go check the clock”) that you can use over and over.

Probably the most practical thing you can do regarding repetitive questioning is to recognize you cannot stop the behavior. You have to try to insulate yourself from it somehow. It is useful to have one or two answers ready for each time the person asks the repeated questions. You might think of this as playing a role in a play. This is a scene that will repeat itself many times during the day and you have a part in it. Develop your “lines.” Rehearse them and learn to deliver them convincingly. When the scene happens – and every time it happens – slip into the role and deliver your lines. This doesn’t require thought or emotional involvement; all that’s called for is a consistent “performance.” To do this is not unkind – you are responding to the person’s concern. It is not unfeeling – you have thought through the matter and recognize that the person needs a reassuring answer to his/her constant question, and this is a satisfying answer. It is good for you – it takes you out of a situation that may feel oppressive.

Often repetitive questioning is a relatively constant part of a person’s behavior, but it is still worthwhile to determine whether there is any pattern to it – when and where it occurs and under what circumstances. If you see a pattern, you will at least be prepared for the questioning to happen.

Shadowing

Caregivers often report that their family members will not leave them alone. They follow them from room to room, always keeping the caregiver in sight. This can be unnerving. And, if a caregiver has other responsibilities, it can be a problem for getting work done. It can also make the caregiver feel that it is impossible to find any time or space for him/herself.

Shadowing likely has to do with the person’s need for security. The confusion in dementia is a problem, and the person is looking for an anchor point – 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.

If you can set up a pattern throughout the day – and stick to it (more or less) over time – this may help to produce an atmosphere of calm and security. This may help with this behavior. Be aware that as the disease progresses people may pass through periods where the world *feels* more confusing and there is a greater need for security. So, you may observe shadowing at different times (for instance, with decline in function).

The best way to work with shadowing is through the gradual introduction of other ways to provide security.

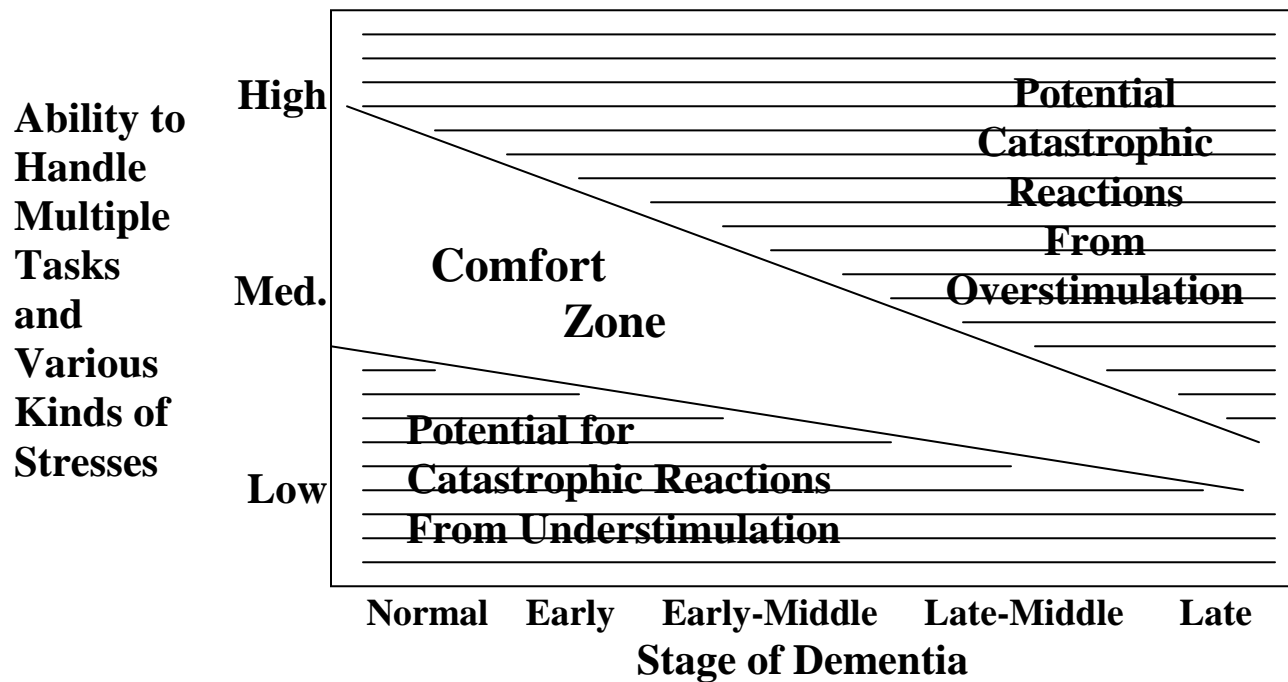
- Involve family members more in doing things. Over time, introduce them to other tasks.
- Have family members help. Encourage them to shadow you in purposeful activities. Have them do things with you (e.g., go with you to get things from the laundry or the kitchen and then carry some of them back).
- Have family members do tasks on their own. Ask them to do something specific by themselves. Be near by, but station them somewhere and give them a task. For example, on returning from the laundry, ask the family member to fold towels 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.” Over time, you will discover what calms your family member. For some it will be an alone activity (looking through a book or album, reading the paper, gazing out the window, rummaging through a drawer, having a treat). For others it might be a particular place or an activity with a particular group. Some persons with dementia – particularly in the later stages of the disease – identify “comfort objects.” They may want to keep near them things like blankets, shawls, stuffed animals, or dolls. If your family member identifies a “comfort object,” use it. Let the person find security wherever s/he can. Don’t take this away from the person, and don’t let yourself be embarrassed by his/her having such an object.

Agitation

People with dementia – like people who are not affected with dementia – get upset. You’ll know the signs. The person seems on edge. S/he’s giving off signals that something is wrong. The problem is that, because of the dementia,

your family member usually cannot give you a clear explanation of what is wrong – what got him/her agitated.

Two nursing professors at the University of Iowa, Drs. Geri Hall and Kathleen Buckwalter, have been successfully dealing with agitation in persons with dementia using an idea many caregivers find very 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 as a reaction that occurs when the person’s tolerance for stress or stimulation has been passed. It can happen the other way around, as well. That is, agitation can occur when a person’s attention is not sufficiently engaged. The diagram below is meant to give an idea of how this concept works.



Persons who are not affected with dementing disorders and who are living normally 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 dementing disorders is that they, typically, have an idea about their limits. They know when they’re getting close to these limits, and have techniques they use to back away from overload when things get to be

* Hall, G & Buckwalter, K. Progressively lowered stress threshold: a conceptual model for care of adults with Alzheimer's disease. Archives of Psychiatric Nursing. 1987 Dec;1(6):399-406.

too much. If those limits are exceeded, 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 progresses:

- The zone of 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 to tell someone – that he or she is close to a limit fades.
- Techniques that used to help to back away from stress are forgotten and unused.
- There is often less warning that the person is nearing his or her threshold. As a result, the reactions are sometimes sudden and unforeseen.
- When the stress threshold is crossed, the person has fewer ways to express the discomfort he or she feels. So an explosion – called by some a catastrophic reaction – often occurs.

The idea of “catastrophic reaction” is pretty self-evident. It means that a person is triggered by things going on and that the response (the reaction) is very strong. There is a clear sense, too, that the reaction comes on quickly and unexpectedly and that the strength of the response is out of proportion to whatever was happening before it. There is also the sense that bringing things back to a normal level is going to be hard.

As a caregiver, you’ve got the responsibility of trying to help your family member regain calm. Here are some things to try (you’ll notice they follow the pattern of suggested ways to deal with behavior problems in general):

- Look for a physical cause. A person with dementia 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 color (pale, ashen, red, darker)? Is s/he sweating or shivering? Is there anything different about his/her breathing (panting, labored)? Does s/he just look “different”? Is there any change in

sleep or eating habits (e.g., very sleepy; pickier at meals)? Is there any change in bathroom habits (e.g., more or less frequent urination; constipation or diarrhea)? The person may not know or be able to tell you that something is physically wrong. For example, urinary tract infections may be the cause. If you see any of these or just feel something is wrong, call your doctor and describe what you're seeing.

- Look for a cause in the environment. Did something happen to trigger the agitation? Is there some beginning point for the behavior? If you can identify something, try changing or removing it and see what happens.
- Is anything causing the person to repeat the behavior? Can you see anything that anyone is doing – or anything in the environment – that is reinforcing this behavior? If so, try to change it.
- Can you divert the person? Can you engage the person in some activity that will get him/her occupied? Occupation should help change the behavior and produce calm.

Pacing and wandering

Many persons with dementia walk a lot. It is important to distinguish good walking from disturbed or troubled walking. For some people with dementia, it appears that pacing provides a way to wear off excess energy. For them, walking is a good outlet and should be facilitated. Others who walk a lot seem to be searching for something. There is a troubled quality about their walking, as if they are lost, looking for something, or upset. 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 family member. If you have a fenced in yard, you could consider leaving your family member alone there. Use caution in allowing the person to walk outside alone. You've always got to keep in mind the chance of the person's getting lost.
- Be supportive. If it seems your family member benefits from walking, reinforce it.
- Monitor your family member. Even if walking is clearly of benefit for the person, there can often be a kind of frantic and very focused quality to the

activity. If this focus is suddenly or unexpectedly disturbed, the person could become agitated.

- Be sure your family member has good shoes. Good walking shoes will assure balance and support and may help the person avoid muscle aches.
- Pay attention to your family member's feet. In the course of helping the person with dressing or bathing, check to see there are no blisters or ingrown toenails. This is especially important with persons with diabetes.

If the wandering is “troubled,” try to find the causes. Whether or not you can exactly pinpoint cause, try to divert your family member to a more contented involvement. If the person likes the physical activity of walking, try walking with him/her. Also look for other diversions and for tasks and activities to involve the person in.

There is another kind of wandering that can be a problem – wandering into your space. For some people with dementia, the boundaries between mine and yours fall away as the disease progresses. This basically harmless behavior can cause disruption. You may find it upsetting to have your family member rummaging through your things. Or it may not bother you, should it occur. In some cases, things will go missing, so it's good to be prepared for it. The only reasonable response to this kind of wandering is vigilance. If it's important to you to keep some private space and places, keep an eye out for where your family member goes, and quickly cue him/her away from areas you'd 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 the person likes to rummage through your drawers, create one or more rummaging areas in that person's own room.

Uninhibited actions and language

One of the consequences of dementia on the thinking ability of the person is that s/he forgets manners 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 with dementing illnesses do not monitor or censor their actions and words. They can become impulsive and uninhibited. This loosening of social control can take any number of forms; for example, the person may:

- grab at food and eat with his/her hands;
- use language the person would never have used (e.g., derogatory or vulgar language);
- become immodest (expose themselves, make propositioning gestures or requests, urinate in public);
- make insulting or demeaning comments; etc.

Look for cause. Sometimes it's possible to identify beginning points for such behavior, and sometimes it's possible to remove or change them. For example, if your family member is urinating in a waste paper container, remove the container. Other times it's not possible to remove the beginning point. For example, if your family member is making comments about someone at church who is of a different race or culture, you can't remove the person, but it might be possible to avoid contact (by sitting elsewhere, for example).

Look for the initial signs of the behavior and intervene. If you can figure out the behavior you may be able to develop a sense for when it is about to begin. In that case you can act to divert. For example, watch for the person who urinates in public to begin to become slightly agitated (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 it.

Be patient. If you are the target of the behavior, remember that this is not personal. Scolding will not work, except to make the person feel bad.

Attempt to introduce a change in behavior. Again, by analyzing the behavior, try to find a point in it where a change might be introduced that might, in turn, produce a changed behavior. For example, try seeing if different utensils (large handled spoon, high-sided plate) might introduce enough sense of control that the person doesn't feel the need to grab handfuls of food. Or see whether serving just one food at a time might help.

Sundowning

For some people with dementia, the late afternoon and early evening are difficult times. They become restless and agitated. They pace and become demanding and are clearly uncomfortable. 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. All, either alone or in combination, may contribute to this behavior. Here are some suggestions for things to try if sundowning becomes a problem:

- 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 the person more energy and helping him/her to get through the afternoon.
- Activity. Is there some favorite task or activity the person can get involved in to feel contented? It may be that an activity with others would "energize" the person. Or it may be that being in a social setting requires too much energy right now. Tailor the activity to the person's mood and to the occasion.

Make allowances. If this is really a low point of the day, try scaling things down. You may need to change the way you approach your family member or the types of activities you plan. For example, you might plan any outside activities involving other people for the morning, and spend time in the afternoon taking a quiet walk to relax your family member.

Night time wakefulness

Some persons with dementia have periods of being awake at night. In some cases, this may be the result of waking to use the bathroom and not understanding that it is still time to be asleep. In others, the sleep cycle itself may be disturbed by the disorder, and the person can sleep for only short periods at a time. If your family member is affected by nighttime wakefulness, here are some suggestions for working with him/her:

- Guide your family member back to bed. Cueing, by itself, may be enough to reinitiate sleep. It may be that the sooner this guiding is done, the more effective it is. In this way the person may not get into a "being awake" mode and will simply get back to sleep.
- Stay with the 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 that your presence will provide. This may be enough to get them back to sleep.

- Cookies and milk. Try some form of a comfort snack if your family member doesn't seem ready to go back to bed. You might let her/him have this snack alone or the two of you can sit quietly together. Either way, try to keep your family member quiet – in an effort to foster sleep.
- Provide a quiet activity. Try to get the person to do something on his/her own, something quiet. Rely on what you know about your family member to make this choice and tailor it to what you know about the wakefulness pattern. If you know the person needs a half an hour before going back to bed, try to get him/her involved in something that might keep him/her focused for that long. If the person typically takes longer to get back to bed and usually has a high energy period, try something else. You might, for example, ask your family member to help you with some of the evening chores.
- Talk with your doctor or nurse practitioner. Careful management of drugs can help the person to sleep without being drowsy the next day.

Tearfulness

Sometimes, for quite unknown reasons, people with dementia become tearful. 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 leads you to believe you have an insight into the cause. This is one of the mysterious areas of the disease – its effect on emotions. The basic recommendation is not to search for cause – unless it presents itself – but to treat the effect.

Diversion and activity are the chief ways to deal with this. A period of one-on-one with your family member may be useful in breaking the cycle of tearfulness and allowing the person to become involved in some other activity. In effect, you may be able to bring your family member out of the loss of control situation (tearfulness) and help him/her to regain focus. The easiest and most effective way might be to try to draw your family member's focus to yourself. Physical comfort – hugs – may help. Then once a connection of some kind is made, gradually try to help the person put his/her focus on something s/he enjoys doing.

As with every other behavioral issue with this disease, knowing your family member will be crucial. This knowledge will help you select some task or activity that is most likely to capture and hold the person's attention.

Suspicion and accusation

These behaviors take many forms in persons with dementing disorders. Persons may believe people have taken (or seek to take) something from them. They may believe people are watching them. They may accuse people of things. For instance, a person may accuse a spouse of infidelity. More commonly, the person with the disease won't recognize his/her spouse and s/he will accuse the person of stealing the spouse.

The causes of this behavior are a bit clearer than some of the others. 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 "feels," for example, lonely for a spouse, child, or parent. But 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. Similarly, at some level, the person "remembers" something about an object. Somehow the object comes to mind. But the person cannot remember where s/he left it. You are there, and your family member isn't at all clear who you are. So somehow there is a connection made, and your family member begins to suspect that you took whatever it is that s/he is trying to find. Below are a number of suggestions for handling these problems:

- Don't dispute. Take accusations as requests for help. If your family member accuses you of stealing something, immediately offer to help find it. If your family member says others are out to get her/him, make the place seem secure and safe— but don't challenge his assertion. If the person says s/he wants to visit or phone a dead relative, try to get the person to reminisce about that relative.
- Work with yourself. It is you who can be most hurt by these behaviors. It is painful when a spouse of 50 years doesn't know who his/her spouse is. Work at understanding the disease and its effects. Keep in mind that it is the disease – and not some choice by your family member – that is causing this problem. Try to develop a set of responses for such situations. For example, when your family member fails to recognize that you are his/her spouse, suggest that you look through a wedding album

together and try to get her/him to talk about his/her feelings about the pictures in the album.

Yelling

Calling for help or just calling out wordlessly and repeatedly is one of the most difficult behaviors. Like tearfulness, this will take a great deal of one-on-one time with your family member, both to try to understand the behavior and to change it. As with tearfulness, yelling can be thought of as a behavioral response to confusion. It is also a habit, a patterned behavior – and that makes it more difficult to change. This behavior is not likely to occur until the person is well advanced in the disease process.

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 – 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 as well as about responses to it that are more or less effective. Again, as with tearfulness, once the yelling starts, your effort has to be directed at recapturing your family member’s attention – getting her/him to focus on you. The more patterned this yelling is, the more difficult it may be to get the person’s attention.

Once you have your family member’s attention, continue to work one-on-one to get the person calm. Provide a sense of security. After you’ve calmed your family member through the one-on-one, you can try involving her/him in some task or activity.

Combativeness in personal care

One of the most common areas in which troubling behaviors are reported is in providing help with activities of daily living (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 family member’s private space. Many of them involve intimate touch. If the person is not ready for this touch, s/he may feel threatened or assaulted and s/he may feel the need to defend him/herself. This can lead to hitting. The principles of communication (**starting on page 140**) provide a number of suggestions for how to approach and touch a person with dementing disorder.

Be patient. In dementia caregiving, whether a behavior is problematic is sometimes a matter of judgment. A behavior considered difficult or problematic by one caregiver might be thought unimportant and not disturbing by another. Sometimes there is little question about whether you need to do something about it. If the person is doing something that could cause harm to self or others, you've got to step in and do something. There are other times, however, when what the person is doing does not create a condition of immediate harm (or even eventual harm) but what s/he is doing is definitely "getting to you." Caregivers have reported many behaviors that "got to them," for example:

- The person sleeping many more hours per day than before the disease showed itself.
- The person spending an hour and a half to two hours a day dressing and primping in her room.
- The person just sitting and staring for hours.
- Someone who re-reads a newspaper multiple times in the day.
- The person going to his workshop and just sitting there.
- Someone who paces for hours on end.
- The person talking to people who weren't there.

Over time, the caregivers came to recognize that what troubled them about these and similar behaviors was not that the person seemed bothered or upset. Rather, the behaviors held up to them – the caregivers – the reality of their family member's illness.

The point here is that it is essential to sort out what it is you are reacting to in a behavior and to respond to that. The caregivers in the examples above all had to come to terms with the sadness and loss they felt about their family member and the frustration they felt in their own caregiving. Some caregivers, for example, felt the behaviors meant they weren't doing enough to provide a stimulating environment for their family member. Eventually the caregivers came to see that

these behaviors alone were not harmful – in fact, many represented forms of contented involvement for the persons. So, even though the caregivers at first wanted to make the behaviors stop – because they were too painful for the caregivers – they came to tolerate them. In a number of cases, the caregivers even came to take advantage of the behaviors – in several cases the behaviors provided the caregivers with time to get other things done.

So this is the message to the Savvy Caregiver: if you're troubled by a behavior, first acknowledge that and then try to figure out why you're troubled by it. If the reason is your own discomfort, work at that level (i.e., work on yourself). See if you can tolerate the behavior – allow it to continue – and deal with your own discomfort. If the reason is that you sense it represents a form of discomfort in or for your family member, then there are three basic choices facing you:

- Wait; see if the behavior will stop by itself – perhaps your family member will forget 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 – but with a plan in mind.

Validation and Reality Orientation

The many effects of dementing disorders on thinking will often result in persons saying things that are incorrect. This can take a number of forms:

- Statements that are untrue or incorrect (saying, for example, that a child will be visiting today when you know the child is out of the country)
- Mistakes about identity (denying that someone is a spouse)
- False assertions (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 associated with losses in thinking ability:

- Repetitive questioning (to the person, each time is the first time; s/he doesn't remember – cannot remember – the answer that was already given).
- Confabulation (making things up).
- Repetition of stories.
- The use of stock phrases.

Because your cognitive powers are intact, you can see patterns in your family member's behavior. You can see that s/he has asked the same question over and over. You know that the parent your family member is expecting that afternoon is long dead. You have heard the same story over and over. You know there is no one outside the window looking in. You know that your family member does not comprehend what is actually going on.

The question is: what can you do? How can you best respond to this kind of incorrect thinking on the part of your family member. There are basically two directions you can take. One direction is to confront the incorrect thinking ; the other is to focus principally on your family member's feelings – rather than on the facts of the situation.

Reality Orientation (RO) is commonly used, particularly in nursing home environments. The basic idea of RO is that the mind should be stimulated and focused regularly on reality and that this will keep the mind “fit.” Thus mistakes in thought should be corrected, and persons should regularly be told or quizzed about where they are, what time of day it is, what day and year and season it is, what events are going on around them, etc. In this approach, it is a task of caregivers to help persons remain focused on and alert to the world around them. For persons not affected with dementing disorders, RO can be an effective help.

For persons with dementing disorders, however, RO is **ineffective** and can be irritating or demeaning. Persons affected with dementing disorders do not benefit from being constantly oriented to person, place, and time. The losses associated with the disease are such that the person is very likely not to remember the information very long after s/he's been told it. In addition, s/he very likely lacks the abstract thinking ability to make any use at all of the

information. In addition, the person might, depending on the tone in which the information is delivered, feel embarrassed at not knowing or being able to recall the information. Finally, trying to orient persons with dementia to the day-to-day reality can frustrate you. The person will not learn or remember what they are told. And your frustration may well communicate itself to the person, further provoking feeling bad about themselves. For all of these reasons, Reality Orientation is not recommended.

Validation is a strategy pioneered by Naomi Feil that accepts that what a person says may be a clue to what s/he is feeling, regardless of the accuracy of the statement. Validation directs caregivers to use the person's words – and the emotion underlying them – as a way to connect with the person. Validation here means that there is a recognition of the genuineness of feelings and of their source. In a way, validation is a special kind of listening – it is a listening to the feelings and yearnings of the person who may no longer be able to reliably express them. The Validation Training Institute website (<http://www.vfvalidation.org>) provides further information about validation therapy. The site also provides links to books and articles on the topic.

The content you have to work with in validation is often content that is contrary to fact. Persons may speak of family members who are dead or distant (a daughter's visit; yearning for a parent). They may speak of events long past or that never happened (a wedding or family event or trips to exotic places). They may speak of events or occurrences that will never happen (getting a driver's license; going to a summer place). In validation, you accept the person's feeling about the content and then use that feeling to move the person to a different activity, one that may involve the content in some other way.

The Difference Between the Validation Technique and Reality Orientation

Validation is the recommended form of response to incorrect thought among persons with dementia. It is important to emphasize that validation is an acknowledgment of and a working with the feelings of the person. Some examples of validation may help to clarify the idea.

Person Says/Does

“Mary is coming to visit me this afternoon.” (In fact, daughter is out of town and hasn't visited in three months.)

Your Response

“I miss Mary, too. Let’s look at some pictures of our grandchildren.”

Desired Outcome

Person will take pleasure in grandchildren and won’t be forced to admit daughter isn’t coming and hasn’t visited.

Person Says/Does

“I liked the movie last night.” (There may or may not have been a movie.)

Your Response

“I like movies too. What do you like about movies?”

Desired Outcome

Person might reminisce (using long term memory). Won’t be frustrated by specific questions about “last night’s” movie.

Person Says/Does

“Every night, there are people looking at me through my window.”

Your Response

“Isn’t it good our doors and windows are locked.” Or: “Maybe tonight, before you go to bed, we can have some cookies and milk.”

Desired Outcome

Rather than dealing with the hallucinations, help the person feel secure (locks) and/or establish a routine. Also: make sure the curtains are drawn so the person doesn’t see reflection.

Validation does not mean you must tell untruths even though it would be easy to do so. It is probably the case that an untruth could help in the moment and that the person, once diverted, would not remember the untruth. So you could “get away with” the lie, and the person would not be hurt by it. But there is something in using untruth in this way that diminishes the relationship with the person. It has a way of eroding a fundamental sense of respect for the person.

Communicating with Your Family Member

Communication means getting across what you really mean and having another person really understand it. This is not always easy under the best circumstances. Communication with your family member with a dementing illness will be even harder. The disease will impair the person's ability to understand words, to find words to use, and to put ideas together and hold them in place.

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

Difficulties in communication may pose special problems. You will need to be aware of your family member's changing and lessening abilities and to become an expert in figuring out her/his communications. You will need to judge when your family member is or is not fully getting what you and others say. As time and the disease progress, you may well have to set up new ways of communicating with the person.

Improving Communication

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

1. Active listening
2. The context of communication
3. Effective self-expression

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 the person is trying to get across.

Context: Some settings make communicating easier, just as certain times seem to be better than others. Be sensitive to potential problems and eliminate distractions.

Effective self-expression: 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 other messages with your tone of voice, your facial expression, or your body as you talk and listen?

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 persons with dementing illnesses.

Improving Active Listening Skills

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

- Stop talking. You can’t listen if you are doing all the talking.
- Be patient. If a thought is hard or complex, it may take longer for your family member to understand or respond. Two or three minutes may be needed before the person can even begin to answer your question.
- Repeat if necessary. Keep in mind that you can repeat the question or idea after waiting a few minutes for a response.
- Keep things simple. Use short sentences and plain words. Avoid complicated questions or directions.
- Do not interrupt. Your family member may need extra time to express what he or she wishes to say.
- Show interest. Let your family member know that you care what he or she is trying to say. Maintain eye contact, and stay near the person.
- Be gentle and make allowances for poor behavior. Outbursts are not unusual with this disease, but these are not deliberate.
- Try to be calm and to use tact, even if your family member is loud or abusive. Try to respond to any negative statements with understanding comments until the angry outburst ends.
- It’s not personal. Sometimes the person will say things that hurt you very much. S/he will use language that offends you. S/he may speak in a way you don’t like. At these times, it is important to remember that, while these things do hurt, they are not meant personally.

- Double-check understanding. Avoid assuming that your family member understands you. The person may even say s/he understands what you have said but still not understand at all. The best way to check understanding is to see what your family member does, instead of trusting what he or she says.

Remember: your family member will forget. The person will forget things you tell her/him. This can be very frustrating, and there is little that can be done to help it. For your own sake, it is probably best to assume that you will have to repeat many things during the day.

Improving the Context

Communication takes place in an environment. The environment can have a powerful effect on communication. Here are some things to think about regarding the environment and communication.

- Make sure your family member can see you well. Sit or stand directly in front of the person, and look at her/him when you speak.

Research suggests that persons with dementia do not see very well to the side.

- Avoid glaringly bright or too dark settings.
- Avoid distractions. Communication will be hard, if not impossible, under these circumstances:
 - ✓ When your family member is involved in some other activity that requires concentration;
 - ✓ When the background is noisy (loud street noise, for instance, or the sound of the television or even loud music);
 - ✓ When other things or people can attract your family member's attention (at shopping centers or restaurants, for example).
- 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 family member.

- Be Savvy. Plan ahead, and take extra time. Try to observe your family member's daily patterns. Does s/he seem better able to communicate at certain times of day? If so, you can take advantage of good times for important activities and communications. You will also be able to anticipate problems during the bad times, and be prepared to allow extra time for explanations.

Improving Self-expression

- Think ahead about what you will say. Know what information you want to tell or find out. Break this information down into individual parts. You will want to simplify everything as much as possible.
- Give just one direction or piece of information at a time.
- Ask just one question at a time.
- Try to think of brief, easy-to-understand words and sentences to explain what you mean, but speak as you would to an adult. Don't talk "baby talk."
- Anticipate problems. Be prepared, for example, to repeat yourself many times without losing your temper.
- Make eye contact before speaking. Try to sit if your family member is sitting or lying down, so you will both be at the same level. Sometimes a gentle touch can be a way of making sure you have the person's attention before you begin speaking.
- Listen to how you sound. Is your voice louder than usual? If so, you may sound angry or upset. Even if your family member has a hearing problem, try to speak in a clear, pleasant voice. Speaking slowly and clearly will help. (Once again, though, remember to speak in an adult-to-adult way.)
- Watch your "body language." Are you smiling when you speak, or frowning? Are you at ease or tense? If your words and the way you say them do not agree with how you feel and what you really mean, you may very well give a mixed message. Persons with dementing illnesses don't

necessarily lose the ability to “read” such non-verbal cues.

The Impact of Added Problems

Communication is made more difficult when a person has dementia. If the person is also affected with other problems that affect communication, the problem is bigger. If the person has problems seeing or hearing, then communication is more difficult. The sections below deal with communication and these added problems.

Problems with Hearing Can Make Communication More Difficult

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 clearly what is being said. Still, they do not ask you to repeat yourself or to make clearer what you mean. Often enough, these people do not themselves know that something is wrong with their hearing. Also, many people, not just those with some hearing loss, “fill in the gaps” of a conversation. They interpret facial expressions and other gestures and read lips.

If you suspect that your family member has a hearing problem, observe her/ him carefully. Seek help. Get a good evaluation of the person’s hearing. Work with your family physician to try to correct problems that might respond to treatment.

Observation and Diagnosis

You may have noticed that your family member seems removed from what is going on around her/him. S/he may seem distracted or not attentive. Or 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 attending is my family member having?
- When did you first notice the problems?

- Do you see any pattern to the problems? (For instance, does your family member seem to have more trouble at certain times and to do better at other times?)

Knowing the answers to these questions will be helpful when you have the problem looked at. 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 a correctable hearing loss. In this case a hearing aid may help. But 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 (which people with normal hearing "tune out") are also made louder. These noises can produce 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.
- It needs to have its battery checked periodically.
- Sound level adjustment should be checked to see it's not too high or too low.
- To be effective, the device has to be properly placed in the ear.

Caregiving Techniques

Here are some tips to help you communicate with a hearing-impaired person.

- Anticipate problems and be prepared to take extra time. If your family member doesn't hear or understand well, you may have trouble even with routine activities. Allow extra time to explain and reassure.

- Always give yourself extra time when you take the person out of the setting s/he knows well.
- Make sure the person can see you well.
- Approach the person from the front, and face the person directly.
- Sit close enough for the person to see your face and mouth.
- Keep your hands away from your mouth while you are speaking.
- Make sure no bright light is shining in the person's face to distract her/him.
- Get and keep the person's attention. Work at getting and keeping the person's attention. Wait to begin what you want to say until the person is focused on you (as much as he or she can). Keep in mind that attention span will be short.
- Try to get and keep eye contact with the person. Sometimes a gentle touch on the arm or hand, if allowed, will help you make eye contact. Physical contact is a powerful form of communication.
- Find out how the person hears best. Perhaps the person has one good ear. If so, you will want to speak on that side. If the person uses a hearing aid, check to be sure it works and is turned on and loud enough.
- Be alert to distracting background noises. Turn off or lower the music system, for example.
- Plan how to express yourself. Think ahead about how to express what you want to say. Short, simple words and sentences will be understood most easily.
- Speak slowly, clearly and distinctly. Don't 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. If your words run together, the

person may not be able to keep up with what you are saying. If you speak slowly, it will be easier to pronounce your words more clearly.

- Lowering the tone of your voice often helps.
- Be prepared to repeat yourself. You will no doubt have to repeat yourself many times. Try to keep in mind that the person is not doing this on purpose. On the other hand, don't deny your own feelings. This can be frustrating.
- Use gestures to support what you say. If the person can still interpret a nod of the head or shrug of the shoulders, these may be better ways of communicating than words.
- 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 can't understand. If the person doesn't seem to understand, try to find a new, simpler way to say the same thing.

Problems with Vision Make Communication More Difficult

Older people often have vision problems. There may be problems with sharpness of vision, with telling colors apart, or with judging what's near and what's far. Also, 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 have to say. Eye contact seems to mean a lot. (Think how uncomfortable you feel talking with someone wearing mirrored sunglasses.) Also, we often use gestures, like pointing or a shrug of the shoulders, instead of words.

Difficulties from the dementing disorder can cause many problems communicating with your family member. If the person is also having vision problems, then communication will be even harder. If it's hard communicating with your family member, consider whether the person may have a vision problem. Watch the person closely. The person may need to see a doctor.

There may be a visual problem that can be corrected.

Observation and Diagnosis

You may have noticed that your family member seems very clumsy. Perhaps s/he has fallen often or keeps bumping into things. Keep track of the problems you notice, and try to answer the following questions.

Questions

- When do these problems occur?
- When did you first notice the problems?
- Do you see any pattern to the problems? (For instance, does your family member seem to have more trouble at certain times and do better at other times)
- Does your family member use glasses now? (If so, these 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. If the person already wears glasses, the strength may need to be adjusted. Cataracts and glaucoma are two other conditions that impair vision. An eye doctor can diagnose and treat all these. Some problems may be caused by the person's progressing illness and not by failing eyesight. The person may see perfectly well and yet still be unable to act appropriately. The disease may have made the person's brain incapable of understanding or remembering what s/he sees. Because the person may easily misplace them, try to have an extra pair of glasses on hand.

Caregiving Strategies

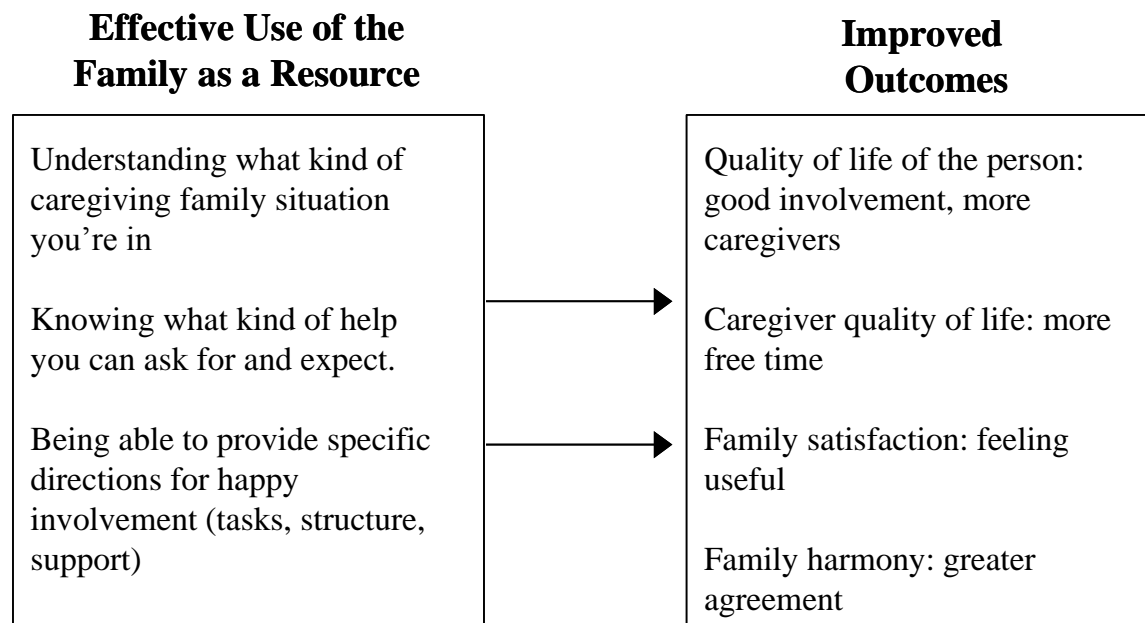
These techniques may help you communicate with your family member in spite of vision-related problems, no matter what their source.

- Anticipate problems and 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, for instance, may take longer or even be startling and upsetting. If you can anticipate such problems, you can prepare the person in advance. Tell the person you are about to turn on the light, for instance. Also, 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 family member can see you well. Approach her/ him from the front. (Suddenly appearing from behind may startle the person.) Also, avoid sitting or standing off to one side.
- Don't have a glaring light or 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 be able to interpret these gestures.
- Don't assume the person understands. Watch to see what the person does, rather than trusting what he or she says. Impaired people frequently become very skillful at concealing the fact that they do not understand.
- If you suspect that the person does not get what you mean, try to find a new, simpler way to express the same idea.

Strengthening Family Resources and Caregiving Alliances

There are several ways to categorize types of caregiving alliances, actual families or families of choice. This section describes the main barriers and the principal aids to improved caregiving. Finally, it is meant to help caregivers to link this new knowledge – what kind of caregiving situation they’re in – with what they have already learned. It should assist you to ask for specific kinds of help from others, especially family members or friends who already share a relationship with the person with dementia.

Why is it important to make effective use of other resources?
What is involved in doing that?



The diagram suggests that the improved use of your family members or others as caregiving resources can lead to a number of positive outcomes. The key to those outcomes is knowing what kind of help you can reasonably expect (hope) to get from others and how to ask for that help. This, in turn, begins with having a basic understanding about the kind of caregiving situation you already have.

Types of Caregiving Alliances

Below we describe several common approaches to caregiving. Families or care teams usually fit into more than one type of caregiving arrangement. One type is not necessarily better than another. In addition, the way people organize their caregiving often changes as the dementia progresses and needs change.

This section of the manual describes a process for strengthening the support caregivers get from family, friends, and community – and redefining it, if that is needed. It first 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. The other is a way of describing the kind of dynamic that might exist between the individual caregiver and that family and community. Taken together, these can help a caregiver to see where help is coming from, where drains and disappointments are present, and where weak support might be strengthened. The section explores possible reasons why people and organizations that might be helpful in caregiving do not meet expectations. It suggests several strategies a caregiver might use to strengthen the support s/he receives from the village. Finally, it frames the disappointments and drains in terms of decisions a caregiver might make to redefine the village.

Why make effective use of caregiving resources?

Effective involvement of family members or others as caregiving resources can lead to a number of positive outcomes. The person who is cared for benefits from having more care; this may improve the person's overall quality of life. For you, as a caregiver, there are also a quality of life benefits. You are less isolated and your role – and 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. In the larger picture, family, friends, and community can take pride in caring for one of their own and in functioning up to their own expectations of themselves. The key to those outcomes is knowing what kind of help you can reasonably expect (hope) to get from others and how to ask for that help. This, in turn, begins with having a basic understanding about the kind of caregiving situation you already have.

Types of Caregiving Arrangements

There are several ways to categorize the kinds of caregiving arrangements that take place in the caregiving village. This section describes five main caregiving arrangement types. Being able to identify the type of caregiving arrangement you are currently in may help you with decisions you may want to make about strengthening or redefining your own caregiving group.

It may help you to understand your current arrangement or to identify another arrangement that might be possible – and possibly better for you. It should assist you to identify what kind of help you can reasonably expect (or hope) to get from others. Later in the chapter, we describe some main barriers to effective caregiving arrangement and provide suggestions for overcoming these barriers. This may assist you to ask for specific kinds of help from others in the caregiving village.

Below we describe five common caregiving arrangements. 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. In addition, caregiving arrangement often change as the dementia progresses and caregiving needs change.

Solitary Caregiving

In Solitary Caregiving, one person does all the work of caregiving. Other concerned people, e.g. family members, may live in the area, but the responsibility of care rests almost solely on the solo caregiver. Social connections have weakened or been severed. The breaking of connections may be from both sides. Those connected to the caregiver may not understand the situation or may feel unsure how to help. The caregiver may not want to ask for help or be unclear about what to ask for or how to ask for it.

Example: Tina married Paul six years ago. Four years ago, Paul started showing signs of dementia. Tina can no longer leave him alone. Her two daughters from her first marriage, who live in the area, have offered to be with Paul while Tina goes out. She doesn't take them up on this because she feels that Paul is not their father and they should not have to deal with his dementia. Plus they have their own families to care for. Paul's two children live out of state. They visit once a year and call weekly, but also have jobs and families and very busy lives. While they stay in touch, they do not offer

to help. Tina is a solitary caregiver. Tina had been active in her church, but she has stopped attending church and being active in its food bank activities. No one from the church has reached out to her, and she hasn't 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, and no one from the group comes around. Tina is feeling cut off and she feels disappointed that her church and her friends haven't reached out to her and Paul.

Observed Caregiving

In Observed Caregiving, like solitary caregiving, one person does all the work of caregiving. In the case of the observed caregiver, however, others are vocal about how they think care should be given. There is a community of sorts, but 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 was not happening.

Example: Agnes was diagnosed with dementia two years ago. Her caregiver husband, Ron, has health problems of his own, and 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 and he knows the people in the neighborhood. What he would really like is for Susan to come and clean the house for him, but he doesn't feel right asking Susan to help him. Their son, John, is concerned, because he knows that if the parents move to an assisted living facility, their assets will soon be used up. He and his sister may then need to assume some financial responsibility and might lose their inheritance. He is encouraging his father to "hang in there" and keep taking care of his mom at home. While the children care, they're not really helping; yet they are putting pressure on their dad. Ron's golfing buddies keep asking him to play in their regular game and are critical of him for not doing so (because he can't leave Agnes alone). He had been active in his precinct political caucus and is getting pressure to continue at a past level of activity. The golf partners nor the community group members keep telling Ron that he's "coddling" Agnes and should get on with his life. Their family doctor tells Ron, "it's dementia; what can you do?" and encourages him to "hang in there."

Tag Team Caregiving

In Tag Team arrangements, the work of caregiving is assumed sequentially. The responsibility of caring for the person with dementia rotates, often among family members. In tag team families, one family member is a primary caregiver at a time. Such arrangements often reflect a high degree of commitment by the caregivers. However, they also may suffer if communication is not very deliberate. In addition, they may not take full advantage of the resources that might be available for caregiving.

Example: Benjamin, the father of three children, has dementia. He can no longer take care of himself, and his wife died two years ago. His children take turns caring for their father. They have arranged it so that Randy stays a month at each child's house. During that month, each child is responsible for getting Randy to his usual day program, and taking care of him at night, and the other two siblings are not expected to help, except in the case of an emergency. Each child functions as a solitary caregiver in each month. The organized arrangement among the children does provide caregiving and it involves backup and support. However, there is little coordination and communication among the children. There is no effort to share with one another their observations about their father's condition. More importantly, there is no sharing of "what works" in caregiving. So Benjamin may be experiencing highly fluctuating kinds of care in the three environments – and no coordinated effort to help him find Contented Involvement in each of the three settings. Because the three children live away from the neighborhood in which Benjamin has lived for most of his adult life, none of his anchor institutions is involved with him any longer. While he might not feel or experience it, Benjamin is isolated from everything in his village except his children.

Uneasy Caregiving Arrangement

In an Uneasy Caregiving Arrangement more than one person cares for the person with dementia over a given time period. In uneasy caregiving arrangements, members share the work but do not necessarily focus on the same goals, or have similar styles of providing care. The unease between or among the caregivers hampers 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 at some distance from – but in the same town as – their mother. They agree it is good that Margaret remain in her apartment, but they disagree on the extent to which dementia has affected her ability to care for herself. Sara believes that Margaret should do as much for herself as possible – that this will keep her alive and alert. Sara has Margaret help her make dinner and do little chores around the house when she brings her mother home to visit. Martha feels Margaret is too frail to leave her apartment and she worries about Margaret’s safety. Martha is afraid that while Margaret is helping Sara cook, Margaret will cut herself or burn herself on the stove, and has repeatedly asked Sara not to let their mother help cook. Sara believes that Margaret enjoys helping and that she is not in danger when she helps. When Martha is with her mother, she does everything for her. 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 and also to take her to the store with him. While Sara is grateful for this attention, Martha is suspicious of it. She worries that the outings may be dangerous, and she’s also worried that Bill might be trying to take some advantage of Margaret – perhaps steal from her. Martha has made comments to Bill that let him understand her suspicions. So he has stopped visiting.

Collaborative Caregiving Arrangement

In a Collaborative Caregiving Arrangement, several key people take part in caring for the person with dementia. Group members share a common understanding of what help is needed, and they work out a plan for delivering that help. Members perceive the help each provides as supportive of the person with dementia and of their own efforts to provide care. Everybody pitches in to help, but each person does not necessarily have to do the same amount of caregiving or same tasks. The common understanding of the situation and care needs also 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 dementia for about 5 years. Though Sharon lives with Ray, she gets a lot 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 and helps her mother clean the house. Both Fred and Paula visit frequently. Ray Jr. lives 10 hours away and can't give the same consistency of help, but he helps Sharon to manage the family's finances. One week each year, Ray Jr. comes and stays with Ray so Sharon can go to visit her sister in Nebraska. Ray Jr. also comes home during long holiday weekends and does what he can. All family members want to keep Ray at home as long as they are able. Though she no longer belongs to the neighborhood church Sharon raised her in, Paula knows the pastor well and has let him know of the family situation. With her siblings' consent, Paula has worked with the pastor and a women's group at the church to arrange for regular home social visits to Sharon and Ray and for bi-weekly respite times that 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 to ask his parents to "check in" from time to time to make sure Sharon and Ray are okay. The friend's father has taken to asking 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 combination of types. Think about under what circumstances or during what kinds of situations or events 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, for example:

- It would be less of a Solitary Caregiving situation if I would ask my grown children or neighbors or friends from the bridge club for help more regularly (or 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.
- We would be a Collaborative Team if my sister managed the finances, my neighbor mowed our lawn, and my husband's best friend brought him to

the barber.

- We would be a Collaborative Team family if my sister, who lives in Florida, would call Dad every week to ask him how he is doing.

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 formulate a strategy for moving closer to where you would like to be in terms of caregiving.

Barriers and Aids to Successful Caregiving Alliances

Caregivers often feel unable to take time for themselves, citing specific obstacles or barriers. For example, caregivers often wonder if others will do as good a job at caregiving as they do. Caregivers are often careful not to impose on others, e.g. ask for help from grown children or friends who are busy with their own careers or families. Some offer but are turned down.

Nevertheless, others often want to provide assistance to caregivers, but don't know what to do. Giving relatives and friends information about dementia, and details on how best to interact with the person with memory problems (communication) helps to overcome hesitance to be alone with the person with dementia, addressing the other's lack of confidence or experience. Not knowing what to do if the person gets agitated, or asks the person who they are, prevents many people from volunteering their help.

There are three main barriers that get in the way of a family (or an extended care group of family and friends) successfully coping with having a family member with dementia: denial or lack of recognition, lack of role flexibility, and lack of experience.

Denial or Lack of Recognition

Sometimes, people are unable or unwilling to acknowledge the presence of a dementing illness or to accept the losses associated with it. This is very common, especially around the time that someone is seeking or considering a medical evaluation.

Both the person 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 fear that they may get Alzheimer's too. Or they are unable to face the loss of their relative or friend as the condition progresses. They do not want to face the fact that life will change.

People cannot cope successfully with dementia if they cannot see or admit there is a problem. Denial (or lack of recognition) is frequently the cause of friction. Family, friends, or community members who do not recognize what is happening are likely to resist the caregiver's efforts to seek their help. Likewise, they may not understand – or may even criticize – a caregiver for wanting to use outside help, such as daycare, or to move the person to 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 signs of being uncaring. Providing information about the disease and having the person spend significant time with the person who has dementia are both powerful tools for getting someone to face the facts of the situation.

Lack of Role Flexibility

A second barrier for families, friends, and communities coping with dementia is the inability to adjust and change roles. Adjustment is often necessary when someone has a disease like Alzheimer's. When someone develops dementia, 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. The caregiver often finds that doing all the things s/he accomplished before the onset of the disease is more difficult, and 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, in church and community groups, and in the neighborhood changes.

Lack of flexibility can lead to disorganization within a family (or a family-friend team). It can also lead to responses by family, friends, and community that exclude and isolate the person with the disease and the family caregiver. If members of a family are flexible regarding who can perform certain roles, the family's transition into caregiving will be smoother and the family will be a resource in caregiving. Take the example of a mother of a large family who used to prepare elaborate holiday dinners for everyone in the extended family,

but is no longer able to because of dementia. If roles are flexible within the family, someone else can take over the role of hosting holiday dinners or other members can share the role. In families that have a lack of role flexibility, the family may stop having holiday dinners together because that was always Mom's job and nobody else feels able to do it. If a family's roles are not flexible, other persons do not take over the tasks the disabled person used to do. They may not be able to assist the caregiver in some of his/her roles in order to lighten his/her load.

In many instances, the caregiver fosters or supports role inflexibility. Parents frequently see their role as providers of assistance rather than recipients of help. Therefore, they believe their children are too busy with their own lives to assist them. Friends may be associated within limited contexts or activities. Then, caregivers cannot or will not ask others for help. In such instances, the caregiver has to recognize his/her own need for help and find ways to ask the family to reorganize itself or friends to redefine roles around the reality of the situation brought on by the dementing disease.

Lack of Experience

People may not know what to do to care for a person with dementia. 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 with dementia because they don't know what to expect. The disease is a mystery. The behavior of a person with dementia is puzzling. S/he might fear being unable to "handle" what the person with dementia might do. Second, people may not know how much work is involved in caregiving or how to do the work of caregiving. To the extent that the disease remains a mystery - and a frightening one at that - or that they feel inadequate about how well they could provide care if they were to be "in charge" of the person, they are less likely to offer help and understanding.

Enlisting Help

There are three ways to help break through barriers to create successful caregiving alliances and help others cope with having a significant other with a dementing illness. Such tools help in everyday life, but are more crucial when an illness invades a family or social circle.

- **Knowledge and skill.** As the Savvy Caregiver program has emphasized, it is important to know about dementia and its 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. If individual members know the types of losses the person with dementia will face, techniques for interaction and ideas to maximize quality of life, the person with dementia and caregiver(s) will benefit.

Share what you've learned in this program. Ask others to take the course, read this manual, view the CD-ROM. Urge them to go through the exercises to estimate your person's cognitive level. Ask them to see, as you do, what the disease means for your person.

- **Have a plan.** Successful caregiving requires planning, short-term and long-term. A plan can include who does what for an afternoon, adapting certain activities and providing support, ways to recognize warning signs, ideas to handle a certain problematic reactions or keep the person with dementia meaningfully occupied. Plans can also include decisions about caregiving in the future. For example, when will residential care become necessary? Each plan (e.g. meal) can be broken down to specifics (e.g. menu, guest list, logistics) and then must be executed (e.g. recipes).
- **Communication.** Caregiving alliances work better when people share common goals and strategies. Communication helps break down the barriers to successful caregiving alliances. Communication also facilitates two aids in developing successful caregiving alliances – knowledge and having a plan. Creating a plan for successful caregiving relies on exchanging information on what individual members need and can provide and what goals each individual has regarding caregiving and the future of the member with dementia.

Talking about the disease and how it affects all members of the family and your social circle, including the person with dementia, can help people let go of denial. Communicating about day to day caregiving with family members and friends enables them to comprehend the effect of

dementia on the person and you. Communication about what works for you in your interactions with the person helps others feel more comfortable around the person with dementia. If you are able and willing to let others know what you need, and what works in day to day caregiving, other people will be more able to assist with, or assume, the tasks that need to be accomplished.

Communicating emotions can also foster feelings of support and understanding. Talking helps get over barriers most people face when struggling with a long-term progressive disease, such as Alzheimer's. When family members and others understand, truly understand, they are more likely to pitch in and offer support.

To conclude this section, 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.

Now, do the following:

- Consider each of the barriers in developing caregiving alliances (denial, role inflexibility, lack of experience) and work through what you see is preventing you and others close to you from more effective caregiving in your particular situation.
- Consider the aids in developing caregiving alliances (increasing knowledge and skills, having a plan, communication). Indicate what kinds of knowledge and skill you wish you and others, family members and friends, would have. Do you have a plan or plans?

With your new Savvy Caregiver insight and confidence, rally resources to compile concrete plans. Work with others to get agreements about specific help they will give, and then give them specific directions about how they can be successful in providing that help. Practice what you'd like to say to others.

Dementia Decision Making Guide for Family Caregivers

Your caregiving role is a demanding one. Along with the day-to-day caregiving tasks come all the decisions that need to be made. These range from everyday concerns such as how much help to provide in daily activities like bathing or dressing, to long-term decisions such as how best to use financial resources, whether or not to remain in the family home, and choosing an adult day center.

For some couples, decision making was previously shared, while for other couples, one of the spouses made the major decisions in the family. When one spouse develops dementia and the caregiving spouse takes over the decision making, issues/problems can arise. For some caregivers, major decision-making is a new experience, an added role and responsibility.

When children are caregivers for their parents, the need to take over decision making can be very stressful. We expect our parents to make their own decisions. This change of role feels 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 help.

This section of the manual describes an approach to helping you make decisions for you and your family member. The Dementia Decision-Making Guide for Family Caregivers (DM Guide) was developed to assist caregivers in the decision making task. 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 DM Guide is a tool to help caregivers break decisions into a number of parts and combine them to make a decision. The DM Guide was developed to enhance people's decision-making skills in general. Therefore it can be used in many decision-making situations.

The DM Guide provides caregivers with a structure and procedure for making choices for themselves and their family members. The four major aspects of decision making: Options, Outcomes, Values, and Likelihoods are described below.

The structure for decision making is represented by a decision grid (see figure below) that relates the four elements, options, outcomes, values, and likelihoods.

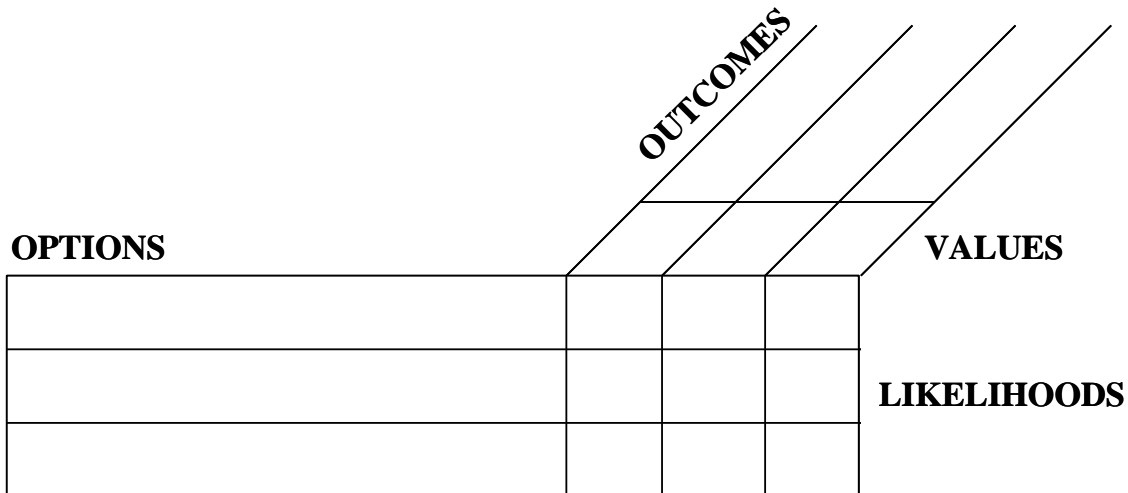


Figure 1
Decision-Making Guide

Table 1 presents a series of questions for working through a decision.

Table 1. Questions to Guide Decision-Making

1. What do you need to make a decision about?
2. **OPTIONS:** What actions are you considering; what choices do you have?
3. **OUTCOMES:** What would you like to have happen as a result of your choice; list immediate outcomes and outcomes down the road.
4. **VALUES:** How important are each of these outcomes to you?
5. **LIKELIHOODS:** How likely is it that each option will lead to each of the outcomes?
6. What option is most likely to achieve the best outcomes?

Let's define these terms:

- Options are defined as the various actions or choices being considered in making a decision. Here it is useful to list up to three options that are different from each other.
- Outcomes are the expected results or consequences of each option. In listing outcomes, the caregiver thinks about what s/he wants to have happen as a result of making this decision. These outcomes involve results both for the person with dementia and the caregiver.
- Values are defined as the importance assigned by the caregiver to the outcomes. Determining what is most important for you and your family member will help in making the decision.
- Finally, likelihoods are the probabilities or odds that outcomes will occur. You will use the information you have learned about levels of performance ability of your family member to help you decide the chance of an option resulting in an outcome you want.

Illustration: How the Decision Making Guide can work in caregiving.

This example will walk you through a decision 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, and the extra money helps. Mr. Murphy, who has dementia, has remained at home alone. Lately, Mrs. Murphy has become concerned about Mr. Murphy's ability to stay by himself after an incident in which she came home to find the front door unlocked and the gas stove on. Mrs. Murphy feels that she must decide what she is going to do about her husband when she is at work.

1. What do you need to make a decision about?

The decision situation is what Mrs. Murphy is going to do about her husband when she is at work.

2. What actions are you considering?

Mrs. Murphy identifies numerous options, but narrows them down to three specific ones:

- Allow Mr. Murphy to stay home alone, but call him every hour;
- Ask her daughter to come and stay with him during the morning; or
- Quit work. The three options are listed on the left side of the decision grid in Figure 2 (below).

OPTIONS	VALUES		
	LIKELIHOODS	LIKELIHOODS	LIKELIHOODS
Allow to stay home, call			
Have daughter stay			
Quit work			

Figure 2
Mrs. Murphy's Options

3. What would you like to have happen as a result of your choice?

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, and what she wants to avoid happening. In this situation, Mrs. Murphy identifies three important results she wants to consider in taking whatever action she decides upon:

- She wants Mr. Murphy to be safe while she is at work.
- She does not want to hurt Mr. Murphy’s pride, because he says he is fine alone.
- She is also concerned about her own sense of well-being. She really enjoys working in the flower shop. She brings in some needed extra money, she loves talking with people, and the work gives her a sense of accomplishment.

The three outcomes of greatest concern to Mrs. Murphy are portrayed in Figure 3.

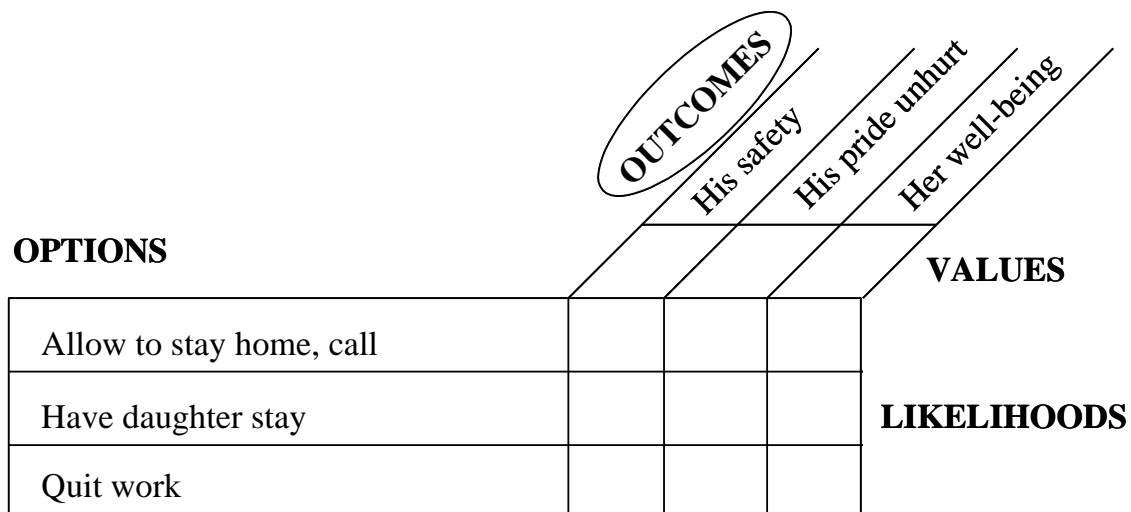


Figure 3
Mrs. Murphy’s Outcomes

4. How important are each of these outcomes to you?

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. Others are outcomes that the person hopes will never happen, or negative outcomes. A simple way to assign values is to rank them with plus signs. For example, outcomes can be assigned a value of +++ (most important outcome), ++ (second in importance), or + (third in importance). Mrs. Murphy considers the three outcomes she has listed.

- She ranks Mr. Murphy’s safety as the most important outcome, assigning it +++.
- She ranks her sense of well-being as a ++, because she knows that if she feels OK about herself she is better able to take care of her husband.
- Lastly, Mrs. Murphy considers the outcome of hurting her husband’s pride. Mr. Murphy has always been a proud, independent person, but lately Mrs. Murphy has noticed that he allows her to do more for him and sometimes even asks for help – none of which seems to disturb him. Mrs. Murphy continues to be concerned about his feelings, however, and assigns a + to this outcome. The values are inserted under the outcomes in Figure 4.

OPTIONS	OUTCOMES			VALUES
	His safety	His pride unhurt	Her well-being	
Allow to stay home, call	+++	+	++	LIKELIHOODS
Have daughter stay				
Quit work				

Figure 4
Mrs. Murphy’s Values

5. How likely or possible is it that each option will lead to each of the outcomes?

Decision making involves looking at each option and determining, to the best of your ability, the likelihood that the option will lead to the outcome. In the context of caregiving, determining likelihoods is based primarily on personal experience as a caregiver, as well as information available from other resources, such as family health care providers, written materials, and community agencies. Understanding what your family member's level of thinking is can help you decide.

One way to rate the likelihoods is to use words such as high, medium, or low. In the example, Mrs. Murphy thinks about the likelihood of the various outcomes in the following ways:

Mrs. Murphy has participated in the Savvy Caregiving Program and has identified Mr. Murphy as functioning at Level 4.0. She knows that means Mr. Murphy is very impaired in memory and thinking, is easily distracted and needs much assistance.

- When Mrs. Murphy thinks about the likelihood of Mr. Murphy being safe at home if he is allowed to stay alone, she knows that he has left the stove on and the door unlocked. Therefore, she rates the chance of him being safe at home alone as low. When she thinks about his safety when either she or her daughter are with him, she ranks this likelihood as high.
- When considering the likelihood of her husband's pride being hurt if she quits work, she remembers some information she learned about persons with dementia: they become less able to understand the meaning of events happening around them. Therefore, she speculates that his feelings are not very likely to be affected by any of the options. For example, he won't understand that her being around more means that she quit her job to care for him; consequently, he won't be as upset as he might have been in the past. So, she rates the chance of his pride being hurt under any option as medium.

- Finally, when Mrs. Murphy thinks about her own well being, she realizes that the chances for positive well-being are high if her daughter comes over, but low if she continues to leave Mr. Murphy alone or quits work.

These likelihood ratings are found in the cells on the decision grid in Figure 5.

OPTIONS	OUTCOMES			VALUES
	His safety	His pride unhurt	Her well-being	
	+++	+	++	
Allow to stay home, call	low	med	low	LIKELIHOODS
Have daughter stay	hi	med	hi	
Quit work	hi	med	low	

Figure 5
The Likelihood of Outcomes

6. What option is most likely to achieve the best outcomes?

Once the decision grid is completed, the caregiver chooses an option by relating the information about each option and then comparing the options. The grid serves as a guide in the process. Mrs. Murphy ponders the grid. She quickly eliminates option 1 (allowing Mr. Murphy to stay alone with hourly phone calls) because it has a low probability of keeping Mr. Murphy safe, an outcome that is most important to her. In comparing option 2 (ask daughter to come and stay with him during the morning) and option 3 (quit work), Mrs. Murphy notices that they both have a high likelihood of keeping Mr. Murphy safe. Now Mrs. Murphy can choose between these two options by examining their likelihood of achieving the remaining two outcomes. This simplifies the decision.

Mrs. Murphy relates the two options and the two outcomes on the basis of the values and likelihoods she assigned. Earlier, Mrs. Murphy assigned a ++ to her own well-being. She continues to feel that it is important for her to have a sense of accomplishment in her job, and to have contact with other people in order for her to provide the best care she can for Mr. Murphy. The option that is more likely to achieve this is having their daughter stay with Mr. Murphy. In addition, their daughter offered to help in any way she can. So for now, Mrs. Murphy decides to ask her daughter to stay with Mr. Murphy during the morning when she is at work.

This simple example was selected to illustrate the structure and procedure of the DM Guide. Mrs. Murphy's situation and her values influenced her decision making. Other people may face more complex decision situations and may think of different options and outcomes, assigning different values and likelihoods because of their unique situations and perspectives.

Early on, as they are learning how to use the Guide, Savvy Caregivers are encouraged to think about decisions using all the components of the DM Guide. Be assured, however, that you do not have to fill out the entire grid for each decision you face. Many times, just considering options, outcomes, and values will stimulate enough reflection to make the best option obvious. Not every decision requires this type of analysis. The kinds of decisions that are worth putting the time and energy into using the DM Guide include serious and complex decisions, recurring decisions, and those that are troublesome, perplexing, or uncomfortable. Decisions may need to be made more than once, particularly as changes occur in the situation or in the condition of your family member. For example, a day-to-day management option that worked in the past may no longer be appropriate or the importance attached to an outcome might change.

The DM 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 grids with other family members. One of the benefits of the grid is that families can discuss a decision situation, see where they may differ in their desired outcomes or the value they place on outcomes, and develop greater tolerance for each others' views.

Applying the Decision Grid to Day-to-Day Management Issues

As a caregiver, you are faced with numerous decisions about what to do in the daily care and management of your family member. Used in conjunction with the information you are learning about dementia and Savvy Caregiving, you can use the decision grid to process care management strategy decisions.

Example. Mrs. L is caring for her husband who has been assessed to be functioning in the Allen Level 4.0-4.5 range. He continues to like to be helpful around the house and she feels it is important for him to feel useful. The problem is he makes mistakes, and she has to clean up after them. For example, he likes to help with the laundry. However he gets confused about when the laundry cycle is completely over and often mistakes the brief pause in the washer's operation (when it is switching operations) for a sign that the laundry is done. As a result, he often 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 and so the floor gets all wet from his transferring them. The washer cycle is incomplete, so it has to be completed. The clothes are either not clean or not rinsed fully. And the dryer takes on a lot of water. In short it's a mess.

Mrs. L. is reluctant to stop her husband from helping her because she's afraid it will hurt his self-esteem. At the same time, she needs to get the laundry done and 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 – and how much – to let Mr. L. continue to help her with the laundry.
2. What actions might Mrs. L. consider in this situation? (OPTIONS)
 - Having Mr. L. continue doing what he's doing and just live with the consequences and the mess.
 - Having Mr. L. not help with the laundry at all.
 - Take Mr. L.'s Performance Level into account and use the Structure and Support guidelines to select portions of the task that he could help with.
3. 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
4. How important is each of these outcomes to Mrs. L.? (VALUES)
 - Mr. L.'s self-esteem +++
 - No extra work +++
 - Get laundry done ++|
5. How likely is it that each option will lead to each of the outcomes? (LIKELIHOODS) - and why?

Option	Likelihood per Outcome	Reason
1. Mr. L. continues	<ul style="list-style-type: none"> • High for self-esteem • Low for no extra work • Medium for getting laundry done 	<ul style="list-style-type: none"> • Nothing will change and he will continue to feel as good as he currently does • Mrs. L. will continue to have to clean up • It will continue to take extra time
2. Mr. L. doesn't help at all	<ul style="list-style-type: none"> • Medium-low for self-esteem • High for no extra work • High for getting laundry done 	<ul style="list-style-type: none"> • Even though his dementia has progressed, he may well notice that he is no longer involved and this may affect him • Mrs. L. will be able to do laundry faster • Mrs. L. will be able to do laundry faster and there will be no extra work to do
3. Mrs. L. designs things so Mr. L. can help with parts.*	<ul style="list-style-type: none"> • High for self-esteem • Medium for no extra work • High for getting it done 	<ul style="list-style-type: none"> • He will feel he is helping and the progression of this disease makes it unlikely he will realize Mrs. L. has taken back some of the tasks • It won't be as efficient as if she were doing it herself, but not as much as if he were doing it alone • Slower, but not the extra work of cleaning up after him – and it gets done

* For example, 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. Still later, he can help to take things out of the dryer and to fold them. What she realizes – as a result of her Savvy Caregiver training – is that Mr. L.'s sense of himself – his self-esteem – has, like all the other cognitive powers, been dulled by the disease. He is no longer so acutely aware of self-esteem as an issue, and it is not so important to him anymore – and not nearly as important as feeling near Mrs. L. and feeling of some use to her.

When all of this information is put on the decision grid, it looks like this:

OPTIONS	OUTCOMES			VALUES
	No extra work	Good self-esteem	Laundry gets done	
	+++	+	++	
Mr. L. Keeps on helping	low	hi	med	LIKELIHOODS
Mr. L. doesn't help at all	hi	low	hi	
Mrs. L. designs tasks for him	med	hi	hi	

Figure 5
Mrs. L's Laundry Decision

The key piece of information Mrs. L. needed in order to have the elements of the decision grid fall into place was that the dementing disorder likely blunts Mr. L.'s awareness of issues like self-esteem. He is probably at a much simpler level in his thoughts and feelings, so that he is satisfied to be helping and is less involved in thinking about how much help he is giving or whether this represents a loss of status. The deterioration of his cognitive processes – by this point in the disease – makes it very unlikely that he would be able to remember what he used to be able to do and compare it with what Mrs. L. is now asking him to do.

This is actually a very key point for many caregivers. They tend to operate on the assumption that the person's feelings about him/herself and about things in general are unaffected by the disease. There is a great deal of worry about how the person will react to changes – like the caregiver taking over the finances. These concerns are often couched in terms of the issue of self-esteem – the person will feel less good about him/herself or will somehow feel diminished. Remember that, as you make choices about how much to involve your person and what limits to impose, the issue of self esteem fades as the disease progresses. So you should be less and less concerned about it. So when Mrs. L. looks at the completed grid, she can see that the option of identifying the parts

of the laundry that Mr. L. can do offers the best set of likelihoods for balancing her need to get the work done with as little extra work as possible and to attend to her husband's feelings.

There are two things to consider about the DM Guide:

- The process of answering the questions and filling in the grid is useful not only for long-range decisions but also for the more day to day matters that caregivers face in managing their family member's life.
- Once you have the questions and process clear, you may not have to go through the formal exercise of using the grid. Often the process of looking at the available options will make the decision clear. Nevertheless, the tool is there, and you should feel comfortable with how to use it. You can choose when to use the whole thing.