

## **PART TWO**

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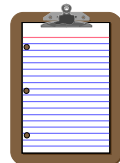
### **Class Sessions**





## Savvy Caregiver Program American Indian / Alaska Native Trainer Essentials

### SESSION 1: CAREGIVING AND DEMENTIA BASICS

<b>Introductions</b> <ul style="list-style-type: none"> <li>• Introduction of participants</li> <li>• Introduction to the Savvy Caregiver</li> <li>• Program goals and expectations</li> </ul>	25 minutes	 SESSION AGENDA
<b>Caregiving</b> <ul style="list-style-type: none"> <li>• Defining and exploring the role of the caregiver</li> <li>• Skills, knowledge, and outlook needed for effective caregiving</li> <li>• The toll of caregiving</li> </ul>	40 minutes	
<b>Alzheimer's Disease and Other Dementias</b> <ul style="list-style-type: none"> <li>• Basic facts about Alzheimer's Disease and other Dementias</li> </ul>	45 minutes	
<b>Program Resources</b> <ul style="list-style-type: none"> <li>• The caregiver manual, handouts, and media resources</li> </ul>	10 minutes	

**Acknowledge that everyone in the course may be related by blood or clan or know each other in the community.**

Some AI/AN tribal communities are very small. As a result, there can be caregiver trainee groups attending the Savvy class that know each other well. Such familiarity may not be a problem for many people. However, the fact of having a difficult life event take place in a family like an elder developing dementia can cause unique stresses to occur.

Caregivers in the class can also be a source of good information based on their real experience as caregivers. Sharing information and reflecting on the teachings of the Savvy course should be encouraged.

Acknowledge to the class that this is a course to make everyone a better caregiver and to adapt more effectively with the stresses of caregiving.



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Emphasize that NO ONE knows everything about dementia and caregiving. All those taking the class will learn something.

**Discuss the ethics of communication outside the course.**

The fact of an elder developing dementia is a tragic and sad event. All family members are upset by this. Some families have more resources than others, whether it is money, lots of caregivers, or a personality disposition that allows for good adaptation. Discussion in the class will reveal ways that participants provide care. Some caregiving practices that are talked about will be good and some not so good. However, caregiving is not a competition to see who is best. Caregiving is a compassionate, long-term, tiring and stressful situation. The course will help everyone improve caregiving. In turn, that will improve the quality of life for the entire family.

No one should criticize other caregivers whether in the class, at home, or in the community.

**Acknowledge that different approaches to caregiving will occur across families and does not necessarily indicate flawed caregiving.**

Caregiving occurs not only in a place, but in the middle of many factors of life, such as family members in the house, health programs, financial resources, cultural events, religious ceremonies, and all the other events of daily life. No one should imagine that they can offer a valid criticism of other caregivers because no one can know ALL of the things that a given caregiver is managing. Everyone “drops the ball” at some point. It is not appropriate for others to do anything about that except be available to help, if asked.

**Discuss the effects of (only those that apply) reservation life, village life, rural life, urban life on caregiving among AI/ANs in ways that help or hinder caregiving to an elder with memory and thinking loss.**

Ask trainees for their ideas on how the local tribal living arrangements may influence caregiving related to:

- Number of people in the community
- How far apart people live
- Access to health care
- Access to traditional health practitioners
- Transportation
- Participation in tribal ceremonies, rituals, Feast Days, fish camp, festivals, etc.

There are no right or wrong answers. Look for community assets related to caregiving and discuss ways to strengthen them.



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## Program Leader's Overview of Session 1

The major aim of session 1 will be to get the participants to begin thinking of this experience as a training program. To accomplish this aim, the session will need to attain several objectives. As Program Leader, you will want to watch the participants to see if these objectives are met.\* Here are the indicators to watch for—as a result of their participation, caregivers should:



INFORMATION

- Become comfortable with the title of caregiver and with the idea of describing themselves by that title.
- Appreciate that caregiving is a “job”—work they have undertaken. It may spring from their relationship with the person—that may be the motivating force—but it is different from the relationship; it is work they have taken on.
- Begin to understand that the work of caregiving can be difficult, demanding, and potentially punishing, and requires an extensive set of knowledge and skills, and an appropriate outlook in order to carry it out effectively—in a way that benefits the person and preserves themselves.
- Begin to think of themselves as “Savvy Caregivers”—because it’s good for the person and for themselves.
- Recognize that the program is a training program. It is a program designed to give them the skills, knowledge and attitude they need to be a Savvy Caregiver—and it is very different from any kind of support group in which they may have participated before.
- Begin to think in terms of developing and acquiring caregiving strategies—ways to work day-today with the person for whom they provide care, but also longer-range strategies for thinking about and making the decisions they will face as caregivers.

\*It is very important to recognize—and to make the point clearly and explicitly with caregivers—that we understand the issues that dementia produces in relationships, but that the program is not going to deal with these. Clearly, caregivers face devastating losses in their relationship with care receivers. Part of the message of the program is that caregivers need to attend to these feelings. The program is, however, primarily about caregiving skills—ways of taking on, doing, and succeeding in the *work* of caregiving. In the course of the program, part of the instruction will involve describing and encouraging a caregiving outlook that is based on the caregiver’s ability to stand back from the person, coolly analyze just what is going on, and develop a plan of action based on that. This is a work skill. It is not meant to suggest a direction for the relationship. These are separate issues, but the program is more focused on the one than on the other, and so caregivers should look elsewhere for help with dealing with those emotional issues—and Alzheimer’s Association support groups are an excellent place to look for that.

- Begin to acquire information—about the disease and about caregiving—in a way they immediately begin applying to shaping themselves as Savvy Caregivers—even in very small ways.
- Begin processes that support their being Savvy Caregivers, including beginning to identify more effective ways of interacting with their person and to state the objectives they have for their caregiving and the rewards and satisfactions they derive from it.
- Become familiar with the resources of the program—including materials available through Healthcare Interactive ([www.hcinteractive.com](http://www.hcinteractive.com))—and be prepared for the homework that will be assigned.
- Recognize that the program will point them toward other learning resources (published materials and on-line resources) and that the process of acquiring caregiving strategies is an on-going one.

### Structure of Session 1

Session 1 involves several interactive exercises. These are designed to draw participants into the content of the program but also into its process. There are a number of brainstorming exercises that allow caregivers to draw on their own knowledge and experience. These should serve as ice breakers but they should also serve to demonstrate that there is a lot of knowledge and experience in the group. It is important that participants feel comfortable and able to share their experiences—particularly those experiences they have in trying out the strategies and techniques suggested in the program. Since the development and reinforcement of their caregiving mastery is a key objective of the program, every opportunity should be provided to encourage participants to interact and to draw on their own expertise to address caregiving problems. Encouraging participation can sometimes lead to awkward silences; your comfort with these will help group members to be comfortable and, eventually, to chime in. Each of the rest of the sessions begins with a group de-briefing regarding the previous week's session and the "homework assignments." These times are meant to continue the reinforcement of the participants' expertise as caregivers. In the second hour of this first session you will give a brief talk on Alzheimer's disease and other dementias. Participants may have attended an Alzheimer's Association Introduction to Dementia Program or read books on the topic. Your brief talk will provide a quick review of that program and is meant to reinforce the idea that caregivers are dealing with a disease. The material for the talk is all in the Caregiver manual and is also reinforced in the on-line materials of the Alzheimer's Association ([www.alz.org](http://www.alz.org)) and the Alzheimer's Disease Resource Centers. The "Alzheimer's Caregiving Strategies" CD-ROM

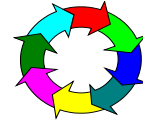
or on-line program ([www.hcinteractive.com](http://www.hcinteractive.com)) also includes much similar material. These are identical, but available in different ways (as a disk or through the Internet). For convenience, the two will be referred to in the rest of the text as a CD-ROM, but both are meant by this reference.

## Introductions

The first session opens with participants introducing themselves. The introductions serve two purposes:

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

The introductions also provide you with information about the caregivers and where they are—and what problems they are facing—in their caregiving. Try to take notes on the introductions—in an effort to tie the content of the program into each person’s individual situation.



EXERCISE

Distribute the Introduction Guide and ask caregivers to take a minute to think through responses to the questions the guide poses. Then give each participant time—but no more than 3-4 minutes—to introduce him/herself (tell the group you’ll keep time and keep each to a limit—this can be done playfully, but you should keep the limit).\* Ask each person to include in the introduction:

- How long s/he’s been caregiving
- What the living situation is (Where live? Live together? Live with others?)
- Does the person have an established diagnosis?
- Does the person have a physician who is helpful?
- What problems s/he’s encountering
- What help s/he’s getting—including help from family and outside resources
- Be sure, for each person, to ask: What do you hope to get from this program?

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

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

### Introduction Guide

Please take 3-5 minutes to introduce yourself to the group. Consider providing information about the following questions.

How long have you been caregiving?

What is your living situation (where does the person live? Live together? Live with others?)

Does the person have an established diagnosis?

Does the person have a physician who is helpful?

What problems are you facing?

What help are you getting—including help from family and outside resources?

What do you hope to get from this program?

### Program Objectives and Materials and Session 1 Objectives

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

- To introduce and provide an orientation to the program and materials (the Caregiver's Manual and Notebook and the CD-ROM fit here), and
- To set the stage for today's session.

Refer Caregivers to the *first slide*.<sup>\*</sup> The slides are provided to participants; they are numbered as they are in the Trainer's Manual.

<sup>\*</sup>The highlighted text following, entitled The Savvy Caregiver Workshop: Objectives, is the first example of what is referred to as a slide in the Trainer's Guide. A number of such slides are used in each of the sessions, and each of the caregivers has a set of these slides. Slides offer a way for the group leader to create focus around an idea. They can be made into overheads or just used in hard copy.



BRIEF TALK



TRANSITION



## The Savvy Caregiver Workshop: Objectives

- **Help Caregivers Appreciate the Scope and Impact of Their Work**
  - **Reduce the Potential Adverse Impacts of Caregiving**
  - **Increase Caregiver’s Skills and Knowledge for Caregiving**
- **Help Caregivers Adopt a More Strategic Outlook on Their Work**
- **Help Caregivers Develop More Effective Strategies for Caregiving and Decision-Making**
  - **Improve Caregivers’ Self-Care Skills**
  - **Improve the Quality of Life of Care Recipients**
  - **Increase Involvement of Families and Other Resources**

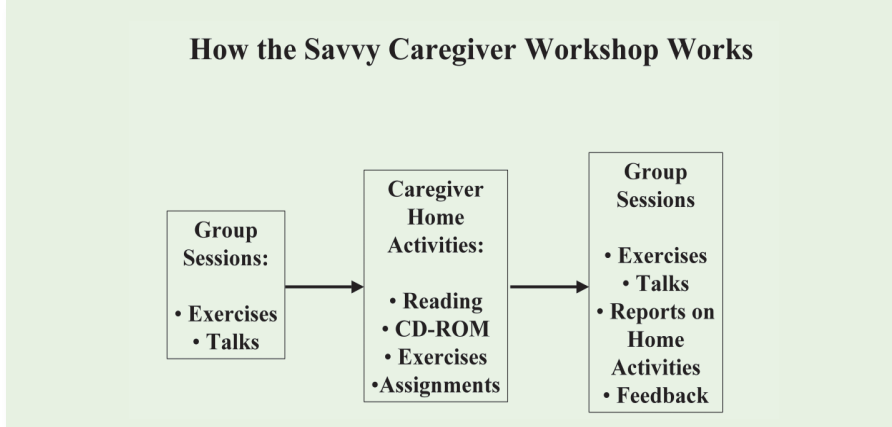
Review the overall program objectives during the first part of Session 1. Read each objective and let each sink in—offer comments and reinforce them. It is important that the point be made early and often that the program is *for* the caregiver. Drive this point home. It is built on a recognition that this is an unexpected role that they have taken on, one that requires lots of skills and can take a lot out of the person. It is not by accident that the first six objectives are focused on the caregiver and that it isn’t until objective 7 that the care recipient is mentioned at all. The objectives give the leaders a chance to emphasize this is a skill, knowledge, and outlook development training program—not a support group—and that there is a strong expectation that learning will be occurring.

The last point—on families—gives the leader an opportunity to urge family participation in the process of the program. Families should be welcome to attend and should be encouraged to read the Caregiver Manual and work with the caregiver as s/he works through it and other resource materials (e.g., the CD-ROM).

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



TRANSITION



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

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



TRANSITION

\*It is important to keep a sense of balance here. Caregivers are busy and may not have the time or energy to do their homework (also, this might not be their learning style). They will still benefit from the workshop even if they don't do their homework. Homework can also provide an opportunity for the caregiver to draw other family members into the process of caregiving by asking them to help with or participate in the suggested exercises. This is a good spot to make the point—which you can reinforce at each homework review—that caregivers will find the workshop materials—the manual, the CD-ROM, the other online references—helpful throughout their caregiving career. They should view these as resources they can use whenever the need or opportunity arises.

## **Session 1** **Objectives**

- **Introduce Selves and Purposes of Program**
- **Gain Appreciation for the Caregiving Role-- an “Unexpected Career”**
- **Appreciate Dementia and its Impact on the Person**
- **Introduce Workshop Resources – Text, Slides and Handouts**

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

### **Define and Explore the Role of the Caregiver**

Following the introduction of the objectives of the program and of this session, you begin the teaching process. This portion of the workshop involves a series of linked exercises. These are meant to help participants to begin to frame the activities they perform in terms of a definable role. The role entails work that has content and can be described. It is a role that demands knowledge, skills, and a proper outlook. It is work with a purpose and that can provide rewards and satisfaction. It is also work that can take a toll. The Savvy Caregiver recognizes s/he has a new role and has begun to acquire the knowledge, skills, and outlook that help make him/her successful in it.

There are four exercises in this series:

- The first is the longest; it identifies the scope of caregiving work. In this exercise you will ask caregivers to brainstorm about all the kinds of work they do to take care of their person.
- The second exercise gets at the idea of the purpose or goals caregivers have about their work—what are they trying to accomplish in their caregiving. This exercise foreshadows material you’ll cover in Session 3 on establishing a reasonable goal for caregiving
- The third is aimed at identifying and making explicit how much a caregiver has to know and be able to do to accomplish these goals.



INFORMATION

- The final exercise regards rewards—what is the payoff (or “salary”) for the caregiver?

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

Recognize the sheer number of tasks they are performing.

- Appreciate that caregiving is a role—that it has a job description, one that changes as the disease progresses (different caregivers at different stages of the disease may list roles that others may not have reached or may no longer play—this will help establish the dynamic nature of the role).
- Recognize that while the impulse to provide care may spring spontaneously from the relationship the caregiver has with his/her person, the wherewithal for the work—knowledge, skills, and attitude—probably have to be acquired.\*
- Begin to identify with the idea that work—like that of the caregiver—should have objectives (that is, the caregiver should be clear about what s/he is doing and why) and that, like all work, it should have rewards and satisfactions.
- Be prepared for the next exercise—defining the knowledge, skills and attitudes they need—as well as the resources—to perform the job well.

### Brainstorm—Caregiving Roles

The point of the first exercise is not that there is an exact job description for caregiving and that every group member should come away with that. Rather the point is that participants reflect on the work they’re doing and appreciate that it is a big and demanding job. It is also meant to tee up the program in that many of the roles on this list are skilled roles—roles for which training is required. And training is what the program is about.

It would be helpful to have a flip chart for this exercise. In some way, try to record all responses in the brainstorm (you will later be able to compare these to the next slide (on caregiver roles) and point out that the group already has a grasp of the scope of the job).

\*This is really the whole point of the workshop; unless a caregiver happens to have been trained as a nurse or other health care worker, s/he cannot be expected to know what the task demands or how to accomplish it. Hence the need for training.



Ask the group to name all of the roles they play and tasks they perform as they provide care for their person. As group members identify roles and tasks, the group leaders should interpret those responses in terms of professional roles. Thus, for example, if someone says: “I take care of arranging all the appointments,” the leader might say, “Right, just like a social worker.” Or if someone says, “I’m the one to keep him entertained,” the leader could point out, “Yes, you’re the household Activity Director.” Or “I make sure she takes her medicine,” the leader could point out, “Just like a nurse.”

In order to keep the exercise going—it should last 5–10 minutes—the leaders could use prompts such as:

“Are there other things you do for your person as a caregiver?”

“What’s the hardest thing for you to do?”

“Do you have to do things to inform or get other family members involved?”

“Do you have a role when s/he goes to see the doctor?”

Once the exercise is over—when people run out of things to say and it’s clear you can’t pull any more out of them—then summarize the results into a list of roles that are encompassed in the caregiving role (you can use *slide 4* for the summarizing discussion).



TRANSITION

## The Role of Caregiver

- Nurse
- Guardian
- Behavior Manager
- Cook
- Companion and Comforter
- Maid and Laundry Attendant
- Safety Officer
- Administrator; Chief Financial Officer; Key Decision Maker
- Home Repair Specialist
- Activity and Tour Director
- Family Counselor and Diplomat
- Liaison with professionals -- doctors etc.
- Social Worker

- If any roles have been left off the list in the brainstorm, add them—it is very likely this will happen.
- Ask the group to validate the list—do they agree that these are all the things they are called on to do.
- Point out the scope of the role—this is a big task they have undertaken and they have many responsibilities.
- Point out, especially, that many of the roles are skilled in nature—they typically require training, training that most caregivers (unless they happen to be health care professionals) don't usually have before they become caregivers.
- Point out that caregiving takes a toll on caregivers—and that minimizing this toll is what this program is about. Note that you'll be talking more about this in a bit.

The previous exercise defined the nature of the work; the purpose of the next three exercises is to write part of the rest of the job description. You can use the Caregiver Role Requirements handout for this, if you choose. The completed description should include:

**Purpose.** What is the object of the work? What will the successful candidate be trying to do with and for the person?

**Qualifications.** Have the group define the set of knowledge, skills and outlook they would look for in a worker if they could hire someone to do the work they are doing.

**Salary.** What will the worker get out of the work—not monetary benefits but rewards and satisfactions?

**This exercise relates to the purpose or goal of caregiving.** What is it that the worker is (or should be) trying to accomplish with the person? To start the exercise, refocus the group on the roles and tasks list that was developed in the previous exercise. Then tell the group that they are to imagine that money is no object and they are going to hire one or more persons to take care of their person. Ask the group to brainstorm (2–3 minutes) on the question: How would you tell job applicants what the overall purpose or goal of their work is to be? The focus here is not on particular tasks, but what you want overall—“At the end of the day, I’ll feel you’ve done a good job if . . . ”

You can use the Objectives of Caregiving *slide, next*, to summarize and discuss this brainstorming.



TRANSITION

## Objectives of Caregiving

- **Person's Safety and Comfort**
- **Meet Daily Care Needs**
- **Contented Involvement**
- **Fulfillment**
- **Reduce Suffering**

The brainstorming will come up with a number of suggestions, but most of them will likely fit into the first two responses above (safety and care needs). The third response—contented involvement—may come up. Often a caregiver will say something like, “I try to see that s/he does something s/he likes to do.” If something like that comes up, use it to introduce and emphasize the idea of contented involvement—people with dementia can get drawn into a task or activity (including the everyday activities of life, like dressing and eating) and do seem to enjoy being focused in on it. This is an important concept in the program, one you’ll deal with at length in later sessions, and one that it is useful to introduce early on.

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

The fifth response category—reducing suffering—may also not come up, but again it is important to introduce it. At this point in most of the caregivers’



careers, they are wrestling with making choices for the person and whether that is okay. They may be feeling discomfort with this. They need to become comfortable with the idea that while the person can still make some choices, s/he cannot make others and will feel discomfort in being challenged to do so. In this way the caregiver reduces the person's suffering. The question will be more difficult and serious later on when questions of life-sustaining care and treatment are raised and when the caregiver will have to make distinctions between life and quality of life for the person. Caregivers should be encouraged to discuss advance directives while the person is still able.

The third exercise is meant to get at the issue of knowledge and skills. This exercise is not meant to be exhaustive but should serve, like the rest of those in this series, to plant in the minds of the participants the idea of caregiving as a big role.

#### *Caregiver Qualifications*

Go to the role and task list and, going down the role list, have the group begin to describe the knowledge, skill, and outlook requirements of each role. Use the Caregiver Role Requirements handout for this exercise (see next page). Keep this brief. The object is not to fill in each cell on the grid but to get the caregivers to see that skills and knowledge are needed for each part of the job. For the exercise, have the participants try to complete just 3-4 cells. For example, ask them:

- What kinds of knowledge would a nurse need to do the job?
- What kinds of skills would an activity director need?
- What kinds of attitude should the nurse have? How about the safety officer?

Once the brief exercise is over, you should summarize the job requirements that participants specified. Next review the Key Caregiver Knowledge handout. It's likely the brainstorming will have resulted in only a partial match with the "Key" list, and that's both okay and to be expected. The exercise is meant to begin to open caregivers up to this way of viewing their role. The "Key" list—which you should review just by briefly reading through it—should continue this process of expansion or opening up. Be sure, after reviewing the "key" list, to assure participants that the Savvy Caregiver Workshop is designed to develop or strengthen in them these key areas of knowledge, skills, and attitude. Get group consensus on the review of the list, and make any additions. Ask participants to reflect about the extent to which each of them possesses the knowledge, skills, and outlook needed for the task.

### Caregiver Role Requirements

<i>Role</i>	<i>Required Knowledge</i>	<i>Required Skills</i>	<i>Required Outlook or Attitude</i>
Nurse			
Social Worker			
Activity Director			
Home Companion			
Chief Financial Officer			
Administrator			
Safety Officer			
Family Counselor			
Lawyer			

*Purpose:* What is the Caregiver Trying to Accomplish in the Caregiving Work?

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*“Salary”:* What are the Rewards and Satisfactions of Caregiving?

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## Key Caregiver Knowledge, Skills, and Outlook

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### *Knowledge*

- Knowledge about the disease—what it does to the person; how it progresses; what it means for caregiving
- Recognize the needs the disease creates in the person (e.g., for security)
- Understand how much the person will rely on you
- Knowledge of strategies and techniques that can be employed to manage day-to-day life with the person
- Knowledge of what the disease does to a family
- Knowledge of what caregiving can do to the caregiver and of appropriate self-care techniques
- Knowledge of community resources that can be drawn upon to assist in the care of the person

### *Skills*

- Be a skilled observer—recognize subtle differences from day to day
- Be able to provide a secure and comfortable routine for the person
- Be able to manage day-to-day life with a minimum of disruptive behavior
- Be able to respond effectively should disruptive behavior occur
- Be able to communicate effectively, given the effects of the disease
- Be able to think up tasks and activities that suit the person and that allow him/her to be enjoyably involved in them
- Ability to make day-to-day and long-term decisions
- Ability to bring family into caregiving, as much as possible
- Ability to recognize the need for self-care activities
- Ability to interact effectively with a wide range of providers

### *Outlook*

- Clinical—have a kind of detached view of the person’s behaviors to allow for accurate observation and informed planning
  - Experimental—be able to try things and learn from the results of the trying (whether they succeed or not)
  - Accepting—recognize that the disease cannot be denied or stopped and that fighting against it is a waste of energy
  - Humorous—trying to see that there might be things to laugh about in day-to-day life
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The final exercise in this series involves getting the group to deal with the “salary” issue—the rewards and satisfactions of the work. It is worth emphasizing that caregivers deserve and need to define the rewards and satisfactions of caregiving. It is okay and good to define a selfish purpose in doing what they are doing—selfish in the sense that it gives back something to them. An example of a selfish motive might be that doing the work makes me feel like a good spouse or child.

#### *Rewards of Caregiving*

Have them do a quick (2-3 minutes) brainstorm about the rewards they do, might, or wish they could get from caregiving. Keep track of the responses and feed them back to the group. Have them fill out the appropriate section of the Caregiver Role Requirement Worksheet (salary) and point out that this corresponds with a section of the Caregiver’s Notebook and that it will be part of their assignment this week to work on that section.

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

#### Talk: The Toll of Caregiving

At the end of the exercise, use the two slides about caregivers (see below) to draw participants’ attention to the toll that caregiving can take. They should be clear that the program is built, in part, on a recognition that the role is a demanding and, potentially, damaging one. Being a Savvy Caregiver is one way to reduce the toll and increase rewards.

Point out that the demands of dementia caregiving (what they are dealing with) do relate to the toll of caregiving. In particular, research does link dealing with difficult behaviors to caregiver burden and stress.



BRIEF TALK



TRANSITION

\*Time management is important in the program. You may find that going through all four of the exercises takes too long and doesn’t allow you enough time to get to the material in the second half of the session. If you feel time slipping away, cut the exercises short. Try to get through the roles and purposes exercises and then give participants the handout and the instructions and review material on knowledge and skills and on reward and ask them to complete the exercise as part of their homework.

### Facts about Family Caregivers

- Provide 80% of community care
- 70%+ of caregivers are women
- Provide 4-6 hours of care per day
- Provide care for 4-5 years
- 20% provide care for more than 4 years
- 30% are employed
- A growing percentage also care for children
- Typically only one family caregiver

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

- The caregiving task is typically a 24-hour a day job (even if the caregiver doesn't live with the person, s/he is involved in visits, phone care, and coordination—and is worried and concerned). The 4–6 hours of care figure relates to the amount of time spent in *specific and identifiable* caregiving tasks—like getting the person dressed or doing extra laundry. It doesn't include all the time of just being with the person.
- The length of time people spend as caregivers varies enormously. The 4-5 year figure is a kind of working average. Some spend much less before their loved one's condition requires more care than they can provide. Some spend much more. 20-year caregivers are not unheard of.
- For many, this is not their only “job”—many work, raise kids, or both
- Even if there are many in a family, it is usually the case that just one person gets to be “It.” This structure—one in the center with one or more satellites—may contribute to one of the greatest sources of caregiver burden, social isolation.
- The obvious point is that this represents a tremendous commitment and it almost always includes a sense of being motivated by love and fidelity.
- For most caregivers, taking on the role involves not only providing physical care but having to acquire large sets of new skills and knowledge—taxing in itself.

### Compared to Other Caregivers Dementia Caregivers Are:

- **Twice as likely to have physical or psychological problems**
- **More than twice as likely to use Medications for mood or nerves**
- **At much higher risk of social isolation and economic distress**
- **Only half as likely to use health care**

There are volumes of research findings to back up this slide, and all the studies basically agree on the impacts of caregiving on the caregiver. Make the general point that caregivers usually spend themselves until there is little left. For most, if not all, this will be new information. The take away messages include the following:

- If you thought you were feeling under pressure, you likely were—it goes with the job.
- You're not alone, unique, or "a failure" if you're feeling burdened, swamped, etc. This is what caregivers regularly report.
- If you're feeling these things, it's important to recognize and acknowledge them. Burnout is an occupational hazard. Since you want to be doing this job, you'll want to avoid burnout.
- Family conflict is not unusual.
- Many caregivers stop doing things they enjoy, stop attending to their own well-being and sense of personal fulfillment.
- Caregivers, particularly spouse caregivers, have their own health problems. Many indicate that they let their own health needs slip in order to provide care.

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



TRANSITION

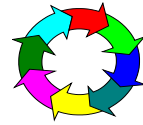
## The Impact of Alzheimer's Disease and Other Dementing Diseases

The initial exercises and the talk on the toll of caregiving are meant to set the stage for the rest of the program—to give participants a sense of the scope of the task facing the Savvy Caregiver. The brief talk that follows is meant to accomplish two ends. The first is to firmly establish that caregivers are dealing with a disease-based problem. The second end is to personalize the issue for the caregiver—to have him/her see that caregiving is not only difficult and demanding work, it can also be dangerous to health. The second end will be accomplished as part of the caregivers' homework assignment. As a part of the talk, you will provide the caregivers with the Cognitive Losses Worksheets they will use in the homework—ask them to interact with you and to jot down notes as the talk proceeds. This may serve to help them with the homework.



INFORMATION

The brief talk begins by drawing attention to the fact that this program is about disease management and the management of very specific problems (like behaviors). This sets the stage for the rest of the talk on the impact of the disease on cognition.



EXERCISE

Ask the participants to read through the list contained on the slide (below) and to think about their experience of caregiving. Ask them, mentally, to number the top three things they are dealing with as caregivers. Spend just 2-3 minutes having them tell the group what they rated their top three.

## What Are You Dealing With?

### Check Those You Think Apply and Identify the Top 2-3 Problems

- Personality Disorder
- Continuation of Personality Traits
- Depression
- Effects of Disease
- Call for Attention
- Selfish Behavior
- Normal Aging
- Substance Problem
- Behavior Problem
- Other (specify)

The point here is that people should understand that they are dealing with a disease. That should be number 1 in everyone's mind.\*

Don't dwell much on this. If everyone has disease checked number one, the lead-in to the rest of the talk can be something like—"Great, we all agree; now let's just have a brief review about the disease and its process. If there's disagreement, the lead-in is something like—"we want to be sure everyone understands that s/he's looking at a disease and we'll talk briefly about that now."

The talk you will give next is important because it sets the tone for what follows in the program. The punch line of this talk is that the caregiver is dealing with a disease, not normal aging or a personality problem. Diseases are real and have to be faced. Diseases and ways of treating and managing them can be described. The first step to being a Savvy Caregiver is to understand just what it is they are dealing with—in this case a progressive (likely), irreversible, and still incurable disease.

The idea is that the more you can get the caregivers to think about dementia in terms of disease, the more they will be able to tap into a behavior pattern they all have of how to deal with illnesses. They all know how to look for signs and symptoms and how to watch to see if various methods of "treating" an illness are working. Similarly, they all know about thinking up ways to interact with family members.

\*If family groups are present, the exercise may call into focus disagreements they may have among themselves about just what is going on with the person and what the caregiving is about.



INFORMATION



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

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

### Talk: Dementing Illnesses

This is intended to be a very brief talk—perhaps 10 minutes at most. This is really an introduction to material that participants have in their manual and it should serve to refresh their memory if they've been to an Alzheimer's Association introductory session. The main focus of the talk is on progressive dementing diseases, like Alzheimer's; make the point that there are some (relatively few) dementias that are not progressive in nature (you'll point some out later in the talk). Point out the sections in their text as you deal with each one. This will make it very concrete to group members that they have this material—and then you can point out that part of their assignment in the next week will be to read through the material carefully. The Caregiver's Manual points them to online sites where they can learn more about the disease and where they can track to other sites where even more information is available. Encourage participants to be active learners about the disease.



BRIEF TALK

### **Understanding Progressive Dementing Disorders like Alzheimer's Disease**

- **Dementia is not part of normal aging**
- **Appreciate the scope and impact of these diseases and their prevalence in the elderly**
- **Separate myths from facts**

The slide above presents the objectives of this brief talk on dementia as a disease-produced condition. Emphasize that dementia is not a normal part of aging. Emphasize, too, that this is a widespread problem and that many people are dealing with it—that the caregivers should not feel alone in their work.

## What is Dementia?

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

There are some key teaching points relating to Slide 10:

- First, dementia itself is not a disease. It is a condition (sometimes called a syndrome) that can be caused by many diseases. A condition describes the effects or signs and symptoms of a disease. Dementia is disease-related—not just a memory problem—and not a personality disorder or a developed character flaw. Clinicians are not always precise in using their terms, so some caregivers report being relieved to have learned that their loved one has dementia but not Alzheimer's. This can be confusing and produce false hope.
- Second, dementia is global in nature—it affects a person's entire range of thinking abilities. Often, dementing diseases are thought of as diseases of memory. Memory is always involved but it is very important to realize that other areas of thought or cognition are also involved.
- Third, dementia *interferes with social functioning*—a person's ability to act thoughtfully and purposefully in the world. As the disease progresses, they become more cut off. The impact on social functioning has enormous implications for caregivers. This really means that the person gradually loses all the abilities he/she once had that allowed him/her to do things in the world—not just hold a job, but hold a conversation; not just perform complex tasks but do even the simplest of self-care activities.
- Fourth, dementia occurs in a condition of clear consciousness. That is, the person is not unconscious. Nor is his/her consciousness clouded. The person is not delirious (delirium is different from dementia—it

is a transient condition that can produce very abnormal thinking). A person with dementia can become delirious. There is no known association between delirium and dementia—that is, a person who once experienced delirium (e.g., following a surgery) will not go on to become demented.

- Fifth, *almost all* dementing disorders are progressive. As you will note in the talk, the most common form of dementing disease is Alzheimer's, either alone or in combination with vascular dementia. Alzheimer's and most other dementing diseases are progressive. A very small number of conditions are not progressive. When you went through the introductions, early in this session, you will have learned what most of the care recipients in the group have been diagnosed with. From this you will know whether there are any caregivers dealing with a more or less static dementia. In progressive disorders, the person's condition deteriorates over time and the effects of the disease become worse.
- Although it is not mentioned in the slide, it is important to note—and this is spelled out in the caregivers' text—that most dementias are irreversible. On the other hand, a few are; and that underscores the need for a diagnosis and for a relationship with a physician they can trust.

## Required for Dementia Diagnosis

- **Serious Memory Problems**
  - At Least One of the Following --
  - ✓ **Difficulties with social functioning**
  - ✓ **Changes in Personality**
  - ✓ **Impairment of abstract thinking**
  - ✓ **Disturbances of other thinking processes**
  - ✓ **Impaired judgement**

These are the standard criteria for the diagnosis of Alzheimer's disease, but they apply to most progressive dementias. You can simply read them. It is important to note that memory plus *one or more* of the others is what is looked for. All of the signs will not necessarily appear in every person. You might want to provide some examples of what some of the points mean:

- Difficulties with social functioning. The person may be unable to participate in social activities s/he previously enjoyed --for example, taking part in family gatherings, remaining active in church groups or in social clubs, entertaining friends.
- Change in personality. Many people's personalities change. Usually, the change seems to be that the person is somehow less of him/herself—quieter, more indrawn. Sometimes the change is more dramatic, and the person can seem to be very different from how s/he was before the disease came on. A usually placid person is reported to be aggressive and to use language that would have shocked and offended him/her before. A friendly and outgoing person goes into a shell or actively pushes people away. And then there are reports of people who were mean spirited becoming very gentle. All that's needed for the diagnosis is a change in personality.
- Impairment of abstract thinking, impaired judgment, and disturbances in other thinking processes all relate to evidence of problems with thinking processes. Examples of this include: difficulties with complex tasks (handling finances, following elaborate plans), making important mistakes (getting lost or becoming disoriented), making poor choices (ordering lots of useless things seen on TV, overspending on a credit

card), demonstrating a breakdown of usual patterns (house not as orderly).

- The point, though, is that to arrive at the diagnosis, the doctor has to see that there is more wrong than memory problems. This is a disease that affects all thinking processes. In effect, it is a disease that affects the whole person.

## Facts About Dementia

- **Not a part of Normal Aging**
- **Produced by a Number of diseases**
  - **Alzheimer's disease is the most common cause**
  - **Vascular dementia the next most common cause**
- **Typically not reversible**

There is a normal slowing of brain function with aging—just as there is normal decline in all organ functioning. That is, the brain may not work as fast, but all its capabilities are intact. But the deterioration in dementia is much more extensive and serious and is disease-driven. Hence it is not normal. It's good to make the point that 95% of the people at age 70 are not demented.

**Alzheimer's disease** is responsible for the great majority of dementia. People generally say that about 60-70% of dementia is from Alzheimer's, but it may be that it is involved in combination with other diseases in an even greater percentage than that (up to 90%). Alzheimer's disease involves a process in which protein structures (called plaques) accumulate in various parts of the brain. These structures affect basic structures (neurons); some process also causes the neurons to atrophy (shriveled and develop internal tangles) and to become less efficient and effective. The chemical medium through which signals are passed between and among neurons is also altered. The result is that communication between neurons becomes less reliable and eventually breaks down altogether.

This communication is responsible for all of the activities we think of as thought. So, as a result, over time, Alzheimer's erodes all areas of thinking. Alzheimer's is the fourth leading cause of death among aged—death usually from complications of undetected infections or illnesses (undetected because, as the disease progresses, the person loses the ability to recognize and report on symptoms).

**Vascular dementia**—produced by multiple small strokes and sometimes called multi-infarct dementia—works differently from Alzheimer's disease

but with many of the same effects. The strokes kill off the parts of the brain where they hit. Since brain tissue doesn't regrow, these areas in the brain are no longer effective. The progress of vascular dementia is step-wise (with each stroke) rather than smooth. There is a very high occurrence of Alzheimer's and vascular dementia combined.

Only a very few dementing conditions are reversible, including Normal Pressure Hydrocephalus (a build-up of fluids in the head, putting pressure on the brain), brain infections, and certain nutritional disorders. The most common reversible dementia is depression—see slide below— which can cause a pseudodementia (a condition that mimics dementia).



## Depression

- **An extended state of sadness**
- **Usually has other symptoms: apathy, loss of appetite, sleep problems, loss of interest in things**
- **Very frequently seen in persons with dementia -- and adds to the problems**
- **Can be successfully treated**
- **Sometimes even confused with dementia**

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

It is very important that people look for this in the persons for whom they provide care. If there are sudden changes in behavior in a person with a dementing disorder, they should be looked at by their doctor—and depression should be questioned.

## Medications for Dementia

- **Some medications have shown some benefit**
  - appear to return the person to where s/he was 6-12 months before
  - don't stop or reverse the disease process
- **Research continues**
- **Beware of Questionable Treatments (Ginkgo Biloba, Chellation)**
- **Treat claims on the internet with suspicion**

This section of the trainer's manual is bound to go out of date quickly as new advances in drug research and therapy continue. In consequence, it is important to check the Alzheimer's Association ([www.alz.org](http://www.alz.org)) and the Alzheimer's Disease Education and Research (ADEAR—<http://www.alzheimers.org>) websites for the most up-to-date information on evidence-based drug therapies.

Cholinesterase inhibitors, the currently most prescribed Alzheimer's drugs, act to improve brain communication affected by Alzheimer's disease (these drugs are only for Alzheimer's)—an excess of cholinesterase in the brain seems to create “noise” that interferes with neuronal communication. These drugs reduce the noise which allows the disease-weakened signal to get through better. People who begin these drugs and are able to remain on them (i.e., are not so affected by the side effects that they discontinue them) seem to return to a level of cognitive functioning that they had been at six to twelve months previously. The drug does not stop the disease process, and gradually that process makes the signal weaker and the effect of the noise reduction is no longer strong enough to allow showing any improvement and there is a return to decline. Some positive effects on mood and behavior have been reported with these drugs.

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

Ginkgo Biloba made a big splash in early 1998 based on a small European study. The study was relatively well conducted but had problems, and a larger trial is under way. But Ginkgo has hit the health stores in a big way. The problem is—aside from the fact there is no conclusive evidence—that

the commercially available Ginkgo is a different compound from that used in the trial. This is a good example of people’s rush to cures—and a good example of how desperate people are to try anything for this disease.

The proliferation of websites that can be identified by searching on the keywords dementia or Alzheimer’s is astounding. A Google search will list the sites in decreasing order of the frequency with which they are visited, but the search provides no guidance about the accuracy of or the evidence for the information that is being presented. Great caution should be advised and consultation with a physician, pharmacist, or nurse practitioner should be an essential part of undertaking any form of therapy, even therapy that involves “natural cures” or complementary medicines. Even substances that might be harmless in themselves could interact with other medications the person is taking, so a consultation should be an essential part of any such undertaking.

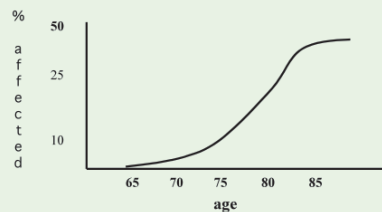
Before showing the next slide, ask learners to estimate how many people have dementia



TRANSITION

## Facts About Dementia

- 4.5 Million Americans Affected
- Equal Opportunity Disease -- Perhaps
- Age Affects Onset



The figure of 4.5 million is for moderate to severe Alzheimer's. This is the commonly accepted figure, but there are other estimates that suggest an even higher number of persons with the disease. The most important thing about the prevalence (how many people have the disease) of dementia is that it is related to age. As you look at slices of the population, the older the slice, the greater the proportion of people within it who have the disease. This means—because the number of older persons, and particularly the number of persons over age 85 will grow dramatically over the next 50 years—that the problem of dementia will continue to grow. By the middle of the century, there will be at least 14 Million Americans with these disorders.

There is no evidence to suggest that dementia strikes one gender more than the other. There is some evidence that there might be racial or ethnic group differences (one study, so far, has suggested that Hispanics develop the disease early than other groups). There are more women who have the disease than men and there are more Caucasians with the disease than persons from other racial groups, but this has to do with mortality and the proportion of Caucasians in the overall US population. Women outlive men, and whites both outnumber and outlive most other groups—and this makes them more susceptible to the disease.

The diagram points out two facts that the learners need to consider. The first is the simple fact that the oldest old (those over 85) are much more likely to show signs of the disease than those who are younger. So there is a very good chance that many of the care recipients will be very old. The

accumulation of dementia among the very old stems from two causes: first, people who develop the disease live a long time, so they live to be old; and second, as people age, there appears to be an increased risk for developing the disease, so as unaffected people age, they are more likely to become demented and to join the ranks of those who acquired the disease earlier in life.

The second fact to consider is that the prevalence of virtually every other problem—other diseases as well as losses in the ability to function and take care of oneself—also increases with age. Alzheimer’s disease or other dementias do not grant immunity from other problems. So the care recipients will very likely not only be demented but frail and/or beset with other health problems as well—so they will also have care needs not related to dementia.

## Myths and Fears

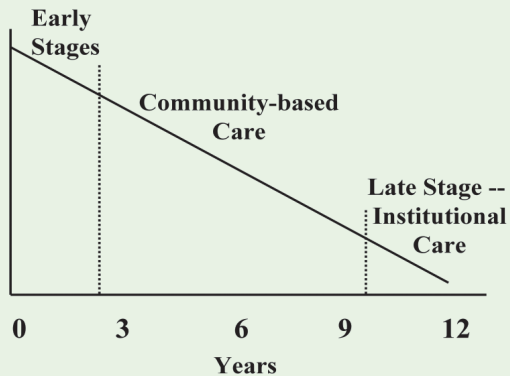
- **Contagious**
- **Hereditary**
- **Bizarre**
- **Violent**

Using the slide, make the following points:

- There's absolutely no evidence that working with persons with dementia causes a person to develop the disease. It's not catching. Mention AIDS dementia—it's the HIV that transmits, the dementia is an end-stage outcome of the disease in a relatively high percentage of cases. Kreutzfeldt-Jacob disease is contagious—through consumption (mad cow disease).
- There is an hereditary component. There is a familial form of Alzheimer's disease (where more than half the members of each generation in a family have the disease), but it is rare—it only accounts for 2-4% of all cases. However, if a person has a first degree relative who has the disease (e.g., a parent), that person's chance of contracting the disease is about three times greater than someone without a first degree relative with the disease. If a person has two first degree relatives, s/he has a 7 times greater chance than a person with no relatives with the disease.
- Most of the actual behaviors of people with dementia are very routine and not bizarre. The fear most people have concerns bizarre behaviors. While these do occur, it is the more mundane behaviors—like pacing, asking the same questions over and over, calling out or yelling, following someone around, wandering and rummaging—that caregivers will have to deal with the most.
- Many people worry that persons with dementia may become violent. It is true that striking out—physically and verbally—does occur. This is almost never spontaneous and almost always defensive. The best

way to think about this is to understand that persons with dementia are very vulnerable. The disease produces profound confusion and this makes it easy to startle someone with the disease. When a person is startled or when s/he feels under pressure, s/he may react defensively. And the defensive reaction may involve striking out. The leader might illustrate this by walking behind the other leader and suddenly, unexpectedly grabbing him/her by the shoulders. This should produce a startle reaction.

## The Course of Dementing Disease



There are a couple of important teaching points:

- The course of any individual's disease will vary. A range of 6-20 years is not unreasonable.
- Dementia is a terminal illness. It is the fourth leading cause of death among older persons. Death is usually from a complication of the disease—the inability to report a problem, like an infection (so, many persons die of pneumonia).
- For the most part, care recipients will be in the middle stages of the disease.

### Cognitive Losses in Dementia

This is a major turning point in the training. It is where we begin to involve caregivers in the development of a strategic perspective on caregiving. The talk and exercise are meant to prepare caregivers to read and understand the material on cognitive losses in their text and to begin to complete the grid on cognitive losses in the handbook. They are principally meant to focus them on the issue of strategy—how everything they do and say with and around their person should be guided by an appreciation of what the disease is doing to him/her and by a planned approach based on this appreciation.

Using the slide below, make the point that dementia affects many powers that we associate with cognition—memory, reason, language, abstraction, judgment, perception, organization, and attention. Then move on to the talk that follows.



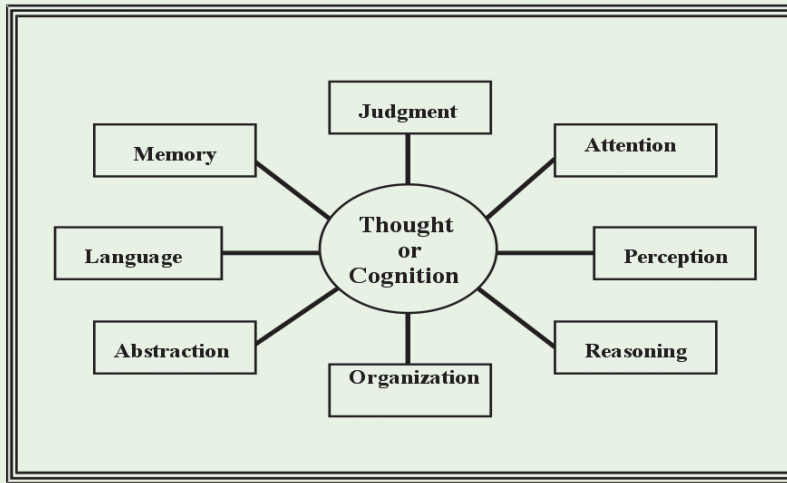
INFORMATION



TRANSITION



## Important Elements of Thought



The talk that follows is meant to draw participants' attention to the way in which our adult interactions assume normal cognitive functioning. The way people interact assumes their thinking functions are normal. It assumes normal reasoning, memory, judgment. It assumes people can deal in hypotheticals (what if) and that they normally create plans and follow their sequences (organization). Practically everything we do as adults with other adults is based on these assumptions. It structures how we treat other people, the expectations we have about them, and the language we use to talk with them. It's important for group members to see this because it leads into the first exercise that deals directly with strategic/savvy caregiving. Caregivers need to understand whether or to what extent the way in which they are typically interacting with the care receiver is based on assumptions of normal functioning. They need to form new ways of interacting based on a more accurate understanding of the person's cognitive capacities.

### Implications of Cognitive Losses for the Savvy Caregiver

This portion of the program uses the slides on the following pages to describe the various cognitive losses and to relate these to practical aspects of caregiving. This material is all in the Caregiver Manual.



BRIEF TALK

As the first part of the talk, point out the Cognitive Losses Worksheet. Encourage participants to use the worksheet to make notes as they hear and think about things during the talk. Point out to them that it will be part of their homework assignment to complete this worksheet. As time permits at the end of each portion of your talk on cognitive losses, ask participants for comments and to share ideas they might be having either about their person's loss or about ways in which they are handling it. Below you will find several suggestions for exercises you would use to accomplish this.

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

#### **Current Cognitive Strengths**

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

#### **Current Less Productive Ways**

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

#### **Current Productive Ways**

This column should be used by participants to record ways in which they see themselves dealing effectively with the particular losses. What caregivers have seen themselves do that they feel are built on a sensitive understanding of the person's current strengths and losses and really work well.

## Ideas

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

### Cognitive Losses Worksheet—Session 1

<i>Area of Thought</i>	<i>Current Strengths and Losses</i>	<i>Ways I Use that Seem to be Productive</i>	<i>Ways I Use that may be less than Fully Productive</i>	<i>Ideas to be More Productive</i>
<i>Memory</i>				
<i>Language</i>				
<i>Reasoning</i>				
<i>Judgment</i>				
<i>Perception</i>				
<i>Abstraction</i>				
<i>Attention</i>				
<i>Organization</i>				

Here begins the short talk on the problems and caregiving issues related to eight areas of cognition that are affected by dementing disorders. The sequence of the presentation of this material is the same as it will be with information about the effect of Alzheimer's and other dementing disorders on feelings/emotions, behavior, and the ability to do things in everyday life. First, the particular losses are detailed—what the disease is doing (over time) to the particular function that is being described. Next, this information is presented in terms of what the caregiver can expect to observe happening—what s/he will see the person doing. Finally, the material covers caregiving strategies—techniques the caregiver might use to compensate for the losses the person is experiencing. The section on losses of powers of thinking begins with the signature loss, that of powers of memory.



*TRANSITION*

# Memory

## Problems

- early loss of recent memories
- long-term memories and over-learned behaviors
  - remain longer
  - gradual loss of detail in long-term
- eventually, virtually all memory fades

## Caregiving Issues

- social skills forgotten
- can't depend on memory to prompt, orient, or stimulate
  - don't expect new learning
- things may feel more familiar, but every day will be new

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

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

## What Caregivers will Observe

Caregivers can expect to see memory functions getting worse over time. The person's ability to recall events and to recognize friends and family will fade. Learned behaviors are forgotten. This is important because appropriate social behaviors (manners) are learned behaviors, so caregivers can expect to see coarser behaviors from their care recipient. Over-learned behaviors—behaviors the person acquired early on and practiced a great deal—may be retained very late into the disease. Such over-learned behaviors might include well-used verbal expressions or physical actions (e.g., playing piano).

## Some Caregiving Strategies:

- Supply what's missing. Don't test or make the person try to remember—the losses are disease-produced, not a matter of choice on the part of the person; you can't jog the person's memory back into working order.
- Demented people may forget their learned manners and behave in an unmannerly fashion (e.g., at table) and they may use language they would be ashamed of—indecent language, slurs, etc. They may behave impulsively and blurt out things—boy, your hat is ugly. Be prepared, and help others around to understand that the person is affected by a disease.
- If you don't remember that the person won't remember, you can get frustrated—and that will communicate itself to the person.
- Be prepared—daily or more often—to demonstrate and remind the person how to do even familiar tasks.
- Repetition and routine are very important and help to develop a sense of the familiar—which is very comforting and security-producing. It may be that repetition will make it easier to relearn something—either because some kind of memory process is still at work or simply because the person is more comfortable and relaxed and therefore finds it easier to attend to what's in front of him/her.
- Loss of memory can work in the caregiver's favor. If a situation is going sour, the general rule is to leave it for a while and then come back. If the person was upset, it is unlikely s/he will remember being upset, and when you return, it will be to a new encounter, one without history.
- Be prepared for the emotional blow that can occur when the person doesn't remember who you are, no matter how long the relationship has been in place.

As a brief exercise get the group to brainstorm the ways we invoke memory and rely on it in our interactions. You might prime the pump by giving an example (“Remember, we’re going to take a break after the next talk.”)

The next Thinking power that is covered focuses on Language.



TRANSITION

## Language

### Problems

- word finding difficulty starts early on
- structure of language breaks down
- eventually, language not at all useable

### Caregiving Issues

- frustration with word finding difficulty -- supply missing words
- language increasingly unreliable for communication
  - shorten and simplify sentences
- visual and tactile communication become more effective
- retained verbal skills may mask actual decline in thought
  - allow pleasure in available verbal interactions

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

#### What Caregivers will Observe

It's very important to note that, in some people, verbal skills remain at a pretty good level, even deep into the disease. They retain many stock phrases and can seem to carry on a fairly ordinary social conversation—and appear to be in really pretty good shape. The content of their conversation is typically not as sophisticated as their speech. Caregivers should be aware of this for two reasons. They can get fooled into thinking the person can do more than s/he really can and they can let themselves expect the person to perform at a higher level than possible. Second, this is a retained skill—something over-learned like playing the piano. As such, the person may take some pleasure in it—and so caregivers should encourage the person to use



the skill. They should have social conversations with the person, allowing him/her to feel as much a part of the social environment as possible. They should remember, however, that the conversation may have no real meaning and shouldn't necessarily be taken too literally.

### Some Caregiving Strategies

Like memory, loss of language skills can't be reversed, so efforts to do so won't work and may prove counterproductive. Help the person; make it as easy as possible to get past moments when word-finding difficulties occur. Note that some people try word games and crossword puzzles as a way to restart the mind. This can be frustrating for the person *and* the caregiver. Some caregivers report their persons enjoy hidden word puzzles—those are really visual games rather than word finding games. If the person enjoys doing these—can become comfortably occupied in them—that's great. Just do not expect a rehab effect—the lost powers will not be restored by use.

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

Next move onto Reasoning as a Thinking power to be examined.



TRANSITION

## Reason

### Problems

- breakdown of connection between thoughts, objects, events, and actions
- behavior becomes more random and self-centered

### Caregiving Issues

- can't reason with the person
- can't bargain or negotiate
- person will, increasingly, not think in cause and effect terms

If you have time, ask the learners to brainstorm about what they use reason for. Try having the learners think about the last time they had a conversation with someone in which they tried to convince that person to do something they wanted them to do. Ask them to recount the strategies they used in this conversation—what did they try. For the most part the answers should be in the general realm of reasoning and bargaining. Alternately, you could do a similar exercise asking them to recount the last conversation in which they tried to explain something to someone. How did they go about it? Almost certainly they used cause and effect thinking.

Use either exercise as a springboard for pointing out how fundamental reason is to adult interactions and that the loss of the power of reasoning may pose as much of a problem for caregivers as it does for the person with dementia. Review the losses, emphasizing the loss of connections and cause and effect. (“You have to get dressed so we can go to lunch.”)

#### What Caregivers will Observe

Perhaps more than any other power of thought, we rely on the presence of reason in other people for the basic way we behave with one another. This ties closely to issues related to behavior because we typically use reasoning as a way to persuade or convince someone to do something. Caregivers will see that, increasingly, the person with the disease will not be able to think through issues and will not be able to assess situations. They might

take a position and stick with it, and no amount of “reasoning” will change the person’s mind. Loss of reasoning powers may also contribute to self-centeredness. The person is less able to think through the consequences of his/her actions—s/he doesn’t think about the whole picture or consider how another may be affected by what s/he does.

### Some Caregiving Strategies

Early in the disease, reasoning may continue to work with the person, but as the dementia progresses, this strategy will be less effective and will actually cause more confusion for the person. Caregivers have to become more directive and provide less explanation.

The next Thinking power covered is Judgment.



*TRANSITION*

## Judgment

### Problems

- increasingly make poor choices
  - safety issues
- may lead to hesitancy or impulsivity
  - insensitivity to others

### Caregiving Issues

- assume responsibility for safety
  - but don't overprotect
- remember: "It's not Personal"

This is a big area of concern for families. They worry about safety and they worry about inappropriate behavior—because the loss of judgment affects both.

It would be useful to let the learners derive the most important consequences of the loss of judgment. You might try setting up a couple of hypothetical situations involving a person whom you could describe as “pretty far along” in dementia and asking what the person might conceivably do or say in each situation:

- having an old fashioned straight razor to use for grooming
- being in a kitchen with an electric stove where you couldn't tell if the heating element was on
- having a bottle of cologne or shaving lotion open in front of him/her
- seeing a park across a busy street
- encountering a person from a racial/ethnic group different from his/her own
- encountering a much younger person

Judgment helps us make good choices and remain safe. In its broadest sense, it is a capacity that allows us to think, abstractly, about a range of possibilities, assess them in terms of our values and the potential outcomes of the possibilities, and make choices that are to our best advantage. Broadly, judgment allows us to monitor our own behavior. For example, thinking before we speak—so as not to offend or provoke others—is an act of judgment. Considered more narrowly, judgment enables us to behave in ways that protect our well-being. Driving carefully and responding to

driving emergencies, using tools, hunting and fishing equipment, and kitchen utensils carefully, making investments and purchases prudently—these are all examples of ways judgment comes into play in everyday life.

### What Caregivers may Observe

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

### Some Caregiving Strategies

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

Certain activities—driving, using power tools, using sharp utensils—leave little margin of error. These activities require that the person be able to see the consequences of his/her actions and be able to respond appropriately when an unexpected event occurs. A person who makes the wrong turn while driving has to be able to recognize the error and fix it.

Getting a person with a dementing disease to cease a potentially unsafe behavior, like driving, is not easy. It helps if there is clear evidence of impaired capacity, evidence that might be provided by a physician or by a trained driving assessor. It also helps if the family can be agreed that continued driving poses a problem. Sometimes a person can be convinced that s/he should no longer drive. Sometimes, recourse to authority—like the department of motor vehicles—can force an end to driving. Some families hide or disable the person's car.

## Perception

### Problems

- misperception -- can't interpret sensory input
  - potential for overload
  - suspiciousness and paranoia

### Caregiving Issues

- knowing how much is enough and too much
- distress related to delusions or hallucinations
  - monitor environment, including media

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

#### What Caregivers might Observe

Problems of perception, particularly reception, can cause distress in many forms. Misinterpretation is a big issue. People may see their own reflection in a mirror or a window and mistake it for a stranger. This can lead to fear or suspiciousness. They may report seeing strangers in their room—consider that they may no longer recognize their own image in a mirror and are mistaking it for someone unknown to them who is in their room. Images on television may be misinterpreted as being real; news reports may be seen as events happening here and now to them. The misinterpretation of events can produce paranoia or accusatory behaviors. For instance, the person may say that the caregiver is stealing things (things the person can't find because they aren't immediately apparent to them—or because they are misplaced) or is being unfaithful.

#### Some Caregiving Strategies

Problems of perception may relate to a basic issue of overload—too many stimuli or stimuli that are, in themselves, confusing—wall or window treatments or carpets that have complex designs, a noisy room filled with people, abstract (non-representational) art. Outings, even to places the person once enjoyed, can be problematic if these places are crowded or noisy.

As the disease progresses, distractions become more and more of a problem. This is one of the reasons not to drive.

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

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

In Session 2, you will introduce participants to the strategy of validation, operating from the emotional truth of the person with the disease. Particularly when suspiciousness and paranoia occur—many times produced by problems of abstraction—seeking to allay the person's suspicious by cooperating with the misperception (let me help you find the lost wallet) rather than arguing and trying to convince the person of something is a preferred strategy.

## **Abstraction**

### **Problems**

- loss of conventional concepts (time, distance, relationships)
- person increasingly concrete in thought
- inability to think in hypotheticals -- “what ifs”

### **Caregiving Issues**

- providing directions -- need to be more and more concrete
- can't depend on abstraction to affect behavior (no “If” . . . “then” thinking)

Point out how much we rely on abstractions for everyday life. Abstraction is the power of thought that allows us to consider the world in non-material, non-concrete terms. Abstraction is the key to the world of ideas and concepts like numbers, time, directions and especially the use of hypothetical situations. Note how dependent we are—in our own thinking and in interactions—on the ability to deal in “what if” and “if . . . then” thinking. The ability to see time as a continuum, with a past and a future as well as a present, is a function of abstraction.

#### What Caregivers will Observe

As Alzheimer’s and similar progressive dementias continue their course, the person lives more and more in the moment—that is the person’s experience of the world. Thinking about things that happened in the past or that will happen in the future becomes harder and harder, and the person is more likely to be confused by references to past or present. Following special directions and thinking about things numerically will also be increasingly difficult.

If you have time, have the caregivers imagine, as a brainstorm, trying to communicate with a person with dementia that they want her to take a bath so she’ll be ready in time for her ride to the doctors office later that morning. First imagine a person with normal thought—what would they say. Observe how much of it depends on abstraction—a sense of time and sequence. Then have them imagine what they’d do if they knew that time and sequence didn’t mean anything to the person.



### Some Caregiving Strategies

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

## Attention

### Problems

- harder to stay on task
- easier to become distracted

### Caregiving Issues

- choice of suitable task
- attention to environment: remove distractions
- increasing need for monitoring and refocusing

Attention allows us to remain focused and to deal with the many distractions that occur in the environment. Attention is the filter we use to make choices among all the competing stimuli in our lives. Some of these are mental stimuli—the agenda for the day or problems we’re working through. Other stimuli are more concrete and immediate: the things and people surrounding us in the environment. Attention allows us to select from among all of these and to focus on whatever it is we decide we need to focus on. It allows us to hold back the attractions of other stimuli or to return to the task at hand when other stimuli do distract us. Attention is weakened as the disease progresses. The person becomes more easily distractible. The person increasingly loses the ability to “stay on track” by choosing among the competing demands of the stimuli in the environment. Practically speaking, every person and object calls out to the person with equal voices, and the person’s attention will move from stimulus to stimulus with little control or discrimination. As the disease progresses, the person requires more structuring, refocusing, and prompting to stay on track with even the simplest tasks.

#### What Caregivers will Observe

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

#### Some Caregiving Strategies

These losses affect a caregiver’s choice of tasks and activities and their choice of the environment for tasks. As the disease progresses, tasks have to be simpler and there should be fewer distractions in the environment. This loss also affects how much attention caregivers have to pay to keeping their

person focused on a task. Caregiver frustration can come from expecting too much and not being prepared for how much time and energy it will take to keep the person involved.

Attention problems bear on the issue of driving. Normal driving requires attention, even though certain parts of it are very routine. Particularly in rapidly developing situations—like emergencies—the ability to remain both calm and concentrated are essential for safety. Dementia attacks this ability to concentrate early on—so driving should be restricted very early in the disease and withdrawn as soon as possible.

## Organization

### Problems

- less and less able to establish and remember that things are happening for a purpose
  - less able to order actions
  - less able to use plan to monitor actions
- size and complexity of tasks become problems

### Caregiving Issues

- right-sizing the task
- providing just the right amount of order -- substitution
- providing appropriate direction (support and prompting)

If there is time, have the participants reflect briefly about how they got to this room today. Consciously or not, they had a plan—an organized set of activities with a clearly defined endpoint that got them through everything they needed to do to get here. Likely they used that plan as a checklist to monitor their progress toward getting here. And they almost certainly have a plan like that for getting home and doing whatever it is they'll do tonight. That's organization.

People, typically, assume organization in their normal interactions. We know things are often tied together in some kind of relationship: step a has to go before step b and the result of these two goes together with the results of steps c, d, and e to enable step f which leads to a desired outcome. The progressive dementing diseases gradually erode a person's abilities to see and act on these relationships. As the disease progresses, the person may get stuck or lost in them or confused by them. The caregiver has to have a good sense of just what the person "gets" about the organization of complex tasks in order to involve the person as much as possible in them. Even concrete tasks like doing laundry or dishes or making a sandwich involves multiple inter-related steps.

#### What Caregivers will Observe

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

## Some Caregiving Strategies

Caregivers replace this power in a number of ways:

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

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

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

### **Consider the Following Sentences**

- **"We're going to your brother's for dinner on Thursday."**  
**[Abstraction]**
- **"If we can have hamburger tonight, I won't have to go to the store till the weekend."**  
**[Reason, Abstraction and Language]**
- **"I'll leave your lunch in the tupperware in the frig; eat at noon."**  
**[Memory and Organization]**
- **"Take the medicine 3 times a day for the next 10 days."**  
**[Memory, Organization, Judgement, Attention]**

Next, have the group reconsider each sentence in light of the material you've provided in the talk on powers of thought. Ask them to suggest how they might modify or change the original sentences in ways that reflect better caregiving strategies. The slide below offers some ideas about appropriate modifications.

## Make the Savvy Caregiver Shift

- Wait till Thursday pm; then inform about dinner at the brother's house.  
[Concrete]
- “We’re having hamburger tonight.”  
[Directive—not Reasoned]
- Leave written note about lunch (plus reminder call).  
[Reminders by YOU]
- Set up the meds and remind—or administer them.  
[No expectation—Take Control]



TRANSITION



MEDIA

### Introduction to Resource Materials

The most important resource program participants will have is the Caregiver Manual. Be sure everyone has one. You’ll also distribute the program slides—likely this was done early on in the session—and you should encourage participants to bring them to the sessions and use them as a notebook for the program. In the course of the sessions, you will use the various handouts that are provided.

The other resource that is recommended is the Alzheimer’s Caregiving Strategies interactive program available in CD-ROM or on the Internet (as noted, this is available from Healthcare Interactive at [www.hcinteractive.com](http://www.hcinteractive.com)). The program includes a great deal of material that is covered in the Savvy Caregiver program, but it also augments the Savvy material in a number of useful ways. There are a number of video clips of persons at varying stages of dementia who are being led through a towel-folding task (the persons in these videos are different from those in the videotape that accompanies Savvy, so the videos reinforce those in the program). Section 5 of the Alzheimer’s Caregiving Strategies provides advice to caregivers about how to structure a number of common daily tasks and provide support for persons to be involved in them at varying stages of the disease. The final section of the program includes video clips from caregivers and professionals about handling various problems and situations that arise in caregiving.

It might be useful, if time permits and if you have a laptop computer, to show a portion of the interactive program so that participants would know what to expect—and, perhaps, also to give them some confidence that they could open the program if they got it. You might, for example, go to the last section of the CD-ROM (advice) and play one of the embedded videos so that participants would know what to expect.

Another resource that participants can access on-line is a series of 21 Caregiver Education pamphlets produced by the Geriatric Research, Education, and Clinical Center (GRECC) at the Minneapolis Veterans Affairs Medical Center. These pamphlets, available at <http://james.psych.umn.edu/~grecc/caring.htm>, contain information and advice to help caregivers with a number of day-to-day caregiving situations (e.g., managing behaviors). Links to the Alzheimer’s Association and other information sources are provided in the Caregiver Manual.

Finish the session by reviewing the objectives set out for the first session (slide 3) and pointing out that they had been met.

### **The Savvy Caregiver Workshop: Session 1 Objectives**

- **Introduce Selves and Purposes of Program**
- **Gain Appreciation for the Caregiving Role--an “Unexpected Career”**
- **Appreciate Dementia and its Impact on the Person**
- **Introduce Workshop Resources – Text, Slides and Handouts**



TRANSITION

End the Group by reviewing the assignments for the following week. Emphasize that these home assignments are enriching and valuable, and encourage participants to try 1-2, if not all, of the assignments.

- Read Assigned materials—the Introduction and the first two chapters (i.e., to page 41 in the manual—these are materials from manual that reinforce and expand on the material covered in session 1).
- Complete or revise handout materials relating to the definition of the caregiver role, sections on the caregiver job description, the goals of caregiving, and the rewards of caregiving.
- Using the Cognitive Losses Worksheet from the workshop, work on the strategies sheet (p. 3) developing what they consider to be more effective strategies for interaction in the various areas of cognition). Ask participants both to observe or think about how they usually interact with the person and then ask them to think about and try out other ways of interacting, ways that better take into account the impact of Alzheimer’s on the person’s thinking powers.
- If they get the interactive Alzheimer’s Caregiver Strategies program, have them play at least the sections on introduction to dementia and introduction to caregiving, but do as much as they want.



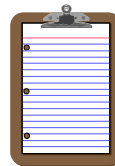
HOMEWORK





**Savvy Caregiver Program**  
**American Indian / Alaska Native Trainer Essentials**

**SESSION 2: SELF-CARE AND  
 CAREGIVING STRATEGIES**

<b>Review Home Assignments</b> <ul style="list-style-type: none"> <li>• Readings in Caregiver Manual</li> <li>• Review of activities to try out caregiving strategies</li> <li>• Work with CD-ROM</li> </ul>	30 minutes	 SESSION AGENDA
<b>Caregiver Self-Care</b> <ul style="list-style-type: none"> <li>• Identifying and Working with Feelings</li> <li>• Developing a Free-Time Repertoire</li> </ul>	40 minutes	
<b>Care Management Concepts</b> <ul style="list-style-type: none"> <li>• Confusion               <ul style="list-style-type: none"> <li>— A Simple Model of Behavior</li> <li>— Understanding and Interpreting Behavior</li> <li>— Communicating with Confusion: Dealing in Emotional Truth</li> </ul> </li> </ul>	40 minutes	
<b>Control</b> <ul style="list-style-type: none"> <li>• Taking Control</li> </ul>	10 minutes	

Acknowledge that “self-care” may seem “self-ish” when elders are so highly valued.

Elders are considered special people in many tribes. Elders have the cultural knowledge of the tribe that no others possess. Elders have lived their lives during times in which AI/AN people suffered many hardships beyond what most experience today.

Caregivers that are the children or grandchildren (or even great grandchildren!) of elders may feel that taking time for themselves is wrong. Time for one’s self would be cheating the elder of time caring for them. However, caregivers must be able to endure. Enduring, staying strong, and



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keeping-up the work requires that caregivers give themselves permission to rest and relax.

**Accepting that the disease is real and permanent may be made easier by the AI/AN general cultural value on acceptance of life events, even if those events are sometimes painful.**

AI/AN people may have a way of looking at life in which both good and bad things are accepted as part of the natural way of life. Nobody likes disease or loss of loved ones. However, constantly fighting against the reality of dementia can be exhausting.

For some individuals or families, looking at dementia as one of the possibilities of old age may help reduce the feeling of being unfairly or wrongly “hit” with dementia. Those who feel that they have been “singled-out by fate” may be distracted by focusing on their fate and be less effective caregivers.

**Anger and depression may be hard to admit because of the high value placed on elders.**

Elders are often held in very high esteem. If an elder develops dementia, they will experience problems that require family caregiver help and assistance. The disruption that dementia can cause may produce upset, anger, and sadness due to the loss of the elder as they used to be.

Caregivers can understand that anger and depression are very normal. Of course, extreme or abusive anger is unacceptable and significant depression should be treated. In general, however, such feelings are part of the reality of the caregiver experience. The Savvy program is designed to reduce negative feelings and replace them with a sense of confidence and accomplishment.

**Adapting to confusion may be more difficult due to a strong desire for keeping a calm and harmonious household and family.**

AI/AN culture often places a strong value on keeping daily life in an orderly, congenial, and coherent way. That is, to keep a harmonious balance in all things.

Dementia can upset harmony. The sometimes unexpected behaviors and statements of the elder can be surprising and upsetting to family members. Such things are almost always due to the brain damage being caused by the dementia.

Caregivers can be reminded that the patient is not intending to cause problems or upset the balance of the household. Loving responses can be given to the elder and others who may be upset by the symptoms. Such responses may focus on re-stating that the elder’s behaviors are symptoms of the condition.



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## Session 2

### Review Homework

This is an important moment in the workshop. The amount of time and attention you and the group spend reviewing participants' activities at home related to the workshop—their completing the assignments and trying out things at home—will reinforce the point you made in the first session that the workshop depends on their participating in their own learning.

Plan to spend the first 30 minutes on homework and questions, including those about the readings and the CD-ROM. Concentrate on getting participants to share their efforts—successful or otherwise.\* Later in the workshop, you will want the participants to understand that they have a great deal of caregiving expertise. They will see this through their own participation. In the later sessions, you will want them to act as coaches with one another on the efforts they are making to put the principles of the workshop into action in their own caregiving. Getting them used to chiming in and reporting back will help develop this kind of coaching culture.

The effort will be to get the participants to be as forthcoming and interactive as possible on each of the three topics covered in the homework assignments (see assignments from session 1). Figure on spending at least ten minutes on each of the topics. Because a lot of the material they covered is sensitive—that is, it puts them in touch with their situation—this could feel like a time when the workshop could turn into a support group. You may have to redirect participants, from time to time, and remind them that this is a class and not a support group.

Listed below are sample lead-in questions for review of each of the three homework assignments. Going one at a time, ask participants the questions marked by the diamond shapes. In several cases there are, below the lead questions, follow up questions or prompts you might use to prime the pump of discussion.

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



INFORMATION

**Did you get a chance to read the material on dementia?  
(or do you have any questions left over from last week?)**

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

Did you notice that anything in the readings applied to your work as a caregiver? (the point here is to encourage the caregivers to respond to the readings—and to begin to engage in discourse that shows them to be more astute and analytical than they perhaps give themselves credit for being. Thus, the manner in which you process their responses is important. Be sure to point out—when caregivers make contributions that represent a digesting of the written material and either an application or an extension of it to their caregiving—that the caregiver has approached the question with a kind of clinical or analytic eye that has helped him/her to see the situation more clearly.

**Did you get a chance to work with the CD-ROM?**

Did you have any problems getting it to work (troubleshoot if there are any problems)?

Do you have any questions, based on viewing it? (It is possible that some will go all the way through the CD-ROM and will have questions about areas other than those assigned this week. If possible, provide a short answer and point out that this is material that will be covered later in the workshop).

Did you make use of any of it? If any have, ask them to report back—was it easy to use the CD-ROM? How did it go when you tried to put the information to work (here again, encourage behavior that is exploratory or tactical)?

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

In particular, did you use the Cognitive Losses Worksheet to think about more effective strategies for interaction in at least one—but preferably more—area of cognition?

Debrief on this experience—did they understand the sections? Ask them to share portions; this will allow you to give encouragement and feedback and as a stimulus to the rest of the group.

Particularly ask if they have seen themselves changing anything they are doing in their caregiving, based on last week's session, their reading/viewing, or the work they did on the losses worksheet.\*

Once past the review portion of the session, you can use the slide below as an advance organizer for this session. This slide will alert participants to what materials will be covered in the session.

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



TRANSITION

## **Session 2** **Objectives**

- **Develop Strategies for Self-Care**
- **Develop Caregiving Strategies Based on Appreciation of Disease Impact**

### **Caregiver Self-Care**

This next session introduces a major theme of the workshop—caregiver self-care. You might want to note to caregivers that this section is given prominent placement—it comes before discussion of dementia behavior management—to reinforce how important caregivers are in this situation. They are the key reason the person is able to remain in the community, and they are the ones at risk for distress and burnout. Taking care of themselves is appropriate and important. The exercise that follows is meant to provide caregivers with a practical tool they can use to classify and categorize the feelings they have that are associated with caregiving. Moreover, the content is meant to help them do something about feelings that are painful or hurtful. You should alert the caregivers to the beginning of this theme and tell them that, from now on, they will be getting assignments about self-care and will be asked to talk about it in the workshop. You can tease them that—whether they like it or not—they are going to have to do something that most caregivers don't do—pay attention to and do something about their own needs. Another point to make is that this focus reinforces the concept that they have undertaken a “clinical” role in caregiving and that this is a kind of clinical training. And part of the education and training of clinicians is the development of the skill of self care. Clinicians have to understand the impact of their work on themselves and they have to develop strategies for taking care of themselves to prevent burnout and to take care of themselves when their work is getting to them in adverse ways.



INFORMATION

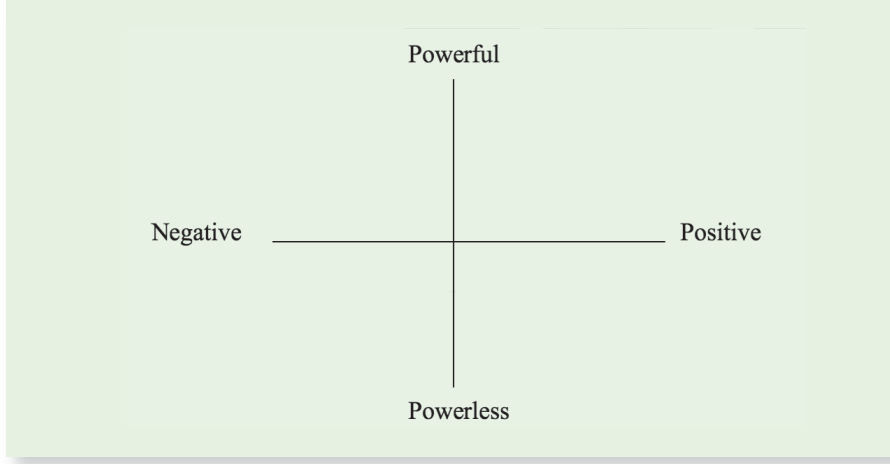
### Exercise: Emotions Associated with Caregiving

The idea of this exercise is to identify and classify the feelings participants have that are associated with caregiving. Let participants know how this section is structured: first there is the first part of the exercise; then comes a brief talk in the middle; and then there is another exercise. Taken together, this segment is meant to help caregivers see the kinds of feelings they have in their caregiving and to help them deal with these feelings so that they are not so hurtful.



First ask participants to spend the next few minutes reflecting on their experience as caregivers and to list the feelings that have been and are a part of that experience. Tell them that first you will make the list, then you will introduce them to a way of sorting these feelings into categories, then you will assign each feeling on the list to one of the categories. In order to get the caregivers to brainstorm about their feelings, you can use a number of trigger questions—for example:

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



### The Feeling Quadrants

Now you will give a brief talk about the four quadrants of feelings. This provides a simple tool for caregivers to use to categorize the feelings they are having regarding caregiving. It also serves to help them organize a way to change how they are feeling. In particular, it offers a way to move to more positive or pleasant feeling states. The talk is built on the figure below. The figure was broadly adapted from the work of a researcher in Psychology 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 and then analyzed the feelings. What he discovered was that he could categorize the feelings using two simple dimensions. For purposes of the Savvy Caregiver program, we have identified one dimension by whether the feeling was a good feeling or a bad feeling (positive or negative). We have labeled the second dimension in terms of how in control the person felt with the feeling. Did s/he feel this was a feeling that stemmed from being in charge of things or was it one that reflected being controlled by something larger than him/herself. What Dr. Telligan did—and the breakthrough part of his discovery—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.

Using the two dimensions we employ in the Savvy Caregiver program, 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



BRIEF TALK



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

	NEGATIVE	POSITIVE
POWERFUL	<i>Anger</i> : a negative feeling, but a feeling in which the person feels a kind of power	<i>Satisfaction</i> : a good, pleasant feeling, one that seems to come from something the person did on his/her own—hence, a powerful or active feeling
POWERLESS	<i>Depression</i> : a negative (feels bad) feeling, one in which the person feels overwhelmed by life and feels s/he has no control	<i>Serenity</i> : a positive feeling, but one of not being in control—in some ways one of being controlled by forces larger than oneself

Up to this point, the object of the talk is to get the caregivers to understand and accept this simple way of categorizing feelings.

The next step is to have them look at the list of feelings about caregiving that they generated and to assign those feelings to the quadrants.



EXERCISE

It's helpful if you have a flip chart when you do this, but caregivers will have a hard copy of the grid. They can write on that and show it to the group. You can keep track of how many fall into each quadrant on a master copy.

Typically, caregivers will indicate that among their feelings are those of: 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.

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

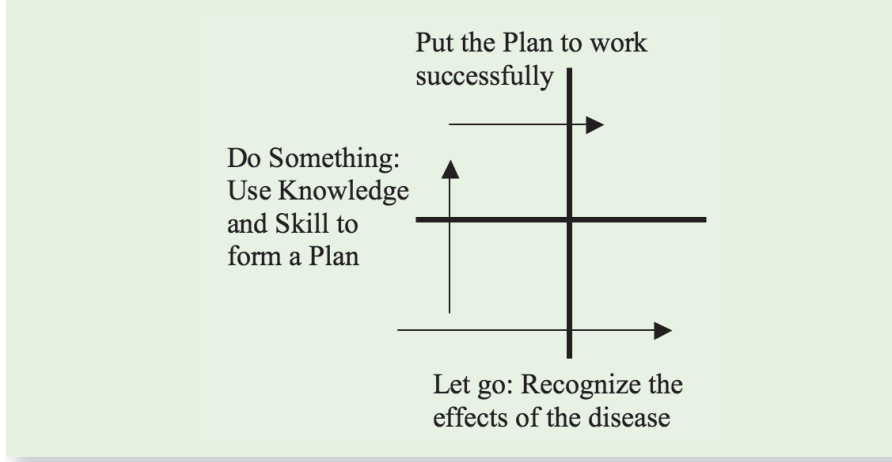
This is a way of getting them to see that this is pretty easy and that they can do it. Thus sadness, devastation, loss, grief, frustration, and exhaustion are all lower left quadrant (negative, powerless) feelings. Rage is upper left (negative but powerful). Satisfaction—being pleased—is upper right (positive powerful) and acceptance is lower right (positive but not in their control).\*

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

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

- It should serve to validate for individual group members that the feelings they are having are common and expected among caregivers. Emphasize that they need not feel guilty for having these perfectly normal feelings.
- You can use it to remind caregivers about the content in the first session and in their readings regarding the toll that caregiving can take. Consistently experiencing predominantly negative powerless feelings is punishing.
- They need ways to get out of the negative powerless state and to move to more positive feeling states.

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



### Strategies for Changing Quadrants

In the last part of this exercise, the leader gives a brief talk about changing emotional states. Briefly, what we want caregivers to see—when thinking of the quadrants—is that the way to move among the quadrants is up, down, and sideways, but not diagonally—at least not in one move. Once they become familiar with this way of categorizing their feelings, caregivers will begin to make the determination that they’d much rather be in another quadrant. For example, the caregiver who comes to see that s/he is situated in the lower left quadrant by reason of her/his sense of being overwhelmed may want, instead, to feel a sense of satisfaction or reward. The point of this brief talk is that they cannot simply jump diagonally in a single move. Instead, they may have to make a series of moves to get to where they want to be.

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

#### 1. The first step the caregiver has to take is to let go.

Another way to think of this is acceptance. The caregiver has to get enough outside the feeling to accept that it is produced by a condition—the dementia—over which s/he truly has no control. The basic action is to recognize that the disease is progressing and irreversible—and that it is futile and counterproductive to act in denial of these things. This action is built on



BRIEF TALK

recognizing the effects of the disease and 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 workshop and in the CD-ROM will help the caregiver to better understand the disease and its effects on the person. Particularly as the workshop focuses on behavior and the way the disease affects that, the caregiver should come to appreciate how little control the person with the disease has and how powerfully that person is affected by the disease. This material is meant to create in the caregiver a way of seeing challenges of caregiving in terms of a disease process that cannot be denied. What this first action means is that the caregiver focuses his/her mind more clearly on the situation and uses that focus to enable him/her to assess his/her response to the situation—and to recognize how fruitless it can be to fight against the progress of the disease (or to expect the person with the disease to be able to combat it).<sup>\*</sup> This action is essentially one of giving up wasting energy. It is meant to assist the caregiver to undertake the second key action.

## **2. The second step is, in fact, to take action—not just any action, but action based on the caregiver’s knowledge, skills, and experience.**

Much of the point of the Savvy Caregiver Workshop is to equip the caregiver in specific ways to take this action. This action involves two steps:

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

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

- The second step involves putting the plan into effect—actually doing something that could have an impact on the situation. If this step isn’t taken, the energy will be dissipated and the feelings will slip back into the lower left, possibly even more profoundly so. If it is taken, there are at least three possible outcomes:
  - The strategy (plan) works perfectly, the situation gets better, and the caregiver feels good because this represents a real accomplishment.
  - The strategy doesn’t work or works imperfectly, so the situation doesn’t really change. Nevertheless, the caregiver recognizes that s/he has done something powerful just by trying the strategy—and that makes him/her feel good. Furthermore, this outcome (as well as the outcome above) reinforces one of the central points of the workshop—that caregivers have to be “experimental” and “clinical” in their approach, and this creates or reinforces a predisposition to try to develop and implement other strategies in the future. Furthermore, the effort will likely generate more information that the caregiver can use to revise the plan which can then be re-tried. Again, a principle of savvy caregiving comes into play: the caregiver needs to maintain enough distance from the situation so that s/he can analyze and learn from whatever s/he tries with the person.
  - The strategy doesn’t work and the caregiver doesn’t appreciate that even trying it was a good thing, so s/he slips back to the lower left quadrant.

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

### Self-Care: Time and Activities for Yourself

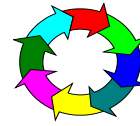
The concluding part of this section of session two is meant to focus caregivers on the development of a repertoire of activities that they can do, should they make some free time available. Many caregivers become so immersed in caregiving that they lose the sense of what it is that delights and refreshes themselves. As a result, they don’t actively seek time for themselves or, if they find themselves with time, they are unsure what to do with it. The exercise that follows serves as a lead-in to one of this week’s homework assignments—to fill in the sections of the Caregiver Notebook regarding the use of various amounts of free time.

**The purpose of this exercise is to enable caregivers to brainstorm about what they need and would like in their own lives.**



INFORMATION

Allow about 5 minutes for the caregivers to write down their answers and discuss for 10 minutes.



EXERCISE

Instruct the caregivers: Imagine you have a fairy godmother and she has granted you 5 wishes. Unlike other fairy godmothers though, she decided what those five wishes are—different amounts of free time. You can choose to do whatever you want to during your free time, with one exception--The fairy godmother also says you can't choose "doing chores or errands" as an activity. The exercise purposefully excludes chores and errands because, even though the caregivers may feel behind in their household tasks, they likely will always feel behind in their chores. Doing chores may make them feel more caught up, but not rejuvenated. The point of this exercise is to assure 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.

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

Here are some reasons people choose certain activities. You might want to read this off—or use them as prompts—while participants are thinking through their exercises.

*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

Ask each caregiver what they put for their answers. Ask them why they chose those activities.

Many caregivers feel there are many things they would like to do, but they just don't have time. Ask what some of those reasons are, and brainstorm how they might get some free time. This can be tied in with Types of Caregiving Families (in Session 4/5) to help caregivers figure out how they might carve out some time for themselves.

Because you will be switching the focus of the session from the feelings that caregivers have in their caregiving and returning to a basic informational segment on the effect of the disease on the person with dementia, it might be useful to make it clear to participants that you are switching gears.

The instructional strategy of the workshop is to present evermore practical material on ways to understand how dementia affects the person and methods to manage day-to-day life with the person. The focus of Session 1 was to examine how dementia affects a number of common cognitive processes. From your perspective as an instructor, it's important to see that this level of understanding is relatively abstract. It is an important part of the knowledge base a caregiver needs to be well qualified for the caregiver role. It helps caregivers to begin to break the dementing conditions into more discrete and understandable parts. It also reinforces the notion that there is a disease process at work. But, by itself, the information on cognitive losses isn't very helpful in improving a caregiver's management skills.

Today's focus on the impact of dementia on the person shifts to looking at the overall effect of the disease on the whole person. This section of today's session introduces the idea of Confusion as the central reality of the disease for the person. The section then provides a linkage between the impact of the disease and the work of caregiving. It does this in several ways. First, it emphasizes the need for and utility of the caregiver's being able to analyze (figure out) what the behavior of a person with dementia might mean—in terms of Confusion. Further, it introduces the idea that analysis—taking time and care to try to understand the behavior s/he is seeing—is the beginning point for developing a successful caregiving strategy. Next, it provides a fairly simple—but powerful—way of thinking about what contributes to behavior. This model offers the caregivers a very clear way of seeing just how what they do can have an impact on what their person does. Finally, it offers a strategy for communication with the person that acknowledges confusion and cognitive losses and provides a way to engage with the emotional truth that the person is experiencing.

You should note—and make this clear to the participants—that this section on Confusion and Behavior touches on the three important elements of caregiver qualifications:



TRANSITION



INFORMATION

- Knowledge—regarding the global effect of confusion on behavior and emotion.
- Skills—the ability to analyze behavior and think about ways to affect or respond to it.
- Outlook—the capacity and willingness to step back from the person and the situation to analyze things as calmly and dispassionately as possible.

You might want to let the participants know that this pattern of instruction will continue into Sessions 3 and 4—in those sessions you will be introducing them to a way of understanding the effects of dementia as the dementia progresses (this will add to their knowledge). Then this information will be linked to ways of improving day-to-day management (thus adding to their skill set).

### **Confusion—The Central Problem in Dementia**

This section deals with the issue of Confusion. Within the framework of the workshop—whether thinking about dementia in the abstract or dealing with it from the perspective of the savvy caregiver—Confusion is a central idea. It provides the easiest—and most accurate—image or metaphor for what dementia is and how it works its harm on its victims. It also provides an organizing image for the work of the savvy caregiver—keeping the person focused so as to keep confusion at bay. The next session (3) will deal with another idea that is key to the development of the skills of the savvy caregiver. This idea is that of contented involvement—a notion that is the flip side of confusion (or, at least, a way to try to avoid confusion).

#### **Exercise: Confusion**

The first part of this session has focused on the caregiver. Now the session swings back to looking at the effect of the disease on the person. This portion of the training introduces a central idea of the workshop. The idea is a straightforward one:

- The central problem of dementia—for the person with the disease—is confusion
- Confusion is the source or stimulus for the emotional and behavioral problems that caregivers find so troubling
- Finding ways to keep persons with dementia contentedly involved in tasks and activities is the best way to keep confusion at bay—and avoid the behavioral and emotional problems (this is dealt with in a later session)





The rest of the workshop will concentrate on providing caregivers with the skills and knowledge they need to keep the person contentedly involved and on giving them the opportunity to practice and master those skills.

The first part of the exercise involves the leader taking the participants through a guided imagery exercise. The purpose of this exercise is to help the participants experience the feelings associated with confusion—to let them feel what it feels like to be overloaded by stimuli over which they feel no control. The image, as presented, works well in Minnesota where participants are very familiar with the conditions imagined. You might want to develop a comparable image that fits better for your part of the world. Also, if you can think of ways to make the situation more tense and overwhelming, you should experiment with the image.

**Note to Savvy Trainers in Indian Country:** Please consider changing the contents of the guided imagery exercise to better fit YOUR tribal area. For example, elders who have participated in pow wows or other cultural events that are comprised of ritual rules, dancing, or regalia and masks may experience confusion due to their dementia. Create a scenario that helps the caregiver trainees to identify with an elder with dementia in those situations that may be confusing. Other possibilities for scenarios may include feast days involving many people and activities, or travelling to an event. Once a scenario has been selected, copy the style of the guided imagery in the manual but with the content of your scenario.



INDIAN  
COUNTRY

*First, tell the participants that you are going to lead them through a “let’s pretend” exercise. Then tell them that you want them to close their eyes and relax and to imagine themselves in the place where you put them. Then, using a low-pitched and slow-paced voice, tell them:*

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

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

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

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

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

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

Imagine that it’s very heavy traffic—very little space between cars. (pause)

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

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

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

And imagine that the car radio is turned on loud and is playing rock ‘n’ roll music that you don’t really like. (pause)

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

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

How do you feel?

What do you want to do?

What would you like to have happen?

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

### Confusion

The concept introduced in the exercise and talk—confusion—is one of the small handful of central ideas we are trying to instill in the learners. The talk and readings on the impact on thought form an essential foundation for participants' understanding of dementia. It is unrealistic that they will keep a detailed memory of all of the points that are made. At best, we can hope they use those as a springboard for adjusting approaches to and ways of interacting with their person to make them more appropriate. Confusion is one way of describing the global impact of dementia on the person. The exercise and talk are meant to convey to the caregivers an overall sense of the moment-to-moment reality of life for a person with dementia—as well as to give them an appreciation for the integral relationship between confusion and behavior. The talk and exercise are meant to engage the learners at a very empathetic—rather than a strictly cognitive—level. Confusion is something everyone has experienced and can understand. Caregivers should leave this session with a firm grasp of the constancy of confusion in dementia—how it is not only *always* present around the edges but it has the capacity to become the central—and controlling and terrifying—experience of the person.



BRIEF TALK

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

- The guided imagery exercise simulates the confusion of dementia but participants need to understand that as dementia progresses:
  - Declining cognitive powers provide less protection from external stimuli and offer less of a sense of security and control

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

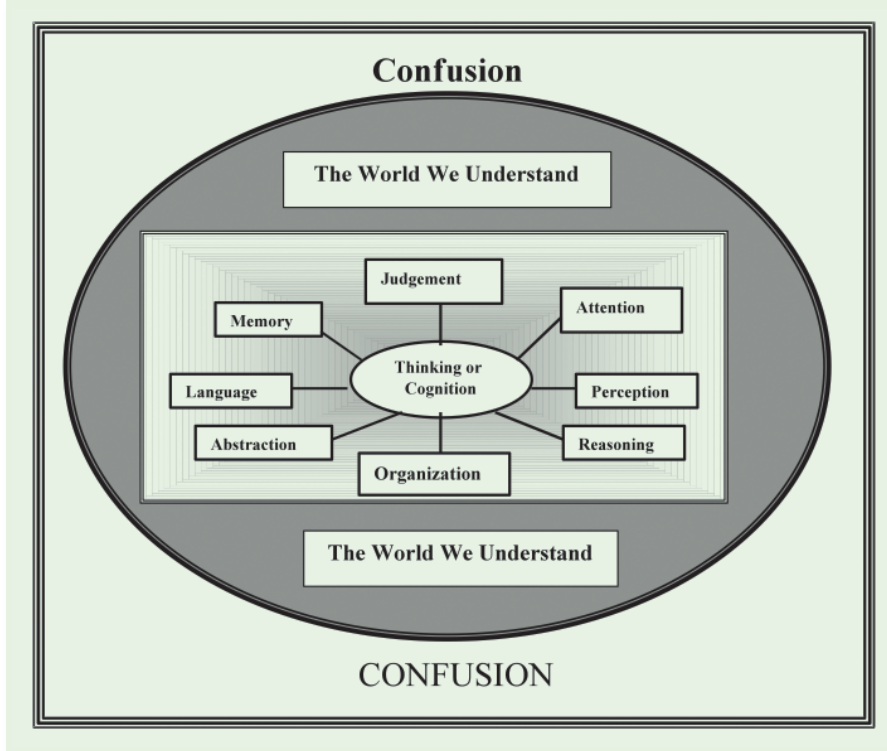
- The bombardment of stimuli seems more intense—intensifying the need for security and control.
- Confusion is the central problem in dementia
  - It is upsetting in itself
  - It provides the stimulus that produces bad reactions in the person (withdrawal, striking out, resistance).
- There are very strong emotions connected to confusion—like fear—and they produce a strong need for control, security, and comfort.
- A lot of caregiving is about keeping confusion at bay or bringing the person back from being confused (calming the person).
- Confusion—and the fear it produces—is at the heart of a lot of the comfort- and security-seeking behaviors.
- Foreshadow future sessions: keeping the person involved helps keep confusion at bay.

This section of the workshop is a platform for other pieces that follow—pieces on behavior and using knowledge about the person’s disease stage and performance level to frame structure and support strategies for encouraging contented involvement. The leader should foreshadow these in this brief talk simply by mentioning them. It is important, as the learners just experienced in the guided imagery exercise, for an understanding of the need for security and for the emotional impact of the disease. An understanding of confusion also prepares caregivers for the idea of Contented Involvement which is introduced later in this session and which is another of the central ideas of the workshop. In effect, Contented Involvement is the alternative that caregivers offer to confusion for those for whom they provide care.

The next slide is meant to picture our normal situation.



TRANSITION



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

We also realize that sometimes we are overwhelmed and that, in those occasions, we sometimes act (behave) in ways that we wish we hadn't. We

might lose our temper, yell at someone, use language we don't ordinarily use, make grave errors in judgment, have accidents, etc. There are three important points to make about this kind of behavior:

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

Persons with Alzheimer's or similar dementing disorders lack the capacity either to reflect back on inappropriate behavior stemming from confusion or to regret it (let alone make amends for it).

So the take home here is that everybody knows that out beyond their range of control there is a universe that can be overwhelming, but, under normal circumstances we control things well enough so that we never feel the terror of being out of control or overrun. The fact that we seem to spend some portion—and perhaps a lot—of our cognitive resources keeping confusion away should tell us how powerfully scary confusion is. It is important that participants get in touch with this in themselves, because they need to understand how vulnerable are the persons for whom they provide care—and what it is that drives many of their reactions and behaviors.

Explain that, as the disease progresses, confusion occupies an ever-larger part of the universe of the person with dementia, and the ability of cognitive powers to keep it at bay dwindles. As this happens, the chances that the person will experience confusion—and will not be able to protect him/herself from it—continue to increase. This will likely result in some kind of behavior that is intended to be self-protective or to create distance from the confusion.

The other important part to emphasize relates to the point made with the last slide about people's normal abilities to recognize that they are about to be overwhelmed by confusion and to do something about it—to protect themselves by reducing stimuli, for example. As the powers of thought decline, so do these abilities. Thus confusion “strikes” with less notice, and the person has fewer protective maneuvers against it. From a caregiver's perspective, this means that the caregiver will have less notice that the person is about to become upset—and therefore, less time to take steps to help the person avoid the discomfort associated with confusion.



TRANSITION

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

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

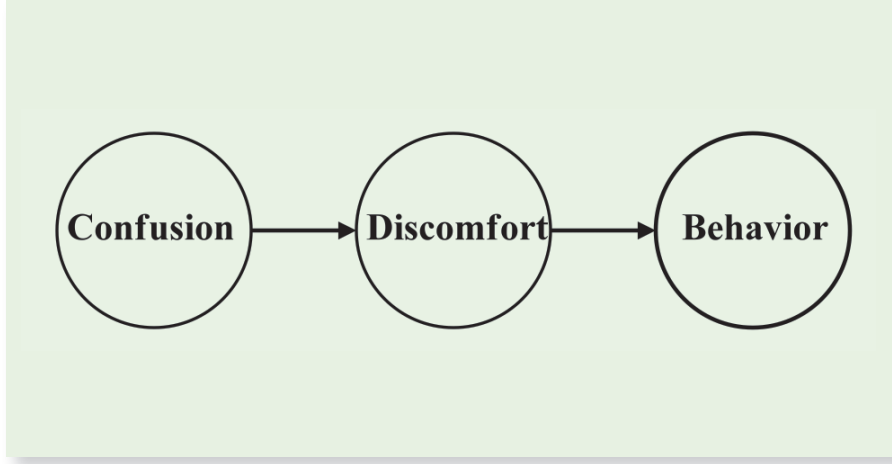
## Emotional Needs Related to Confusion

- **Calm**
- **Safety**
- **Security**
- **Control**
- **Reassurance**

The key here is that this set of feelings has a lot of power for explaining two of the often annoying day-to-day behaviors in dementia: shadowing (not letting the caregiver out of his/her sight) and repetitive questioning. When seen in the context of confusion and the fear of confusion, these behaviors are more understandable. The person sees the caregiver as the fixed point of stability in an otherwise uncertain and confusing universe. The caregiver is the touchstone—keep in contact with the caregiver (visually or through repeated verbal interactions) and the world snaps back into focus, at least for a while. Beyond this, the idea of confusion and the feeling needs that are produced by confusion or the desire to avoid it also offer insight to other troubling behaviors, particularly those that involve agitation. In many ways, agitation is a signal that the person is seeking calm, control, security, etc, and the caregiver needs to find ways to offer these. We will return to this idea later in the session when we examine specific troubling behaviors. [Once you have made this point, you might ask participants to identify other behaviors that they have seen in their person that might stem from confusion.]

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





The slide above illustrates the point that confusion, when unchecked, promotes discomfort for the person. When the person experiences discomfort, s/he does something (behaves). In the case of a person with dementia, the behavior may take many shapes.

Two key ideas—Confusion and Contented Involvement—intersect and interact over time as the dementia gets worse. The force of confusion is outward—it causes the person (or the person’s mind) to spin outward and out of focus or control—and that is the frightening part, like coming apart at the seams and fragmenting. The counter-force to confusion is the ability to focus on something—the ability to become zeroed in on some person (the caregiver), task, or activity. The ability to focus shrinks in dementia, so it’s in a kind of losing battle with confusion. The shrinkage is of two kinds. There are fewer and fewer things (or persons) that will capture the person’s attention, and the attention is likely to have a shorter and shorter span.

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



TRANSITION

In this section of the workshop, the focus will be on the behavior of the person with the dementing disease. Research about caregivers shows that behavioral problems—difficulties the caregiver has either managing or coping with the behaviors of the person with the disease—are the greatest source of caregiver distress and burden. Behavior—understanding it and being able, within limits, to control and/or tolerate it—is a central focus of the Savvy Caregiver program. Up to now, your work has been to get the caregivers to understand what the disease does to the person’s cognitive or intellectual abilities and to begin to relate these losses to the conscious development of caregiving strategies that take these losses into account. The next section of the workshop begins to introduce caregivers to the more complicated topic of behavior and managing behavior.



INFORMATION

The concentration on behavior will be the main focus of instruction for the next three weeks, and it will be the main focus of participants’ homework for the rest of the workshop. This section will introduce some background material on behavior—a model of how behavior works and how dementia affects it. More specifically, the remainder of this section of the session will cover the following material:

- It will provide participants with a fairly simple way of thinking about and being able to analyze behavior.
- It will link the material already covered—about cognitive losses and particularly about confusion—to the behavioral difficulties persons with dementing disorders experience as the disease progresses.
- Taken together, these two points will emphasize the importance of the role of the caregiver in terms of the behavior of a person with dementia.
- Furthermore, this will begin to focus caregivers’ attention on an important theme of caregiving—and one that is a dilemma for many caregivers—that of control (versus the autonomy of the person).
- This segment will conclude with a brief discussion—augmented by the readings—of a number of common behavioral problems in dementia. This discussion will include an interpretation or analysis of these behavioral problems, seen through the lens of the confusion produced by dementia. It will also include strategies for handling or managing these behaviors. The readings provide a supplement on communication strategies and on a Validation approach to interaction.

These materials on behavior will be background for the sessions in the following two weeks. In those sessions, participants will be introduced to another key idea of the Savvy Caregiver program—that persons with

dementia can be content to be involved in things (activities, tasks, events, etc) and that there are Anchor Points that caregivers can use to facilitate this kind of involvement.

*In this segment, you are trying to get the caregivers to arrive at just three basic insights:*

- Dementia affects behavior; and, since dementia is, typically, a progressive condition, it affects behavior more seriously as the condition worsens.
- As the condition worsens, the caregiver will be increasingly responsible for guiding and directing the behavior of the caregiver.
- As the caregiver becomes increasingly responsible for the behavior of the person with dementia, s/he needs skills—techniques—to help him/her manage and guide the person’s behavior. The caregiver will also have to become comfortable with the idea that s/he is in control and that the person cannot reasonably be expected to act as a free and autonomous agent.

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

Use brainstorming to demonstrate to the learners that they have an intuitive grasp of how behavior works and to show them that they have frequently engaged in “behavior management.” (a talking point here is that the idea of managing behavior is not inherently bad—something some people may feel or fear.)\*



Have the learners tell how they get things done. You might ask them, for example:

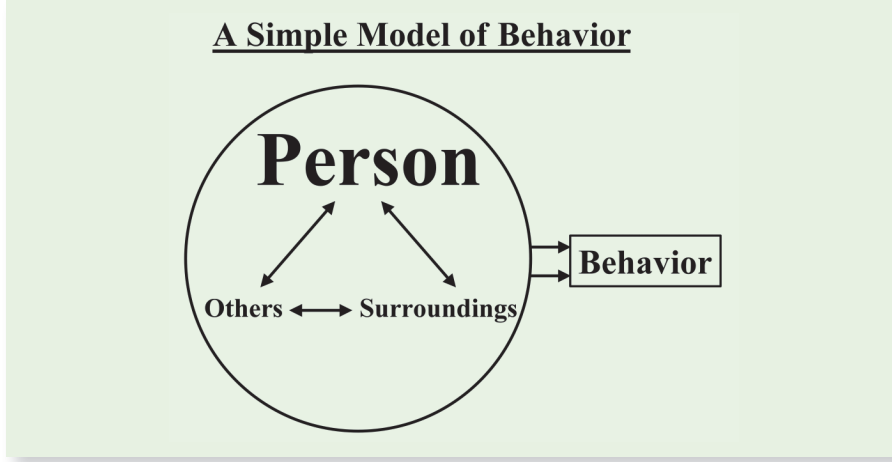
- How would you get a child to do his/her homework?
- How would you get your spouse to do a chore needed around the house?
- How would you get yourself to do something that is good for you (exercise, relax, diet, stop smoking)?

\*It is a key idea of the Savvy Caregiver program that the caregivers should leave the program feeling both competent (they can manage this situation) and comfortable with what they are doing. We are trying to make them more “clinical” in their approach to caregiving. That is, we want them to develop or strengthen the ability to step back from the immediate situation, scope it out, figure out what might work best to keep the situation calm and under control, and then put that plan into effect. To be able to do this, the caregiver has to feel, at some level, that s/he is more in control of things than the person with the disease and that s/he

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

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is better able to make choices about the situation than the person. A simple example of this—and one that many caregivers have found pivotal in their development as Savvy Caregivers—is that of the caregiver telling the person what to do instead of giving the person a reason for doing something. Instead of saying, for example, “You need to shower now because we’re going to our daughter’s house this evening,” the caregiver might say, “I need you to shower now.” This is a small point, but an important one. Instead of offering information and choice, the caregiver is directing the person without providing any information other than that s/he needs or wants something done. Beneath this simple example is a whole cultural value system related to independence, freedom, autonomy, and the sacredness of the individual. What the Savvy Caregiver program is teaching is that dementia is progressively depriving the individual of his/her ability to exercise informed choice and that, as the disease progresses, choice making becomes synonymous with Confusion. The program further teaches that, as a result, it is appropriate for the caregiver to substitute his/her judgment for that of the person and to control the situation on behalf of the person in order to maintain a sense of calm and security—both of which are key needs for persons with dementia. As the leader, you will be in a position to detect participants’ comfort or discomfort with this idea. Try to keep this in mind throughout the program, and raise the issue as you feel it is appropriate to do so.



The first point to be made here is that, under normal circumstances, we expect people to be primarily in charge of their own behavior (that's why Person is larger and bolder than Others and Surroundings). Other people and the setting or environment contribute, but the individual choice factor typically is the main one. Review the results of the exercise to check this out—see the extent to which participants have listed forms of persuasion and reasoning as the way in which they try to get others or themselves to do something. Use the next slides to provide more background and detail on the three elements of behavior.

## Person

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

This is really just a point to be made, but you can reinforce it by asking people to share how they came to some recent judgements like taking part in the Savvy Caregiver program.

Most likely, you will hear answers that reflect an expectation of benefit to themselves (“I thought I’d learn something.” “I thought I might get better at something.”) It’s important that frank reasons—selfish motives in addition to altruistic ones be surfaced, acknowledged and accepted (e.g., a reason like: “I thought that if I could be a better caregiver I could find more time to do the things I want to do”). The nature of the motive is irrelevant—the key point is that the person makes the choice for a behavior and is responsible for it.

## Support from Others

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

You might want to give an example from your own life about how you got someone to do (or not do) something you wanted. Look back on the exercise for examples of how they (or someone else) influenced a behavior.

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

\*This exercise introduces a term—Structure—that will be an important concept in the next sessions, especially session 4 and afterwards. This discussion of behavior is really just a background piece. You will have occasion to refer to it later, but the Anchors of Contented Involvement model that is introduced in session 4 and which uses Structure (along with Person and Support) as essential parts of the model—will provide caregivers with a technique that will have greater day-to-day applicability. So you might want to emphasize to the participants that Structure is a term that they can expect to hear more about as the Savvy Caregiver program continues.

## Surroundings

- **The place or setting where a behavior takes place can have a powerful effect**
- **The way an activity is prepared, displayed and monitored affects its success**

### Structuring Surroundings Helps to:

- **Channel behavior**
- **Encourage or discourage it**
- **Reduce options -- or increase them**

The idea of how Structure affects behavior is more abstract. The easiest examples are of children—alone in a room with a jar of candy, for example. Here the power of the environment (setting) is very strong. Try to draw on your own experience to demonstrate how an environment has contributed to behavior. It may be, for example, that driving past a mall, a coffee shop, or a park might stimulate your behaving in a certain way. Likewise, a very cluttered environment might detract from your ability to do work. Again, ask participants to recount situations in which the Structure of an activity (the setting) exercised a powerful influence on behavior.

You can use this as an opportunity to just touch on some of the ways in which Structure (the setting or environment) can help or hinder caregiving. For example:

**Note to Savvy Trainers in Indian Country:** Consider using settings or situations from YOUR tribal area to replace the examples below.

- A cluttered room might prove distracting to a person with dementia. In order to help the person to focus on a task or activity, the caregiver might simplify the room (remove a lot of the objects from it).
- A noisy, crowded area (e.g., a restaurant or a shopping mall—or a big family gathering) might be overwhelming for a person whose confusion is already high.
- A table with just one model car kit on it might prompt a child to play with that whereas a table that has a dozen toys and model kits on it might cause the child to skip from one to the other without much focus.

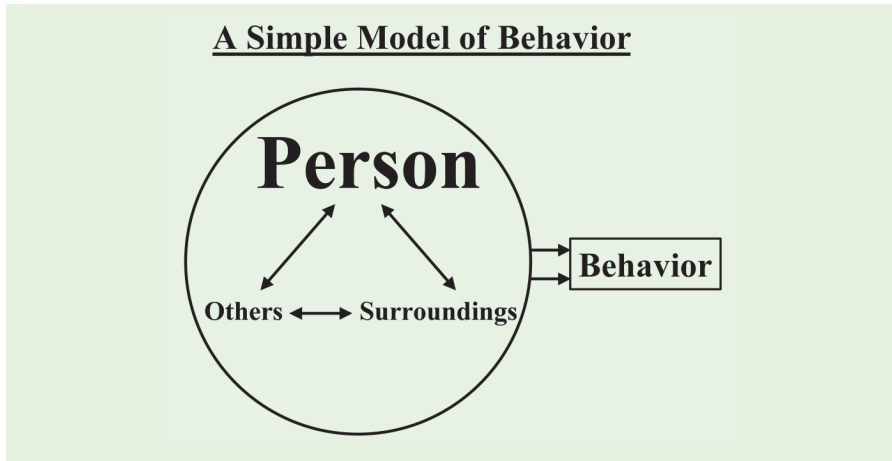


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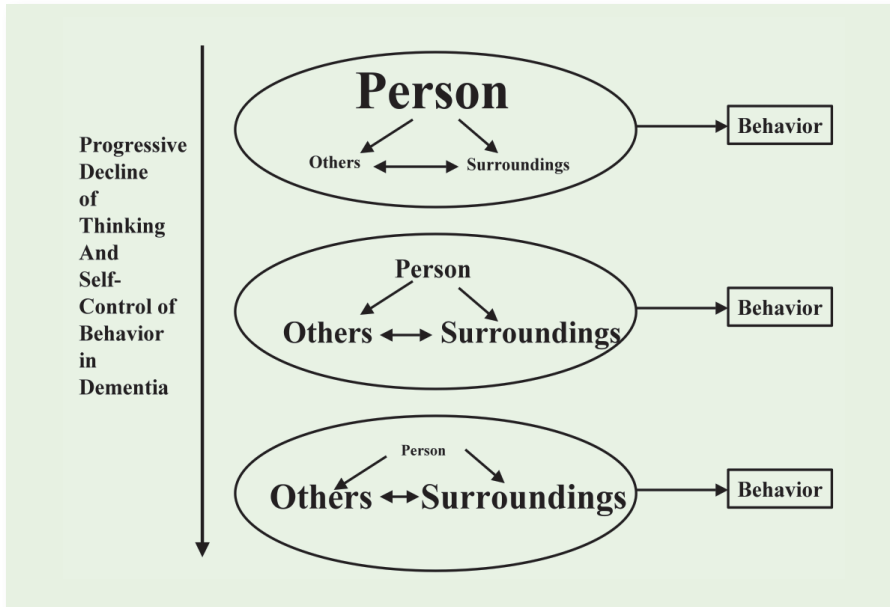


The idea of structure is one to which the program will return repeatedly in the next few sessions.

Now refer the participants back to the first slide on the behavior model (slide 33) and check with them to be sure that they see how the model works.



Ask them what they think happens to this model when a dementing illness is introduced into it, and then use the next slide.



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

The initial talk on the impact on cognition should prepare learners to understand this. When powers like reason, organization, judgment, and perception are compromised, intentional behavior becomes more difficult and unlikely.

Emphasize that the proportions in the slide are just illustrative. That is, we are not introducing the learners to a very precise calculation about the relative influence of the three factors as dementia progresses.

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

#### Communicating at the Level of Emotional Truth

Caregivers frequently report that the person for whom they are providing care says things—and clearly believes them—that are untrue. The person may, for example, say that s/he plans or wants to visit his/her parent (who is long dead) or that s/he's looking forward to visiting a country home that

was long ago sold. Such statements emerge from the confusion and cognitive losses the person is experiencing; they may be triggered by something the person sees or hears, or they may just come from a random recollection. In any case, the caregiver is faced with having to do something in response to such statements. The section in the Caregiver's Manual on Validation and Reality Orientation covers this topic in some depth, but this is an opportune moment to bring it up in the workshop (and it will be in the home assignments).

Caregivers often feel that they are confronted, at these moments, with an untenable choice: they can either confront the factual truth of the statement or they can deal in what they feel would be a deception—pretend that the statement is true and make something up to placate the person in the moment. This latter choice feels to many like lying to the person, and that makes caregivers understandably uncomfortable.

The material in the Caregiver's Manual essentially suggests:

- **Don't Confront.** Given the losses the person is suffering, it is likely the effort to "convince" the person (i.e., reason with him/her) will be unsuccessful and may likely lead to greater confusion and upset.
- **Deal with the Emotional Truth of the Situation.** Don't lie, but search for what the person may be feeling in the topic s/he is bringing up, and do something that validates that feeling. So, whether it is a long lost parent or place or a distant child or friend or a favorite spot or pastime, engage the person in something that taps into those feelings. Try to get the person to talk about the topic; look at pictures that relate to the topic; tell your own stories about the topic. Let the person have time in the emotional moment, and then work to move him/her on to some other task or activity.

### Taking Control

At this point, introduce participants to the notion of Taking Control. They have already learned a lot about the ways in which Alzheimer's and similar diseases take away a person's ability to function in the world. They have seen—and experienced—the distress that accompanies confusion. And in this most recent segment of the session, they have considered that the disease gradually deprives the person of the ability to take self-directed action.

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

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

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

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

In general, encourage participants to continue to put things into practice that they are learning. They should continue to work on developing strategies to deal with the losses in thinking capacities that their persons are experiencing. They should also begin to watch for signs of confusion in their persons and to notice the way things influence their persons' behavior. They should try some experiments with “shaping” behavior. These will be hit and miss, but it would be good for participants to begin efforts to assume more control over their persons' behaviors.

In addition, ask participants to:

- Read the material in the Caregiver manual corresponding to this session's work—on Self-Care, Confusion, Behavior, Taking Control, and Validation.
- Read ahead on the Staging System for Dementia that will be covered next week.
- Examine at least one feeling that you have this week that is in the lower left-hand quadrant. Develop a plan to move from that to another quadrant, either by taking some informed action or by consciously attempting to accept or let go.

Participants should continue to explore the CD-ROM. In particular, they should:

- Go through Section 2—on Caregiving
- View the videos in Section 6 that have to do with caregiving and caregiver self-care (#'s 1,3, 5, and 7).



TRANSITION




HOMEWORK



MEDIA

Savvy Caregiver Program  
American Indian / Alaska Native Trainer Essentials

**SESSION 3: CONTENTED INVOLVEMENT  
AND DEMENTIA STAGES**

<b>Homework Review</b>	30 minutes	 SESSION AGENDA
<ul style="list-style-type: none"> <li>• Reading in Manual</li> <li>• Review of Self-Care Activities (feeling quadrants and self-time)</li> </ul>		
<b>Goals for Caregiving</b>	30 minutes	
<ul style="list-style-type: none"> <li>• Contented Involvement</li> <li>• Fit</li> </ul>		
<b>A Staging System for Alzheimer's and Similar Dementias</b>	60 minutes	
<ul style="list-style-type: none"> <li>• The Key Elements of Doing Things</li> <li>• Staging Systems for Dementing Disorders that Relate to Everyday Life</li> </ul>		

The AI/AN value of harmony and balance in life may be extra motivation for caregivers to achieve “Contented Involvement” for the elder with dementia.

“Contented Involvement” (detailed in this session) is the goal of keeping the elder included in family matters and daily life *at a level that produces contentment because it is not overwhelming*. “Contentment” is very much a part of “harmony” and “balance.” Emphasize to caregiver trainees that the effort to meet the goal of “contented involvement” by the elder is also meeting the goal of a more harmonious and balanced life for all in the family.

Make sure to show trainees that “Contented Involvement” makes a type of balance in the elder’s life.

Harmony and balance for the family is very good, but the emphasis here is on the elder experiencing a sense of being included, needed, and wanted.



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Be sure that the efforts to reach the goal of “Contented Involvement” by caregivers are clearly for the elder first, then others.

**Tell the caregivers that in spite of faulty memory ability, elders with dementia still have many capabilities, gifts, and purposes in the family, community, and tribe for many years from the start of the disease.**

For many caregivers, the most striking symptom of dementia is memory loss and reduced thinking ability. Both of these symptoms are certainly present and cause much of the need for caregiving by others.

However, affected elders usually keep much of their memories from years ago. This allows them to continue to be story tellers holding large amounts of information from days gone by. The history of a person, family, and tribe weaves a tapestry of identity found nowhere else.

Ask caregivers for examples from their elder that shows the elder’s strengths and contributions to the family. Recalling the old days is one way to honor the elder. “History” of AI/AN life is not always accurate, especially when written by outsiders. The elder may have truly unique information of the ways of the tribe.

**Elders with dementia can also communicate much longer than is obvious.**

Communication is much more than just words. People communicate with each other using voice tone, facial expression, body posture, speed of movements, and strength or gentleness of touch. All of these parts of communication remain much longer than correct use of words alone.

Encourage the trainees to keep talking to the elder AND add an awareness that they may need to emphasize voice tone or facial cues in order to get the best communication possible.



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In this session caregivers get introduced to the last of the backbone content information on dementia, information on the impact of Alzheimer’s and similar progressive dementias on the person’s ability to do everyday tasks and activities. They begin to get information that they will be able to apply to their day-to-day caregiving; this information will be continued in the next session.



INFORMATION

This information provides caregivers with yet another way to develop strategies to meet what this session will offer as a reasonable goal for caregiving—helping the person to become and remain contentedly involved in everyday tasks and activities. Doing things and being zeroed in and pleased while doing them is presented as a goal that promotes the quality of life of the person with the disease. To be effective at this, caregivers have to have a basic grasp of what goes into doing things and also of what dementia does to the person’s ability to do things. This session introduces them to the idea of Contented Involvement and to a staging system focused on doing things that derives, in part, from an occupational therapy focus. At some point, caregivers should be able to arrive at a ballpark estimate about at what stage their person is in the course of the disease. This estimate will be helpful for caregivers’ understanding of their person’s ability to do things. More practically, it will help the caregiver begin a process of choosing and setting up the kinds of tasks that best fit the person’s abilities—and to be as effective as possible in the ways they communicate with the person and support him/her in doing things. The context for this is the introduction of the idea that persons with dementia can be described in terms of their remaining strengths, a concept that will be worked on through an exercise.

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



EXERCISE

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

- Participants were to read their manual on self-care, confusion, behavior, and communication. See if they have any comments or questions. They were also told they could read ahead on strengths and the staging system; if they begin to raise questions, point out they’ll be

covering this later in the session and have them hold off on them.

- Ask them if they had a chance to examine a lower left-hand quadrant feeling. Did anyone work on a plan to move from that to another quadrant, either by taking some informed action or by consciously attempting to accept or let go? Remember that the emphasis here is more on their developing skill with the tool than it is on talking about their feelings.\*
- Ask if any participants have used the CD-ROM/Internet Dementia Caregiving Strategies program? Did they have any technical questions? What did they think about the sections they viewed.

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

\*This goes back to the point made in the introduction that this is a workshop about learning new skills and knowledge—and it is not a support group. Clearly, you don't want to squelch feelings or a discussion of feelings, but you do want to be alert to whether the emphasis and meaning of the group has shifted and you want to be able to bring the group back to its basic work.



TRANSITION



### Session 3: Objectives

- **Develop an appreciation for the benefits to the caregiver and care recipient of Contented Involvement**
- **Appreciate how Fit contributes to Contented Involvement**
- **Understand a Staging system for persons with Progressive Dementing Disorders**

#### Contented Involvement

Attention now turns to a basic concept for caregiving. Contented Involvement—a somewhat awkward and cumbersome term—is a very intuitive and easily grasped idea. It is helpful for caregivers because it provides them with a goal that can be applied in virtually all caregiving situations. A person with dementia can be content and involved in a car ride, looking through a photo album, or peeling carrots. S/he can also be enjoyably involved getting dressed in the morning, having lunch, or taking a bath. The concept is also useful because caregivers can use it to monitor almost any caregiving situation. They can use the concept as a yardstick to judge how well an activity is going or to look back and assess how the day went. This is a useful analytic technique, but it requires that the caregiver be able to stand back from the situation to see what's happening and how it's going—and this is just the outlook the program is trying to strengthen.

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

- Be aware of—and have an intuitive grasp of—the idea of “contented involvement.”
- Appreciate that persons with dementia can be engaged throughout the day in activities that result in “contented involvement” and that helping them to be in this condition is a reasonable goal of caregiving.

The first part of the exercise involves another guided image. The two slides that follow the exercise lead you through the debriefing and summarize the key points of the exercise.



INFORMATION



EXERCISE

This is another guided image. Follow the same procedure as with the guided image in the earlier module on confusion. Have participants relax—close their eyes if they want. Give them a moment to get calm.

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

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

Let the participants bask in this image, and then conduct a two-part debriefing. In the first part, have people talk about what it felt like to be in the image—take notes on a flip chart and summarize using the next slide (use that slide now). Be sure to get from them whether they liked—enjoyed—the scene.

## Content and Involved

- Without distress
- At Ease
- Pleasant
- Within one's limits and abilities
- Not a Stretch
- Familiar
- Sensible
- Fits with you
- Engaged
- Zeroed in
- Attentive
- Focused
- Using one's available skills
- Busy
- Concentrated

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

Next, ask participants to identify, through brainstorm, other activities in which they themselves often or sometimes find themselves contentedly involved. Ask them, while dwelling on these pleasant activities, to identify things that take them out of the zone of contented involvement.

Find some way—perhaps a flipchart—to record participants’ responses. Some examples might include leisure activities of various sorts (a runner’s high), fixing a special meal, being involved in a hobby or favorite pastime (doing a jigsaw puzzle, playing cards), or even those parts of work that are particularly challenging or enjoyable. Record all the things participants identify with contented involvement and then record all the things that take them out of this zone of contentment and involvement.

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

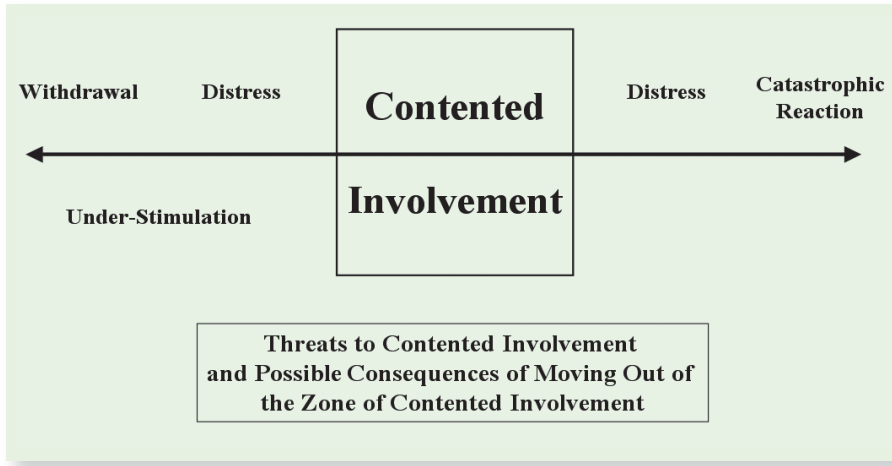


TRANSITION

## Things that Take us from the Zone of Contented Involvement

- **Distractions**
- **Overload**
- **Boredom**
- **Fatigue**
- **Other physical needs (pain, hunger)**
- **Depression**

The exercise takes participants to the point of your summarizing the experience in terms of the concept of Contented Involvement. The next slide provides a conceptual map or diagram for what the participants have been describing. The slide provides a graphic representation of the idea. Some phrases that might equate with enjoyable doing include “being in the zone” or “being zeroed in” or just “being tuned into something.” You might ask the group to tell you what phrase they use to represent this state of being.



The point that is relevant for dementia care is that the farther a person with dementia gets from the central zone the more likely that an undesirable behavior will occur—either some form of catastrophic reaction\* or eruption or some form of pulling away and into the self. Both are troubling—to the caregiver and to the person.

It's important that caregivers recognize that physical discomfort of all kinds—including fatigue as well as pain (which gets harder for the person to recognize and report)—can be very distracting (imagine trying to concentrate on the class if you have a tooth ache). So one of the things we need to remember is to be constantly alert to the possibility of pain of one sort or another—including psychological pain. Even as we work at adjusting the tasks to fit the person, that work can be defeated if the person doesn't feel rested or well. So those factors have to be taken into account.

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

- at the center is contented involvement—which you've just gone over. It is the target of our work.
- The two “enemies” of contented involvement are over- and under-stimulation. The freeway image (session 2) is a good example of over-stimulation. A good example of under-stimulation is what they would

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

feel like if what we asked each of them to sit alone in a room for 2–3 hours and read manuals and text books.

- At some point, when someone is over- or under-stimulated, they typically begin to experience some form of distress or discomfort. This increases as the person becomes more over- or under-stimulated.
- **Withdrawal and Catastrophic Reaction.** The main points are that, especially with the more explosive and potentially violent catastrophic reaction, there is a lot of discomfort involved and it takes a lot of work to bring the person back to focus afterwards. So it is an important caregiving principle to try to avoid having happen. It is also important to point out that as dementia progresses, these reactions happen more suddenly and with less warning. People’s tolerance to over- or under-stimulation is reduced as the dementia progresses, their ability to recognize that this limit is being reached is reduced, and their ability to self-direct away from a reaction is likewise reduced. Catastrophic reaction is what it sounds like—an eruption or outburst that is extreme and/or intense. Such reactions are frequently sudden in onset, and caregivers often report they seem to come “out of the blue.”

Withdrawal is what we think of when we think of people who are zoned out and sitting in a corner. It’s different from gazing pleasantly out a window taking time out or down time, both of which are forms of contented involvement.

### Fit

Fit is another central idea in caregiving. It has to do with creating and maintaining a situation of contented involvement by establishing a match between task and ability. Behind the idea of fit is the further idea that the savvy caregiver is trying to find a match or fit between the person’s remaining strengths or abilities and the tasks and activities the caregiver sets out for the person. Fit is one of the key elements involved in helping someone to zero in on a task and to remain focused on it. The exercise that follows is meant to remind participants that they already know what fit means.

The Cookie Making exercise you use in this session also anticipates material you will cover in session 4. In this exercise, you will be showing caregivers that they have an intuitive sense of fitting tasks to abilities. You will be also be showing them that their sense of fit leads them to specific strategy decisions—decisions about structuring each child’s activity as well as about how to communicate with each child and support him/her throughout the task.

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



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

Start this exercise by having the group brainstorm all that goes into making cookies—instructor records on pad. Then show the slide below and do any filling in on the pad (or the slide) that might be necessary. You could even jazz it up by pretending that the cookies have to be baked in an old-fashioned oven that you have to light with a match.



## Cookie Making

### Materials needed

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

### Actions Taken

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

Now, have the group imagine that they are taking care of a group of four children, aged 5, 8, 11, and 14. The group's task is to organize the cookie making so that the children all get to do as much as they can, that they all have as good a time as possible, and that no harm comes to anyone, especially the young ones.

- First, ask them to surface their concerns—what will they be worried about (that the big kids will be bored and drift off; that the little kids will be pushed aside and feel hurt or bored; that the kids will fight among themselves; that they'll get burned or blow up the house; that they'll eat the dough and not cook the cookies. The least important concern will be that the cookies won't be very good.)
- After this, have them decide which tasks they will assign to which child or group of children (for example, the oldest might do all of the measuring, light the oven, and supervise the two youngest. The 5 year old might be assigned to spoon the dough onto the cookie sheet and to put margarine on the sheet. Etc.)
- Have them say—briefly—why they make each assignment.
- Next, have them describe how they will set up the task for each kid. How much help will they provide (e.g., in getting things out or in hands-on help) and what kinds of directions they will give (for example, they might just hand the cookbook to the 14 year-old and ask him/her to get everything ready; they might ask the 11 year old to do the measuring and pouring things together and the 8 year old to do the stirring and mixing; they might ask the 5 year old to use a measuring spoon to scoop dough onto the cookie sheet. Their



directions to each kid would likely be more or less sophisticated, depending on the age of the child, and with the younger children, they might use visual cues and demonstrations more than with the older ones.

- Next, have them briefly imagine what would happen if they switched the assignments—ask the 5 year olds to measure and the 14 year old just to stir things up (this represents misfit—and it produces chaos and unhappiness among the children and feelings of tension and frustration in caregivers).
- At the end, ask them to say how they would know that they had done a good job as an adult in this situation.

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

- name a set of “caregiving” concerns that they bring to the situation
- establish generally appropriate involvements for each child—and be able to link these to a rationale that is based in their grasp of each child’s abilities (not losses, but strengths)
- recognize that each kid could get involved in this task and that each could have a good time
- recognize, especially, that *fit was the thing that promoted both enjoyment and safety (and that misfit can produce very bad results)*.
- recognize what it will mean (feel like) to have done a good job caring for this group of kids.

#### Behavior, Contented Involvement, Fit, and Savvy Caregiving

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

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

\*While it is a good idea to keep things simple and to keep the number of terms used to a minimum, you might find that repeating the term “contented involvement” over and over feels cumbersome. You could substitute some similar terms (“being content and involved,” “enjoyable activities,” “being happy and engaged”), but related them to the root term, contented involvement.

- Confusion is a major problem in dementia, and the savvy caregiver wants to keep confusion as far away from the person as possible.
- Contented Involvement is something we all relate to—and it is something that remains available to persons with dementia, even far into the disease (they will have all seen their person involved in some task or activity in which s/he was zeroed in and having a good time; and you can assert for them that this kind of involvement and enjoyment remains possible even much farther into the disease than they now experience).
- When tasks are fitted to abilities—as in the exercise—contented involvement is promoted and confusion is prevented.
- When fit is applied well, the caregiver feels a sense of satisfaction or success and does not become frustrated.

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



TRANSITION

### The Teaching Videos

The videotape used in this portion of the program shows four people diagnosed with a progressive dementia and at different stages in the disease making a sandwich and folding towels (these same tasks are shown with different people in the CD-ROM). The teaching sequence is to show the first person doing the two tasks, ask participants what they observed about the way the person did the tasks (and the way the Occupational Therapy assistant worked with the person), and then give a brief talk on the stage that is being portrayed. Both tasks are concrete and not abstract, and all the materials needed for the tasks are right in front of the person. The Occupational Therapy assistant who is guiding the persons through the tasks is following instructions regarding the way to work with these persons in these tasks. The first instruction that she is following is to ask the person (when she sees that the person has lost track of the task (i.e., forgotten the purpose) or is leaving something out or making a mistake): “Can you remember what I asked you to do?” You will notice that, as the tape goes on and the people are in the later stages of the disease, this kind of prompt is not very helpful and may even be confusing to the person.

Again, you might want to warn participants—particularly those whose persons are in the earlier stages of the disease—that the material they’ll see in the videos (and in the CD-ROM) will show what someone might come to look like (and perform like) in the later stages. This might be upsetting. The

videos will be helpful in teaching about the stages, but they will also provide participants with a sense of the trajectory of the disease and what happens over time to people who are affected with it.

### Teaching about the Stages

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

### Early Stage (Allen Level 5: The First Signs Show)

Show the tape of the first person making a sandwich and folding towels (these same tasks are repeated by the other three people shown on the video (and by the people in the CD-ROM). The person's performance in those tasks exemplifies Early stage (level 5) performance.

She can handle both tasks without difficulties—except for one minor bobble in memory. She keeps a running conversation going while carrying out the plan she obviously made in her head to make the sandwich and fold the towels. It is useful to point out that, on three different occasions during the tasks, the person mentions her brothers and sisters. Note that each time she mentions them, the number of brothers and sisters changes. So it's interesting to observe that some evident loss of cognitive functioning has taken place, yet the person can proceed with the tasks in front of her with no apparent loss of effectiveness. From a caregiver's perspective, people at this stage can be pretty reliable with everyday tasks.

Use the slide below to outline the points you will want to make about a person in the Early Stage (Level 5) of a disease like Alzheimer's.

**Early Stage (Level 5.0: Signs Begin to Show)**

- **Relatively able and independent**
- **Problems with short-term memory**
- **Problems losing track in complicated tasks**
- **Problems with planning, problem-solving, and judgment (Executive Functions)**
- **Should be able to manage most concrete tasks**
- **May affect “quality” of performance— may behave impulsively or hesitantly**

Persons at this level will be able to function independently in most areas of life. They will experience difficulty with complex tasks—tasks that require many steps and abstract thinking—for example, managing a checkbook or household finances. They may have to quit their jobs earlier than they had expected to because they can no longer handle the difficulties of the job.

A person at Level 5 may appear to be functioning quite normally in a great many situations and might only show signs of a problem when under stress. People seem to vary a lot in terms of the amount of insight they have about having the disease. Some seem to understand there is a problem and are able to talk about it. Some become depressed—in fact, depression is very common in early stage dementia. Others might not be aware—or might deny awareness.

**Early-Middle Stage (Levels 4.5-4.0)**

As described in the Caregiver Manual, the Early-Middle stage encompasses the Allen Levels extending from 5.0-4.0. The material in the Caregiver manual describes these two Allen levels, and that material is summarized in the two slides below.

### **Early-Middle Stage (Level 4.5: A Time of Increasing Problems)**

- **Seems to perform normally, but errors creep in**
- **Will keep a goal but may need reminders**
- **More easily distracted; needs help staying on track; readily redirected**
- **Language still works to give information**
- **Problems begin to show with thinking – handling abstract ideas is harder**
- **Easily frustrated; may be impulsive**

Depending on their own awareness of and sensitivity to their own condition, persons in the Early-Middle stage may become withdrawn unless encouraged to remain a part of things. They may show frustration at their own inabilities and take this out on themselves (disparaging their own abilities) or on others. In other words, they may become more emotionally difficult. Again, depression is a frequent and serious problem—one that should be looked at, since depression is treatable.

In terms of performance, they will still be able to relate to a sense of purpose and will be able to set up and follow straightforward sequences. They'll be ok with using things correctly—though, since judgment is more impaired, they need to be watched more closely when safety is an issue with use. Written information may become less useful at this stage, though verbal information should still be effective. Even now, though, the Savvy Caregiver should be simplifying verbal expression and beginning to use visual cues more.

### **Early-Middle (Level 4.0: Impairments More Noticeable)**

- **Limited attention and easily distracted -- reacts to pressure; abstract thought very weak**
- **Simple and familiar tasks with few steps**
- **Knows there's a goal, but needs reminders**
- **Clear trouble with memory, language, orientation, perception, and attention**
- **Performance quality poor**
- **Needs help organizing tasks**
- **Needs short, concrete directions -- visual cues**

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

The key things to point out:

- The trouble she has opening the jar is not related to the dementing illness; it has to do with a problem she has with her hands. It is important, however, to remind participants that dementia does not protect against other problems; in fact, other problems can make the problems with dementia worse.
- She gets involved in opening the package of ham and seems to lose track of the purpose of the sandwich-making activity. The Occupational Therapy Assistant (OTA) has to prompt her to put the cheese on the sandwich.
- In the towel-folding exercise, she seems to be confused by the verbal instructions. There is a lot of verbal interaction—perhaps too much—and she seems to lose track of what's being asked.
- After folding one blue towel, she begins to fold a white towel and has to be redirected to the task (to folding the second blue towel).
- Once back on task, she completes the exercise, folding the two white washcloths.
- As with the first person, Ida Mae is able to keep up a certain amount of verbal interaction without getting too confused (though, as noted,

she does get confused by the towel-folding instructions). She may be a bit impetuous—leaping into action before fully absorbing the directions.

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

#### Late Middle Stage (Level 3.5-3.0)

Again, use the material in the Caregiver's manual to describe this stage; the two slides below highlight the two Allen Levels that are encompassed by this stage. Use the slide below to make the key points about persons functioning at Level 3.5

**Late-Middle Stage (Level 3.5: Becoming Dependent in Basic Daily Tasks)**

- **Confused -- vague about purpose (may not feel any sense of purpose). Easily rushed or startled**
- **Needs direction, may need help starting and with steps throughout the task**
- **May be able to do 2-3 steps in order on own**
- **Performance quality very poor. Still relates to objects. Easily frustrated**
- **Needs visual and tactile information -- language too abstract and must be simplified**
- **Thinking severely impaired in all areas -- may not remember caregivers**

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

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

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

Use the slide below to highlight the key points you will want to make about the functioning of persons at the lower level of this stage in the disease.



**Late-Middle Stage (Level 3.0: Person Experiences General Confusion**

- All thinking powers seriously affected.
- Very confused. Hard to understand what's happening or what's wanted of him/her.
- No purpose; order with help.
- Needs help starting and staying with all tasks
- Very concrete -- visual and tactile cues
- Step by step help
- Very easily distracted, frustrated, upset, confused. Don't rush or pressure. Reassure

Show the video of the third person in the set of four.

Key talking points for the video:

- The person retains pretty good verbal skills. Her performance is nowhere near as good as her speech.
- This kind of retained skill—in this case, a verbal skill—can be confusing for caregivers. They see the person doing so well in one area of function and have a hard time keeping in mind that this is a disease process that has a global effect.
- She's past the point of having much if any understanding of purpose in this action. She needs help to order the actions leading to making the sandwich and folding the towels. Note, for example, that she uses the table to slice the bread, rather than putting it on the plate. She does still use things relatively well.
- She seems confused by all the things in front of her.
- She fixes on the lettuce and is cued to do something with it; the OTA has to draw her back to the task and to pick up the ham.
- She seems stumped by the task, so the OTA puts the sliced bread together on the plate to create a cue for the next step (though Libby seems not to understand what the bread is). The OTA has to cue her to put the ham on the plate and then to put the cheese on the bread.
- The OTA completes the task for her by putting the second slice of bread on top.

- She does seem to take pleasure in being praised for doing a good job of making the sandwich.
- In the towel-folding task, she is almost immediately confused. The verbal directions not only don't help, they seem to make the situation more confusing. It is only when the OTA hands Libby the towel and helps her that the task moves along and she seems to become less troubled and more involved.
- The last prompt by the OTA is very simple: "Fold two white washcloths"—four words. Libby is able to do this.
- Note how patient the OTA is with her throughout the two tasks—she doesn't expect her to do any more than she does. Also, she adjusts what she does to her abilities. She notes, for example, that Libby isn't getting the folding task so she joins in with her and helps her directly.
- Because she doesn't expect Libby to perform above her stage-specific ability, the OTA seems able to remain warm and encouraging and to accept the person's functioning without any kind of blame or frustration.
- Note that Libby does get the jobs done (in some fashion) and has taken part throughout. It might be easy for her to feel some sense of failure or inadequacy, but the way the OTA is working with her allows her to do things. And even when she is being very directive, she's using a neutral or positive tone and never blames or scolds him. Again, at the end, there is delight in the praise.
- Persons at this stage of the disease need more or less constant attention. This is full-time care. Many at this stage are in an organized help-providing setting.

#### Late Stage: Level 2\*

Use the slide below to highlight the key points about level 2 functioning in Late stage dementia.

\*You may get a question about why we don't describe a level 2.5 or even 1.5. Recall that a full-scale assessment using the Allen techniques can result in a "score" at any decimal place (e.g., 4.7, 3.6, etc.). The Savvy Caregiver program is attempting to get the caregivers in the vicinity of what the results of such an assessment would be—not to substitute for an actual assessment. The program's goal is that the caregivers develop a "feel" for how the progression of the disease works, in terms of the Allen Levels. In concert with developing that feel, the key point of the program is that the caregivers then understand that there is a relationship between Level (what the person can do) and the kinds of Structure and Support help the caregivers can give to help the person become and remain enjoyably involved in various tasks and activities. So it is less important that participants see examples of the finer increments of the Levels than it is that they develop a sense of how the levels work and what they mean.

### **Late Stage (Level 2.0: Functioning with Minimal Abilities)**

- **Powers of Thinking** virtually gone
- **Purpose and order** are no more -- have to come entirely from outside
- **May or may not** relate to objects
- **Needs total care**
- **Goals of care** are comfort
- **Involvement, at this stage, is almost entirely passive**

Follow with the next slide to highlight the end stage of the disease.

## Late Stage (Level 1.0: In Bed and Unresponsive)

- **Little or no consciousness or awareness**
- **Sleeps much of the time**
- **Total care**
- **Comfort is the goal**

This is late into the disease; it is very unlikely (though not impossible) that anyone in the group is caring at home for a person this far advanced in the disease. It's probably very important to make it clear that when persons reach this stage, caregivers will very likely not be able to care for them at home, at least not without a great deal of help. They may have to move to more of a full care facility. Persons at this stage and the next require almost complete care and are no longer capable of doing much for themselves except cooperate passively.

By this stage, persons would almost certainly be in a care center and would require round the clock total care. An appropriate care goal for persons at this Level is comfort—freedom, as much as possible, from pain and confusion.

Persons at this stage will not be able to communicate at all, so if there is anything wrong with them it will likely go unnoticed until it is at a critical state. Thus infections are seen only when they are very serious. Death from pneumonia—or other infections—is very common.

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

Some talking points about this segment:

- This person has a very expressive face, and the sense of distress and confusion are apparent in her face at a number of points in the video.
- Note, in the sandwich-making task, that she doesn't seem to relate to the things in front of her and explores the objects by touching them.

- When it's clear to the OTA that Catherine doesn't understand the task (make a sandwich), she, in effect, changes the task: "Can you get two pieces of bread?"
- When she cannot do that, the OTA gets the bread out for her, puts it on the plate, and uses it as a visual cue for her next request, "Can you put ham on the bread?"
- Note that Catherine's verbal response ("Yeah, I think so") isn't carried out in an action.
- Toward the end of the sandwich-making task, it appears Catherine is getting a bit upset or disturbed, though she does complete a portion of the task with continued direction.
- Note how she seems to deflate when the OTA gives her the whole direction for towel folding—as though she can sense that this is too much for her.
- The OTA gets her to be involved by demonstrating the action (folding) and by physically guiding her hand to complete the fold
- Again some distress or frustration shows toward the end of the towel-folding task (as though she's being pushed too hard).
- When the OTA puts the white washcloth in front of her, she does fold it—though in a unique manner. But note that the OTA doesn't worry about the quality of the fold.
- Nevertheless, she does show delight when the task is completed and she is praised for her work.



TRANSITION

## Strengths

The brief section on strengths serves a number of purposes.

**First, it gives the caregivers a concrete way to relate to the process in dementia by which behavior is less and less in the control of the person and relies increasingly on external factors.**

The exercise below asks the caregivers to make relatively fine distinctions about the amount that the person can do for him/herself and the kinds and amount of help, direction, and direct doing that the caregiver contributes to the successful completion of an activity. (Make sure to point out to the caregivers that "help" comes in at least three forms: planning (thinking through the task for the person and then leading him/her through it); supervision and direction or advice; and direct, hands-on help.



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**Second, it presents the caregivers with the idea that persons with dementia retain abilities throughout the disease.**

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

**Third, the exercise reinforces the material on the stages introduced earlier in the session.**

It helps the caregivers to consider, if only on an intuitive level, that there is a kind of order to the losses that occur (or the strengths that remain). It also helps them to see that the level of strength tends to be consistent across activities. This last point is very important and should be emphasized in the workshop at this point. It’s important because a key message from the staging material should be that if they have an idea of where their person is in the disease, they should have a pretty good idea where to start in designing their structure and support strategies *for almost all tasks and activities*.

### Exercise on Strengths

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



EXERCISE

Have the participants use the Tasks and Activities grid (following) to indicate what strengths their persons retain for self-care—have them take 2-3 minutes, at most, to complete the form.

### Tasks and Activities Grid

The Tasks and Activities grid that follows gives participants a way to think globally about their person’s performance in daily life. The grid is linked to the staging system that was just described. In the second column of the

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

Have the participants look at the grid and ask them to reflect spontaneously on their person's performance in light of the descriptions provided: where does the person seem to fit? This exercise links with watching the videos in the workshop and (optionally, on the CD-ROM). It is useful for participants to “get a feel” for the stages and to estimate into which stage their person falls. People may say that their person looks like one stage in one activity and another stage in another activity (e.g., needs more help getting washed up than eating). The stages merge into one another, and it is not unlikely that persons will exhibit behavior that straddles stages. The point is that if the caregiver can say: “Well he's somewhere between Early-Middle and Late-Middle,” that is a starting place for appropriately designing and helping with tasks and activities—the main focus of the next Savvy Caregiver session.

## Tasks and Activities Grid

<i>Stage</i>	<i>Description</i>	<i>Examples</i>
Normal: non-demented (Allen Level 6)	Independent in all activities, including complex cognitive tasks requiring intact executive function	<ul style="list-style-type: none"> <li>• Managing a checkbook</li> <li>• Making and following shopping lists</li> <li>• Planning and taking a vacation</li> <li>• Taking care of all daily needs (dressing, eating, toileting, hair care, etc.)</li> </ul>
Early Stage Dementia (Allen Level 5)	Though independent, makes errors in complex and simple tasks. Errors in complex activities more serious than those in daily care activities*	<ul style="list-style-type: none"> <li>• Makes mistakes with finances (checkbook doesn't balance; impetuous purchases)</li> <li>• Difficulties in complex activities (problems on trips or in unfamiliar places; difficulties navigating while driving in unfamiliar places; confusion carrying out complex tasks such as preparing a large meal)</li> <li>• Needs reminders (e.g., to come to dinner, wash up, comb hair, or get to the bathroom)</li> </ul>
Early-Middle Stage (Allen Levels 4.5–4.0)	Clearly cannot manage complex activities; clearly needs assistance with activities, even daily care activities. Shows an increasing need for cuing and direction	<ul style="list-style-type: none"> <li>• Cannot manage checkbook or finances; cannot successfully plan complex activities</li> <li>• Occasionally becomes lost or confused in places outside his/her normal routine</li> <li>• Makes occasional errors with daily care activities (may perform in a careless manner— spill food, make a mess while washing up, have accidents getting to toilet)</li> <li>• Needs help getting started or continuing with daily care tasks (e.g., needs prompting to keep eating; needs to have things [e.g., hair brush, washcloth] handed to him/her; needs reminders to finish brushing, eating, washing, etc.)</li> </ul>

\*Even in the early stage, when the person seems to be performing well, issues of safety must be raised. Caregivers can't take safety for granted even now.



<i>Stage</i>	<i>Description</i>	<i>Examples</i>
Late-Middle Stage (Allen Levels 3.5–3.0)	Remains somewhat independent in everyday care activities Requires increasing amounts of assistance. Eventually needs full assistance with even simple tasks	<ul style="list-style-type: none"> <li>• Has to be handed things (grooming objects, dinner utensils)</li> <li>• Needs prompting and cuing—more and more in a step-by-step way—to get all the way through a task (has to be reminded to do each step of the task; may need to be served just one thing at a time at meals; has to be reminded to finish the task).</li> <li>• May need direct assistance (need help finishing cleaning up after toileting; have food handed to him/her; have washing-up materials handed one at a time and have their use cued; need demonstration of what to do)</li> </ul>
Late Stage (Allen Levels 2.0–1.0)	Fully dependent in care activities. May cooperate some or be fully passive during care.	<ul style="list-style-type: none"> <li>• May cooperate during everyday cares (e.g., move head while being washed, having hair combed, having incontinence products changed, or while being fed by another).</li> <li>• Gives no response while another does the daily care activities for him/her.</li> </ul>

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



TRANSITION

## Remaining Strengths

- **Completely Independent**
- **Acts Effectively, but with Errors (of performance or memory)**
- **Needs Help Starting (may need prompting)**
- **Needs Direction throughout; follows appropriately and is independent in small parts**
- **Needs Detailed, Step-by-Step Directions**
- **Cooperates with Care Provided by Others**

The main points to emphasize are the following:

- There is a kind of general order or hierarchy to the strength profile, and there will be a general pattern of retained strength across activities.\*
- The person can be described in terms of remaining strengths (s/he's lost powers, but s/he has also retained some).
- Identify behaviors that have been problematic in caregiving. Look for the pattern: do they occur at certain times or under certain circumstances. Does anything bring them on or calm them down?
- Identify activities that are enjoyable to the person—what kinds of things does s/he become easily involved in?
- Continue work on the Tasks and Activities grid (on previous page).
- Continue to describe their person's strengths.




HOMEWORK

# 4

## Savvy Caregiver Program American Indian / Alaska Native Trainer Essentials

### SESSION 4: STRUCTURING SUPPORT AND UNDERSTANDING BEHAVIOR

<b>Homework Review</b>	30 minutes	 SESSION AGENDA
<ul style="list-style-type: none"><li>• Reading on Stages</li><li>• View CD-ROM Assessment Section</li><li>• Review Tasks and Activities Grid and Personal Care Worksheet</li><li>• Discuss Stage estimated for Person</li><li>• Self-Care Activities</li></ul>		
<b>Managing Day-to-Day Behavior</b>	75 minutes	
<ul style="list-style-type: none"><li>• Understanding the Design of Tasks and Activities Structure, Support, and Personal Preferences as Important Anchors of Contented Involvement</li><li>• Linking Design to Levels of Thinking</li><li>• Adapting Communication Skills to Support Effective Interaction</li><li>• View Video fo “Activities”</li></ul>		
<b>Behavior</b>	15 minutes	
<ul style="list-style-type: none"><li>• Common Behavioral Issues</li></ul>		

Encourage trainees to identify the four factors of managing behavior (Contented Involvement, Person, Structure, and Support) as the Four Cardinal Directions.

Many AI/AN people have an awareness and value placed on nature, earth, place, water, the sun, moon, skies, stars, and planets. One theme that comes from this partnership with nature is the importance of the Sun and the Cardinal directions that its position implies. Also, remember that the Medicine Wheel often has colors and powers associated with each direction. The main point is that the Cardinal Directions can be a powerful symbol



INDIAN  
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onto which the four factors of behavior management can be symbolically attached.

For example, “Contented Involvement” may be East (the Rising Sun), “Person” may be South, “Structure” may be West, and “Support” may be North. This can vary in a way that best fits the tribal or family culture.

**Emphasize that caregiving is ACTION ORIENTED.**

Proper caregiving for the elder will require some thinking and action. Caregiving is a way of honoring the elder in the same way that certain ceremonies or rituals are ways to honor and “connect” with others.



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## Session 4: Objectives

- **Discuss Caregiver’s Estimates of Dementia Stages –these are “Starting Points”**
- **Introduce Anchors of Contented Involvement**
  - **Matching Structure, Support, and Personal Preferences to the Strengths of the Person**

This session continues the workshop’s focus on developing caregiving strategies. Up to this point, almost all of the material dealt with discrete or particular impacts of dementia on the person—and with strategies that the caregiver could develop and employ to work more effectively with the person as behaviors occurred. By now, the home applications should have encouraged a degree of active learning and participation. In this session the learning should feel more global. The introduction of the staging system and the home exercise in which participants were to review the CD-ROM and “score” the Personal Care Worksheet to arrive at an estimate of the Level of Thinking of their own person make this material much more specific and personal. The teaching material with which you will deal in this session is also more personal.

This session will get to the daily work of Savvy Caregiving—how to work with the person with dementia so that s/he will be as content and involved as possible throughout the day. The keys to doing this will be establishing a linkage in caregivers’ minds—and in their practical behaviors—between the stage of disease (and level of performance) of their person and the way they set up the day. The session will focus on the design of tasks and activities. It will build on the idea that people with dementia will likely continue to enjoy doing things they enjoyed before they were affected by the disease. It will also introduce the important notion that the way they design tasks (Structure) and the way they help the person with them (Support) can affect how well the person becomes and remains involved in them.

It is quite possible that some caregivers may not have tried or wanted to try to make an estimate of the person’s stage. Others may not have even looked at the videos in the CD-ROM. For some participants, estimating the

stage will confirm and give name to what they already knew. For others, the exercise can be difficult in a number of ways:

- For those whose acceptance of the disease has been incomplete to this point, looking at the videos, reviewing the tasks and activities grid, and trying to come up with a stage estimate may clash with their own efforts to deny the reality of what is happening.
- For those caregivers and/or family members who are denying the disease, estimating the stage might cause them to look clearly at the situation for the first time.
- For other caregivers, seeing the progression of the disease—in terms of seeing persons who are further along in the disease process—may be something they didn't want to look at or that they find hard (distressing) to look at. You may have some reactions like this in the group.

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

### Continuity and Follow Through

#### Review the Home Assignments

- It is useful to get an initial sense of who among the participants has read the materials in the manual, viewed the videos, reviewed the grid, and done the estimation. This will give you an indication of how to pitch this session. If there are some who haven't yet done the exercise, keep referring, during the session, to what they will learn by reading, viewing, and completing the estimate.
- Did participants have any responses or reactions to the videos in section four of the CD-ROM?
- Were there any additions or changes to the caregivers' reflections on remaining strengths?
- *Identifying Behaviors.* Have caregivers report on their efforts to identify and analyze behaviors they found difficult or challenging.



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

- *Self-Care Activities.* Ask the group to report back on activities aimed at dealing with their own feelings related to caregiving (identifying and transforming “negative powerless” feelings to more positive and powerful ones) and at taking some time to do something for themselves.
- *Estimating the Stage.* This will likely be the most involving part of the review of homework activities. Here are some questions you might use to get into this part of the exercise and to keep it going:
  - Do you have any questions about the staging system?
  - Were you able to view the CD-ROM section on assessment and read the material in your manual?

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



TRANSITION

### **Managing Behavior Day-to-Day: The Anchors of Contented Involvement**

This is the “how to” part of the workshop; how to fit tasks to abilities and how to help the person to get and stay involved in those tasks and activities. It is during this portion of the workshop that you will provide substance for two of the most important terms that you will continue to use throughout the program,



INFORMATION

#### **Support and Structure**

Along with personal preference (Person), these concepts form the anchors of Contented Involvement—the guides caregivers can use to keep their person doing things.

The foundation of this brief talk is that there is a basic inter-relationship between the kind of Structure and Support one provides and the stage of the person’s disease. This is a circling back to the idea of “Fit” that was introduced in the last session. A task or activity that enables a person with a dementing disorder to be content and involved in it is one that somehow taps into the person’s own personal preferences, is shaped in a way that matches his/her remaining abilities, and is guided by help that also matches the person’s abilities.

*The emphasis should be on positive involvement.* The basic idea is that persons with dementia can do things and can enjoy and be content in doing them. It is very possible that—once the topic of behavior is introduced—participants will want to discuss the opposite of this topic. They will want to engage in conversations about how to get the person to stop doing certain things—troubling behaviors. Recall that a portion of session 2—along with sections of the manual and the CD-ROM—dealt with this topic; also portions of session 5 will cover this as well. Once, however, participants get the idea of Structure and Support, these sources of information will mean even more. It is important that the topic of quelling difficult behaviors be understood through the same framework that encouraging positive involvement is understood. Therefore, ask them to hold off further questions on difficult or troubling behaviors until you’ve completed the part on Structure and Support.

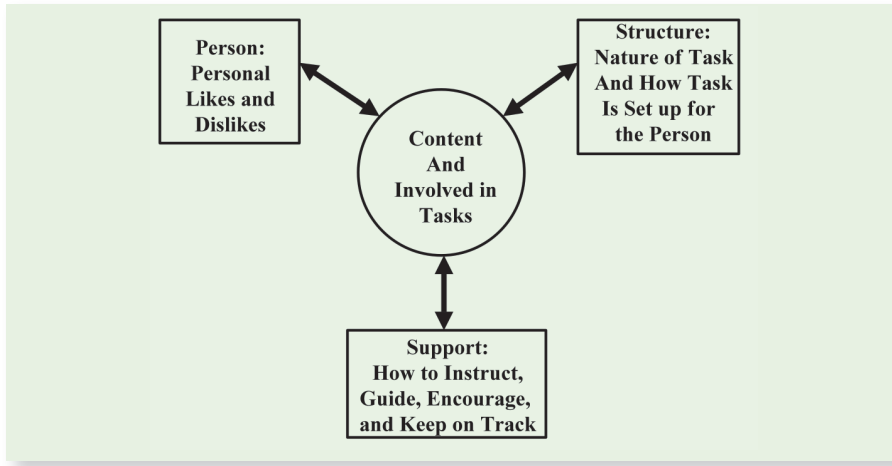
#### Person, Structure, and Support

The following diagram offers a beginning point for the talk.



BRIEF TALK





Slide 56, above, illustrates the point that, in almost any activity we can think of, there is a process of ongoing assessment that is necessary to maintain a condition of contented involvement. This is as true for our own involvement in things as it is for the involvement of a person with a progressive dementing disorder.

In this process, caregivers use what they know about a person to adjust the kind of task or activity they seek to involve him/her in. That is, personal preferences—what the person likes or dislikes—affect the choice of tasks. Of similar importance, the nature of the task, the way in which it is set up, and the help that is given to get and keep the person going in the task—all these play critical parts in helping the person to be content and involved in the task.

Always, this is a dynamic process. Caregivers use their observation of how the person reacts to a particular activity on a given day to readjust their estimate of the person's overall ability to perform tasks.

When considering how such adaptation might work for their person, participants will have employed principles that are portrayed in this diagram. Again, we are emphasizing three major ideas and strategies:

*Right-sizing.* Caregivers will need to pick tasks that are the right size and complexity for their person at a given moment.

*Set-Up.* For each person, the caregiver has to decide just how much front-end help they will need.

*Appropriate Assistance.* Each person will require different kinds and amounts of help to get started with and keep going in their parts of the task.

The first two of these principles relate to the idea of Structure; the third relates to the idea of Support.

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

Use the slide following (57) to talk about ways to think about tasks. In particular, try to get participants to see that there are important dimensions of tasks. From their perspective, the importance is that these dimensions relate to the choices they have to make to provide Structure for the activities, tasks, and events that they will hope to get their person to be enjoyably involved in. They should have some kind of framework for analyzing tasks so that they will have a systematic approach to tinkering and experimenting with them to try to arrive at an appropriate fit for the person.

## Important Dimensions of Tasks

- **Size**
- **Complexity**
- **Space/Distance**
- **Time**
- **Skills**

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

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

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

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

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

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

**Structure.** The next idea you'll want to present is that of Structure as it applies to caregiving. Structure is simply the total manner in which a task, activity, or event is presented to a person. Appropriate Structure takes into account the abilities of the person to whom the task is presented.

The next slide (58) provides a concrete representation of the relationship between disease Stage (and level of performance) and Structure. It suggests starting points for the basic relationships between disease stage and the key dimensions of tasks.

Stage (level)	Size	Complexity	Space/ Distance
<b>Early</b> (5.0)	4-6 steps	Can involve some abstracts	Can travel outside
<b>Early-Middle</b>	(4.5) 3-5 steps	should be simpler	might travel
	(4.0) 2-4 steps	more concrete	in one area reduce inputs
<b>Late-Middle</b>	(3.5) 1-2 steps	only concrete	at a table no distracts
	(3.0) 1 step or passive	concrete or passive	table facing wall
<b>Late</b> (2.0)	passive	passive	watching

Walk through the chart, stage by stage. Try to use some examples. A person in the Early stage who is functioning relatively independently can run errands around the house (and possibly in the immediate neighborhood). As the person's disease worsens and s/he enters the Early-Middle stage (level 4.5), the person would likely be able to navigate a large room easily and might go outside the room—s/he may function better at this with a companion. A person at level 4.0 might be more comfortable and less distracted doing something in just one part of the room, something that doesn't involve too much moving around. A person in the Late-Middle stage (e.g., at level 3.5) will likely do better at a small table with a 1-2 step task. A person at level 3.0 will be easily distracted, so remove stimuli—perhaps have him/her facing a bare wall and do a 1-step task. A person in the Late stage of the disease (level 2.0) might enjoy watching an activity and taking part passively in it.

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

## Support

Support has to do with the help a caregiver provides to a person with dementia to help him/her to become and remain involved in a task, event, or activity. Use the slide below (59) to talk about kinds of support.

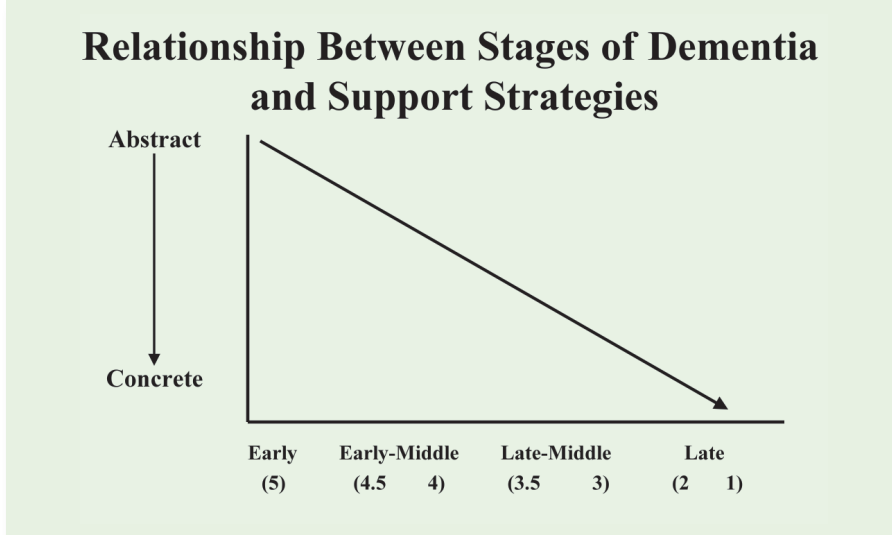
This introduces the idea that all support strategies are not equal—that they are of different sorts.

Ask the group to try to differentiate among the support strategies. This leads to the next slide (60).

**The Order of Support Strategies  
as Dementia Progresses**

Early	$\longrightarrow$	Late
<p><b>Writing</b></p> <p><b>Complex verbal directions</b></p> <p><b>Verbal suggestions or reminders</b></p>	<p><b>Simple verbal directions</b></p> <p><b>Words linked to demonstration</b></p> <p><b>visual cue (pointing) or examples</b></p>	<p><b>Visual cue linked to naming</b></p> <p><b>Handing step by step</b></p> <p><b>direct by touch</b></p>

The concept is straightforward and intuitive. Some forms of help and communication are more complex than others; some are more concrete. As the dementia progresses, the kind of Support (communication) caregivers use should be matched to the person's abilities. Early in the disease, fairly normal forms of communication—forms that rely on language—will remain effective. But as the disease progresses, other forms of communication—forms that are less abstract and more direct and concrete—will need to replace language. Thus, pointing to things becomes an important support strategy in the Middle stages (think back to the stage videos that were shown last session; recall that with the later participants, the Occupational Therapy Assistant often used pointing and tapping on things (like the ham) to call the participants' attention to them). Eventually, more tactile methods are needed (again recall how the OTA guided the last participant's hand in the towel-folding exercise). Participants should be encouraged to think about how they can make their interactions increasingly clear and concrete with their family member.



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

#### A Basic Note About Communication

Take a moment, while dealing with Support, to make a few basic comments about communication strategies. There are a few basic points to emphasize about communication with a person with dementia:

- *Make sure you have the person's attention.* Don't assume the person's attention is on you. Give the person time to recognize you are there and to focus on you before you start talking or engage in any form of communication (e.g., touch).
- *Try not to startle the person.* Don't come upon the person from the back or side. Have the caregivers imagine what it's like to have someone touch them from behind when they don't know that anyone is there. Usually, people jump. There is research that indicates that the visual field of persons with dementia shrinks as the dementia progresses. Gradually peripheral vision is lost and the person sees only a narrow band directly in front. As a result, persons approaching from the side may seem to appear suddenly, producing a startle reaction.

- *Make sure the environment is not working against you.* Many things in an environment can distract the person. Too much clutter and a bright light behind you are two of the main problems. Similarly, too much noise—the TV or even music in the background—can easily distract the person.
- *If possible, deal with sensory deficits.* If there are hearing and/or vision problems for the person, make sure that they have whatever aids (glasses, hearing aids) that s/he need to correct the problem. Hearing aids are tricky. They amplify sounds. A person with dementia may no longer be able to filter out background noise from meaningful sounds, so a hearing aid may make matters worse by just making things louder. In addition, if the person is not used to having a hearing aid, putting it on may prove difficult—it could even become a source of struggle. Moreover, most hearing aids need to be manually adjusted, and this could be difficult for the person.
- *Use appropriate techniques.* Issues of pitch, tone, and volume of voice are important. The person has to be able to hear you, and you don't want to sound like you're angry. Beyond this, choice of words, length of sentences are important as the disease progresses. Savvy Caregivers have to learn to rely less on language and to begin to use visual and tactile signals as an integral part of communication.

**[There is more on communication in the Caregiver Manual, and you can refer participants to the GRECC pamphlet series that includes three pamphlets on communication issues.]**

Have the participants take out the *Support and Structure Sheet* (see next page). Go through it stage by stage and discuss the various support strategies for each stage. Keep pointing out how the strategies become more concrete as the disease progresses. Relate the chart back to the lecture and related readings from session 3—on the stages and performance levels. Relate the Structure portion back to the point made earlier in this session about the important elements of task—note how, as Thinking declines, task size, complexity and geography all need to be decreased—made smaller and more immediate. Note too that the chart refers back to the point made in session 3 about the three elements of performance (Purpose, Order, and Use)—as dementia progresses, these capacities are lost, in order. As a result, the caregiver, in providing Structure and in thinking about a Support strategy for a task or activity, has to keep in mind what parts of performance are still present and what parts will s/he have to substitute for.



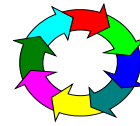
## Support and Structure Sheet

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

## Video of Activities

This is a good place to view the Video section of Activities. In this segment, the O.T. leads a small activity group for several women with dementia. She demonstrates many of the skills - support and structure—that we are talking about in this session. The video takes about 18–20 minutes. It will reinforce the content, and may open up questions or comments for discussion.

This talk has thrown a lot of material at the participants. The caregiver manual contains a discussion of Structure and Support, so they will be able to read and re-read it if they need to, but now would be a good time for them to get some practice in applying the ideas. The exercise will ask the participants to use the information about stages and levels of performance as a key to designing tasks (i.e., deciding on the kind of Structure and Support they might provide) for a number of persons with dementia who are at various stages of the disease.



EXERCISE

**Note to Savvy Trainers in Indian Country:** Consider using examples from your tribal area to replace those provided below.



INDIAN  
COUNTRY

Ask the participants to imagine that they are volunteer visitors for a number of people with dementing disorders. Have them use the Structure of Tasks slide above (Slide 58) and the Structure and Support Grid (above) to design tasks for the following people (part of the design task should involve taking into account who the people are—what interests and abilities might participants draw on to try to get them involved in tasks or activities?):

- Mrs. L. is a retired librarian. She had been an avid traveler and a prize winning gardener. She is in the early stages of her illness and has been assessed in the Early stage of the disease (approximately Allen Level 5).
- Mr. B. is a retired engineer. In addition to his interests in the details of elaborate projects, he was a life long tinkerer around the house and still has a big and well stocked tool shop. He has been assessed at the Early-Middle stage (about Level 4).
- Mrs. J. had a career as a homemaker, parent, and grandparent. She was a good and enthusiastic cook and a doting grandparent. Her dementia has progressed considerably to Late-Middle stage (Allen Level is in the low 3's).

*The group's task, with each of these people, is to design an activity that might keep each involved for a short period of time. The questions to ask/answer are:*

- What activities might interest the person?
- How should the activity be Structured? What should the dimensions of the task/activity be? How many steps, what kind of space/geography, how complex, what kind of environment?
- What kind of Support should you provide? Will the person be able to understand the whole task or just the steps? Will s/he be able to get started on his/her own, or will you have to give help? How much step-by-step help might you need to give? What form of communication might work best with the person?

See some examples of the kinds of things the group might try for the three people on the following page.

---

**Mrs. L., Early (Level 5)**

- Possible Task:*
- Looking through travel photos
  - Sorting things (use a librarian’s skill)
  - Some kind of gardening task—e.g., repotting)
- Structure:*
- Can handle multiple (4–6) steps and can move from room to room
  - Will likely understand purpose of task
  - Might have to help setting things up or finding things
- Support:*
- Once attention is engaged, she will likely begin task on own
  - May become distracted and need verbal refocusing
  - May chat during task
- 

**Mr. B., Early-Middle (Level 4)**

- Possible Task:*
- A simple assembly task
  - A Shop task—e.g., sanding
  - A sorting task—e.g., putting nuts and bolts into jars
- Structure:*
- Things will have to be all set up in front of him—have him at a table—and he may not be too clear on the nature/purpose of the task
  - Not too many steps (2–4)
- Support:*
- Provide visual cues
  - Help him get started (hand objects and give start cue)—might need to demonstrate
  - Be prepared to help him refocus throughout the task if distracted
- 

**Mrs. J., Late-Middle (Level 3)**

- Possible task:*
- A food preparation task (e.g., peeling)
  - Reminiscence—looking at family pictures
- Structure:*
- Everything in front of her; minimize distractions
  - May actively do a 1-step task or participate passively
- Support:*
- Hand objects and show what you want her to do
  - Go slow—see she’s focused on task/activity
  - Keep focus with visual and tactile cues
-

The linkage between stage (and Level of Performance) and caregiving strategy (Structure and Support) is central to Savvy Caregiving. The main “homework” for participants this week and next will be for them to try to apply these ideas at home. *Summarize the main points.*

**1. A Key goal of the Savvy Caregiver is to help the person get and remain content and involved in things during the day.**

Several words of caution here. Caregivers have to be careful not to become slaves to this goal. It doesn't mean that they have to worry that the person is content and involved every minute of the day. Both they and the person would find this exhausting. But it does mean that they should have the mindset that even a person with dementia can get involved in things and can enjoy them. It also means that they can use their new skills (taking disease stage and performance level into account in designing the Structure and Support for tasks) to help the person become involved. Point out, too, that if the person can become involved—and/or if caregivers can find a small set of things that they can use to get the person occupied when s/he is becoming agitated or confused—the caregiver may find s/he has a bit more space for him/herself as well. Remind them of the point made in session 2 about the power of Confusion and of the person's need for security. The Savvy Caregiver establishes a routine that provides comfort and security. If the caregiver can figure out a set of activities that characterize everyday life—things the person does (either to help the caregiver with things around the house or on his/her own), that set of activities constitutes a routine. In the same way, if the caregiver can have a repertoire of activities s/he knows the person likes, the caregiver can call on these in times when s/he (the caregiver) needs a break or when things are starting to get out of hand. It is also the case that knowing this set of preferred activities will help the caregiver to use outside help. The caregiver can instruct someone else—for instance a member of the family or a paid helper—about a set of activities they can give the person to do, activities the person is likely to enjoy and become involved in.

**2. Interest in involvement starts with the Person. What did the person like to do and what was s/he good at? What interests did s/he have and which ones does s/he still show?**

**3. Having a good ballpark estimate of the disease stage (and level of Performance) helps the caregiver to decide on the kind of Structure and Support that might help the person become and remain enjoyably involved in the task/activity the caregiver selects.**

It is worth mentioning to the caregivers that persons with dementia can sometimes become involved in tasks or activities in which they had had

no previous interest. As a result, they should feel free to try some different things. For example, a man who had never cooked or laundered might be persuaded to help with some parts of these tasks (like peeling carrots or potatoes, shredding lettuce, drying or stacking dishes or sorting silverware, sorting laundry or folding clean clothes). Similarly, a woman who had never shown any mechanical inclinations might be happy to sort through a jar of nuts and bolts and separate them into piles. At worst, the person will show no interest; at best, the caregiver might discover another activity for the daily repertoire.

As caregivers begin to apply these principles in their caregiving, ask them to keep a couple of guidelines in mind:

- *Be flexible.* The guidelines in Section 5 of the CD-ROM and those that are in their readings and handouts are broad in nature, and the estimate of the stage that they have arrived at is only a ballpark estimate—it's probably pretty close, but it's not as accurate as if it were a professionally done assessment. So use the guidelines in a relaxed manner.
- *Be experimental.* Try different kinds of tasks and activities—even things the person might not have done much or at all before (for example, try having a person who never cooked or cleaned house help with these chores or a person who showed no interest in home repairs or gardening try her/his hand at some of these tasks). But most importantly, experiment with the kind of Structure and Support you provide. Just because you think your person is at a at the Early-Middle stage (e.g., Level 4.5), don't limit tasks to the 3-5 step range that is suggested. Try tasks with more or fewer steps; see what fits. The same holds true for Support. Maybe a person in the Early stage will benefit from more visual cueing as well as the verbal help you provide. Perhaps a person estimated at the Late-Middle stage (Level 3.5) is happier as a passive participant or maybe s/he still gets more from verbal information that one might expect.

This is like adjusting an old color television. You've got several dials—for color, tint, contrast, and brightness—and it is finding the right balance among all of them that will produce a clear picture with good color. You've got to fiddle around till you get it right. The added problem with dementia is that, once you get it right, you know that something will happen that will cause you to have to readjust. The person's condition will change over time, or the person will have a good day or a bad day and somehow be different from how s/he was on the day you got all the settings right.

- *Recognize you are developing a skill.* Keep working at this. It may be that you won't get it right the first time, but you should begin to see elements of success in your efforts. Try to learn from what works and what doesn't, and give yourself credit for even partial successes.
- *Link Successes to Self-Care.* Remember that every time something works, that's an accomplishment—an upper right quadrant feeling (positive and in control). And even when something doesn't work, you're taking action—moving from not being in control to being in control.



TRANSITION

## Common Behavioral Issues

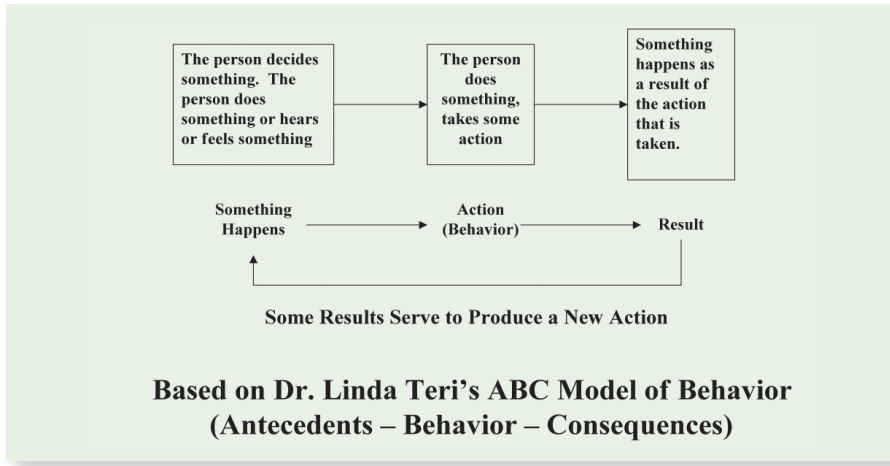
### Understanding Behavior Problems

This section of the provides you with a way to add to participants' understanding of behavior, introduce key issues of behavior in dementia, and tee up a major reading assignment (Chapter 8 of the Caregiver's Manual). The assignment covers typical behavior problems and strategies for dealing with them. Time may not permit you to cover this material in this session (though you should be able to pick it up in the homework review next time). Use your judgment about how much, if any, of this to cover in the group setting.

The first point to make involves an expansion on the simple model of behavior that was covered in session 2. The slide below is included in the Caregiver Manual.



INFORMATION



The main point to make here is that **All Behavior has Meaning**. Behavior is the middle point in a process; typically, it is the reaction to or result of something that occurs beforehand. Usually, what occurs beforehand is something the person is thinking about or assessing, and the action is taken deliberately. Thus, a person who is crossing a road sees a bus coming at him/her and behaves (jumps out of the way) in response to this antecedent stimulus. One possible result of this behavior might be that the person will be more cautious in crossing streets.

From what participants already know from the workshop about the way dementia affects thinking and the central role of confusion in dementia, they should be ready to accept the notion that, while the behaviors that people with dementia engage in are responses to antecedent stimuli, the behaviors themselves are not necessarily self-directed or connected (in a straight-line fashion) to the antecedent stimuli.

So it is left to caregivers to figure out what the behaviors mean. Actually, people are quite good at this, and the next exercise is meant to remind caregivers of their skill at discovering the meaning of behaviors—and in dealing with them.

You can use this exercise to make participants aware of the ways in which they usually handle unusual behavior. The exercise involves a very simple guided image.



EXERCISE



Ask the participants to imagine that they are in a shopping mall. It's the holiday season and the mall is very crowded and very noisy. Loud holiday music is being piped over the loudspeakers. The crowds are intense. People are jostling and bumping each other. Little kids are being dragged along, bumping into other people and shopping bags.

Out of the corner of your eye you see a little girl—you judge her to be 2–3 years old—sitting alone on a bench. She is crying frantically, but no one seems to hear her or to pay attention.

You decide to help her.

Ask the participants to brainstorm about what they will do. Make a list of the things they say. After they finish responding, point out that the list will almost certainly include the following:

- They will try to figure out what is troubling the girl (though this will be intuitive, since the child will likely not be able to provide much useful information)
- They will try to calm her and offer reassurance
- They will try to get the girl to feel trust in them
- Only after this will they try to do something about the situation—go to the security office and have a parent paged
- They would probably not leave the child alone until the parent is located.

The point of the exercise is to get the participants to recognize that they have a process that they use when they encounter a situation that is rooted in confusion:

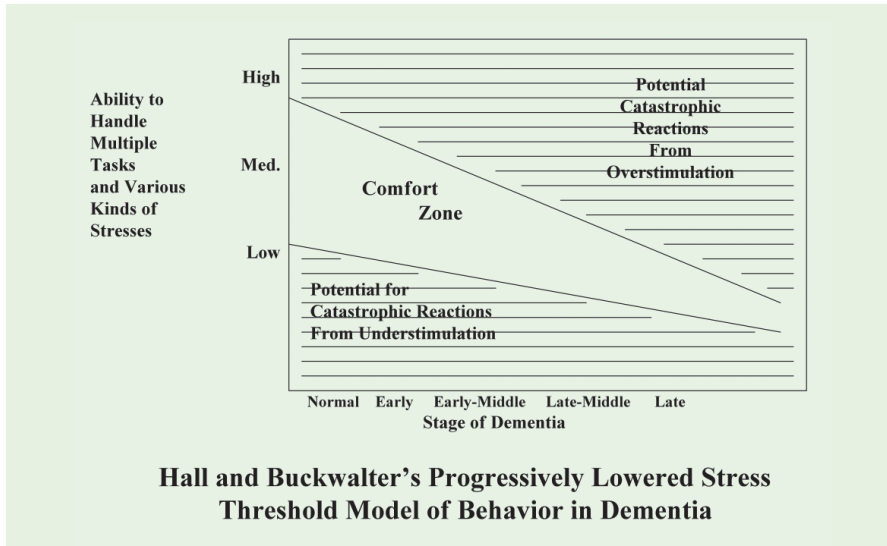
- They look at the situation and analyze it
  - The child has lost her parents
  - She is frightened and confused
  - She hasn't got the capacity to figure out or correct the problem—it is beyond her abilities.
- They seek first to establish some kind of calm in the situation
  - Get the child to focus on them
  - See if they can get her to stop crying and calm down
  - See if they can get her to feel—at some level—that they will make the situation alright

- Only after calm is established will they try to remedy the larger problem

This pattern—figure out the disturbance, re-establish calm, and deal with the larger problem (if possible)—is the basic pattern suggested in the Savvy Caregiver manual for handling the troubling behaviors they may face. The first session of the workshop has provided information about cognitive losses, and this should help them to understand that the person cannot think his/her way out of situations that may be confusing. The portion of the workshop on Confusion should help participants to appreciate the emotional state that persons with dementing disorders find themselves in. With this understanding of the situation, then, caregivers need to approach troubling behaviors with the general framework they applied to the situation above.

It might be useful to remind participants about the confusion issue. The slide below illustrates a model developed at the University of Iowa School of Nursing to explain troubling behaviors in persons with dementia.\*

\*Hall, G. and 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.



The slide should draw participants' attention to the idea that, as dementia progresses, the person's capacity to anticipate, analyze, and produce a measured response to an antecedent stimulus, a response whose meaning might be clear to an observing caregiver. So, the caregiver has the task of figuring the behavior out. To do this, they should follow the same pattern they followed in the exercise above: Observe; Analyze; Seek for Calm; Work toward a Larger Solution. This pattern is covered in detail in Chapter 8 of the Caregiver's Manual.

#### Common Behavior Problems

There are a number of problem behaviors frequently associated with dementing disorders. Included in these are, for example: wandering, repetitive questioning, shadowing, and sundowning. The Caregiver manual discusses a number of these behaviors and relates them basically to the problem of confusion and to the emotional needs (for security, control, and calm) that stem from confusion. If there is time and you think it would be fruitful to do so, you can use this portion of the session to draw caregivers' attention to these issues and to this section of the manual. You should again assure them that—whether they know it or not—they have a framework that they typically use to analyze behavior—one that involves trying to figure out what the behavior means and then responding appropriately.

- Read the material in the Caregiver Manual regarding Dealing with Daily Care and Complicated Behavior (Chapter 8).
- View section 5 of the CD-ROM. Start with the management advice at the Level you have estimated, but be sure to navigate up and down at least to the next level to get a fuller picture of how to handle various levels.
- **Pick one behavior you would like to work on and, using the materials from the workshop, design the Structure and Support strategy you think might work to accomplish the. AND THEN TRY IT OUT.\***
- **Work on designing a task or activity in which to involve your person in the morning or afternoon. Use the Structure and Support guide to help you design the activity and to get and keep your person involved in it.**
- View selection # 4 in section 6 of the CD-ROM (Activities Possible at Home) and review section #9 (Communicating at the different levels).
- Continue Self-Care activities related to the identification and transformation of negative powerless feelings and to taking time for yourself.



HOMEWORK



MEDIA

\*This is an important—perhaps the most important—moment in the workshop. Some—if not many—caregivers may have, up to this point, been content to see this as a passive experience salted with some in-class exercises. You’ve got to make it clear that the expectation is that they really will attempt to put what you’re teaching them to work. Let them know that the sessions in the next two weeks will center on their reports from home—and that you and all the classmates are counting on them to make an effort.

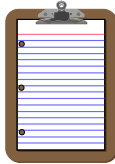
At the same time, make it clear to the participants that they should not see this as a life or death experience. Emphasize that they should work on a small thing, not necessarily the thing (behavior) that is bothering them the most. For example, they might see if they can get the person to engage in some kind of activity that s/he has not done before—e.g., helping with chores or meals. Or see if they can find something that the person might be content to do on his/her own, even for 10 or 15 minutes. They might try to see if they can do something about a small thing that is bothering them (e.g., the person always wants to wear the same thing). If the person always asks the same question, they might try strategizing about an answer they want to give.

Basically, what you want them to do is to make an effort to make some basic change in strategy. It might even be a change in the way they talk to or provide information to the person. Might, for example, talking in shorter sentences or providing less information until a time at which it is absolutely useful change the way the person behaves (for example—might it change the questioning the person does during the day)?

# 5

## Savvy Caregiver Program American Indian / Alaska Native Trainer Essentials

### SESSION 5: APPLYING SKILLS AND MANAGING DAY-TO-DAY

<b>Homework Review</b> <ul style="list-style-type: none"><li>• Work on Issues of Behavior</li><li>• Work with the CD-ROM</li><li>• Self-Care Activities</li></ul>	40 minutes	 SESSION AGENDA
<b>Managing Day-to-Day Behavior</b> <ul style="list-style-type: none"><li>• Linking Structure, Support, and Levels of Performance</li><li>• Taking Care of Daily Needs</li><li>• Facilitating Contented Involvement</li></ul>	50 minutes	
<b>Decision-Making</b> <ul style="list-style-type: none"><li>• A Model for Decision-Making for Family Caregivers</li></ul>	30 minutes	

Encourage trainees to “keep at it” like warriors when they try to use the Savvy techniques.

AI/AN people have “kept at it” over several hundred years of efforts to defeat them. Defeat did not happen. AI/AN people persisted. They overcame hardships and protected their culture to the best of their ability. Caregivers often have to keep at it, too.



INDIAN  
COUNTRY

Emphasize to trainees that caregiving sometimes requires a warrior-like approach.

Caregiving is often frustrating, tiring, and sad. However, like warriors, caregivers hang-in-there as best they can. Caregivers, like warriors, should also take care of themselves.



INDIAN  
COUNTRY

**Caregiving can often require courage to continue.**

Dealing with an elder with dementia can be scary at times. Angry outbursts or striking-out at someone can sometimes happen. In spite of fear, warriors continue. However, notice that such problem behavior is usually a brief matter and elders with dementia do not launch a sustained physical attack on caregivers.



INDIAN  
COUNTRY

**Caregivers have to endure.**

Dementia is a long, progressively worsening disease. Caregivers must take care of themselves to keep their ability to provide good care. Warriors trained and prepared to go war in the same way that caregiver trainees are preparing themselves to be good and lasting caregivers.



INDIAN  
COUNTRY

## Session 5: Objectives

- **Participants will appreciate that they have developed/strengthened their caregiving skills**
- **They will experience an increased sense of mastery in their caregiving role**
- **They will acquire additional skills – Introduction to the Options, Outcomes, Values, Likelihood Decision-Making Model**

A shift takes place in this session and continues through session 6. Last week's home assignments were aimed at having caregivers put the main lessons of the workshop into practice. This week and next, you will want to spend significant time during the session debriefing caregivers about their efforts to put instruction into practice. A goal of this session will be to have caregivers describe their efforts at putting caregiving strategies to work this week. In addition, there are two "classroom" pieces in this session; one that gives more examples of using Performance, Structure, and Support to anchor Contented Involvement and another that introduces participants to a model of decision-making that they can use both with larger, long-term decisions and with making choices about day-to-day management.

There are several home assignments to check on. Reporting on the caregivers' efforts to put behavior management principles into practice should be the major activity. You also want to check on their reading of Chapter 8 of the Caregiver Manual, their continued interaction with the CD-ROM, and their comprehension of the staging system.

*Work on Issues of Behavior.* The main assignments were to try to change some behavior that was bothering the caregivers and to try to design a morning or an afternoon activity the person would enjoy.

As usual, have the caregivers volunteer to describe what they did. Those who tried and met with success will usually want to step forward to talk about their experience. Those who tried and did not meet with success—or at least what they had in mind that success might look like—will also likely step forward. You may find that you will need to prompt caregivers'



INFORMATION



EXERCISE

participation, so it may be useful to remind them of the homework (work on a behavior that bothers you and work on finding a morning and an afternoon task or activity that the person gets involved in and likes doing). Then try asking them (for example):

- Did anybody work on trying to change some behavior of your person last week?
- Did you think about something that was bothering you and try to use what you know about the Levels of Thinking and the ideas of Structure and Support to do something with the person about that?
- Did you try to design things the person might do in the morning or in the afternoon?
- Did anybody try things but find they didn't work?

*This exercise involves a very important facilitation task, and it is important that you know what you are expecting.* Do not expect that there will be a lot of reports of success in session 5. The distribution of caregivers' experience with this homework assignment will likely look something like this:

- One or two will have tried the assignment in a way that suggests they really understood a lot of the workshop principles and ideas, and they will have met with success. That is, they will
  - Describe what they did in terms that reflect the content of the workshop (applied, for example Structure and Support strategies appropriate to their person's stage [level of performance]).
  - Report that their person's behavior changed in ways they (the caregivers) both anticipated and appreciated, and
  - Demonstrate a sense of pride or accomplishment in what they did.

This expression—that they feel good about having taken what they have been learning, put it into practice in their caregiving, and met with success—is Mastery. This is a key goal of the workshop—that the caregiver feel more in control, more skilled, and more confident that his/her skills and knowledge make him/her more able to handle the caregiving they have undertaken.

- One or two will have tried to apply the principles and ideas of the workshop, but they will seem not to have worked.
- The others will report that they did not try to do the assignments (change behavior or develop a morning or afternoon activity).

Be sure that you “call on” all of the caregivers. Those who didn't have much success or those who didn't do the homework—or who



think they didn't—should be asked what they did or tried during the previous week. You are likely to find that even those who say they didn't do the homework did, in fact, put some of the lessons of the workshop into play. Try to draw this out of them—they may not have realized at the time that they were doing this but the class conversation—particularly the part where they are hearing what others did—may make them aware that they did try some things, even if not consciously. So don't let them off the hook.

**Think of each report—whether of success, failure, or not trying—as an opportunity to teach the savvy caregiving model. You will have a number of different kinds of opportunities to support caregivers' attempts at applying the new information and strategies.**

It may be that success came from application of some of the ideas presented earlier in the workshop. For example, we have found that for some caregivers an appreciation of the concept of Confusion has been very important in their becoming more understanding of and patient with some troubling behaviors of the person. This understanding has, in turn, allowed them to develop responses that are effective but that also allow them (the caregivers) to be less drawn in by the person's behaviors. A good example is with the issue of repetitive questioning. Seeing that the questioning is driven by a need for security—rather than a desire to annoy or be difficult—might help the person to develop one or two responses that are meant to address the feeling and to reassure rather than to directly address the question. Another example goes back to the material on cognitive loss presented in the first session. A caregiver who comes to see the impact of diminished capacity in language and reasoning might, for example, consciously decide not to present too much information—for example, not to tell the person what the whole day will be like but to deal with things only as they come up or are about to happen. S/he may decide to change the way in which s/he speaks to the person. S/he may have decided to shorten sentences or to use declarative sentences rather than to ask questions and involve the person in decisions. So, for example, instead of saying, “would you like to go for a walk after lunch?” the caregiver may now say nothing about the walk until it is time for it and now say, “Come with me. We're going for a walk.”

### **Reinforcement**

Clearly, those who put the principles into play and met with success should be praised—and they should have an opportunity to talk about how they feel about the success they met with. Their success also provides you with an opportunity to review how they approached the task. This lets you go back over it and make whatever the appropriate points might be about

the way in which the caregiver used knowledge of the stage (performance levels) or of the design principles (Support or Structure) to achieve success. Use this as a chance to review the steps the caregiver took—to go back over the ground s/he covered in putting together the Structure and Support steps to achieve the end s/he achieved.

A very common problem you might encounter is a too rigid application of the principles. The first place you might see this is in a too fixed estimate of the person's stage. The caregiver may be thinking of the person as being more or less impaired than s/he actually is. This, in turn, would cause the caregiver to be applying management principles from section 5 of the CD-ROM or from the Structure and Support worksheet that don't actually fit the situation. A simpler example might be that the caregiver is using the Structure and Task worksheet too stiffly—"It says 5-6 steps, and that's what I tried."

#### Clarification

Even with the class exercises, the readings, and the material in the CD-ROM, the material is not always easy or easily understood. For all the caregivers who are reporting, listen for how they talk about what they did and how they used the materials of the workshop. Make sure that their understanding of the ideas and principles is correct, and if it is incorrect in any way, take this as an opportunity to review the material and make them clearer on it. Remember, too, that even if the effort didn't yield the desired effects, the caregiver should be praised and encouraged for making the effort. *The experimental attitude is very important and should always be encouraged.*

#### Encouragement

Particularly for those who reported that they didn't do the homework, this portion of the workshop should be used to encourage them to do the homework this week (it will be virtually the same assignment). This is also an opportunity to draw the "non-doers" out—to get them to talk about what they did do during the past week to put some of the Savvy Caregiver principles into effect. Some participants will just be too shy to report to the group until they have what they define as a clear success. Until that time comes, they may report that they didn't do anything—or at least not anything very much. Probe to get them to talk about what they did do. It may be they really did not try anything, but there is a good chance that they did make some attempts, and this will give you an opportunity to reinforce them for their analysis and to encourage them for their efforts.

## Review Self Care Activities

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

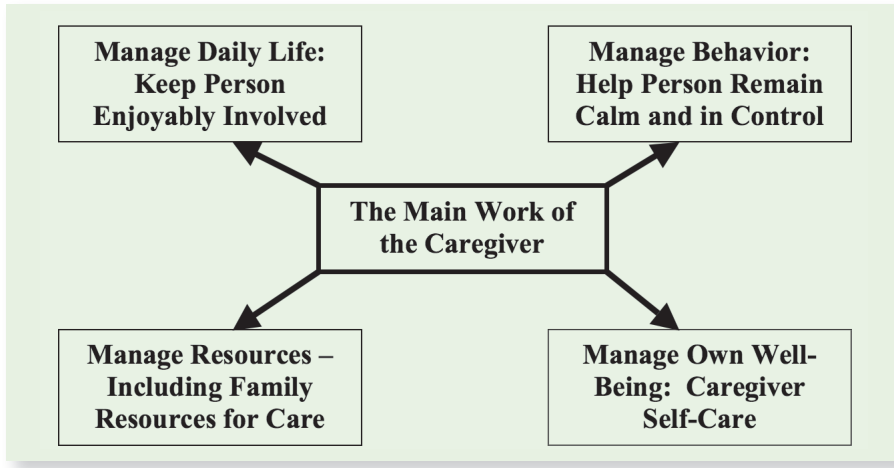
This portion of the workshop focuses on strengthening caregivers’ understanding and use of the Anchors of Contented Involvement, Structure, and Support—as well as on their ability to make practical use of these tools in their caregiving. By this point in the workshop, caregivers should be relatively comfortable thinking and talking about what they do as a “job,” or at least recognize that caregiving requires a set of skills, knowledge, and strategies. It might be useful to use the diagram below as a way of reminding them about the main components of the job they have undertaken.



TRANSITION



INFORMATION



Remind participants of the information on managing behavior that they learned earlier (Sessions 2 and 4). The discussion on Confusion was a key part of that—focusing on the roots of the kinds of behaviors that caregivers often find troubling or difficult. Readings in their manual and videos in sections 5 and 6 of the CD-ROM relate to the issue of managing troubling behaviors.

Caregivers may be making their first efforts to apply the principles of the program to managing life around the home with the person affected with dementing disease. When it is broken down into its simplest form, the idea of managing daily life comes down to two big categories:

- Taking care of the person’s personal daily needs (keeping clean, getting dressed, eating, etc.).
- Getting the person appropriately involved in things so the day is pleasant and full. The rest of this portion of this session will focus on exercises designed to get participants to apply what they have learned about the design of tasks and activities.

**Applying Knowledge to Practice:** In this exercise, caregivers will design and specify the kinds of Structure and Support strategies they would use to involve persons at various stages of the disease in a task related to personal daily needs. In this case ask them to think about helping a person to get dressed in the morning. Have the participants review the handout on washing up. This handout brings together all of the key concepts you have introduced and focuses them on the issue of managing a daily task to meet personal need.\*

\*The handouts and exercises in this section derive from and link with material in section 5 of the CD-ROM.



The first part of the exercise is to walk participants through the handout (which they have in their Caregiver Manual).

Show caregivers how the handout works. Note that the columns relate to stages and corresponding levels of performance—each column focuses on working with a person at a different stage of the illness. The first row relates to Structure and the next two relate to components of Support. So, reading down any column, the table provides an outline of information about how to Structure the washing up task for a person at that stage and level of performance and then how to Support the person through the task—what kind of help to expect to give and how best to provide the information that conveys the help.

After reviewing the handout, have the caregivers focus on the matter of helping a person to get dressed in the morning. By now, participants have all settled on an estimate of their person's stage. Go around the group and have each person say what s/he thinks her person's stage or level is. Let participants working with persons at the same stage form sub-groups. Ask the groups to describe—in a fuller way than is in the handout—just what they would do to provide Structure and Support for helping their person to dress in the morning.

Have each of the groups report back to the larger group, and use the larger group to provide comment—offer additional suggestions for what might be done at each stage—on the way in which the stage-specific groups had set up and carried out the Dressing task. You might have to prompt the group to provide feedback and comment. Since they may feel they are criticizing their colleagues, so here are some prompts you might try:

- Okay, what do the rest of you think about the way this group set things up for that person at (fill in) stage?
- Would you have done it the same? Might you have done more—or possibly less?
- What about the way they plan to help the person through the task? What might you add or take away from what they're planning?
- How would you suggest communicating what you want the person to do?
- Are there other ways you might help the person to get through the task?

The key in this exercise is that participants appreciate that they are developing a kind of fluency with the Savvy Caregiver principles—that they see the relationship between stage of disease and level of performance and the way they work with the person (through Structure and Support). In addition, it is very important that caregivers *begin to recognize that keeping the person’s disease stage in mind provides them with a strategy for helping the person that can be generalized across most tasks and activities.*

\*This is a major point, and, by now, you should be seeing participants “getting it.” It’s really helpful for you to reinforce this point as you see the lightbulb go on in participants’ minds about how this works. If it doesn’t come up spontaneously in the exercises, you should make the point—thinking about the stage of the disease and having a good working estimate of it gives information that can be used in Structuring and Supporting a wide range of tasks and activities.

## Washing up in the morning

Stage	Early	Early-Middle		Late-Middle		Late
Level	5	4.5	4	3.5	3	2.5
activity/role	Should be able to wash up by self—able to shower and groom.	Should be able to wash up by self—able to shower and groom—but may, at times, lose track of the task.	Can perform the physical activities involved in morning washing up, but is likely to lose track of the task.	Able to perform discrete actions (wash, brush, etc.) but won't understand or keep goal in mind and will need help with sequence.	Should be able to perform gross actions (wash, brush, etc.) but will likely be ineffective or repetitive.	Might perform some gross task by self (e.g., using washcloth on face).
set-up	Be sure the wash-up area is accessible and ready.	Be sure the wash-up area is accessible and ready.	Make the wash-up area accessible and ready. Have materials (cloth, soap, toothbrush, toothpaste, comb, towel, etc.) laid out.	Specific materials (cloth, soap, toothbrush, toothpaste, comb, towel, etc.) laid out.	Specific materials (cloth, soap, toothbrush, toothpaste, comb, towel, etc.) laid out.	Specific materials (cloth, soap, toothbrush, toothpaste, comb, towel, etc.) laid out.
assistance	Should be able to do by self; check back.	Give overall direction, check back more than once to redirect if necessary.	Set stage (it's time to wash up), give directions (okay, wash your face); return frequently to check and prompt.	Focus on the individual actions that make up the washing up task. Will remain with person to cue.	Each sub-task is an end in itself. Hand needed. Start on task, refocus and redirect as needed.	Each sub-task is an end in itself. Person can do as much as able. Likely most done by caregiver.
cues and communication	Normal greeting and general direction: "Time to get going; I'll need your help with breakfast; wash up then come help me."	Specific direction (no big context): "It's time for you to wash up." Then specific cues: "Have you (washed, brushed, etc.)?"	Have all equipment laid out and in sight; provide reminders to stay on track; may need to direct for each sub-task.	Verbal and visual cues (pick up washcloth and hand it; say, "Wash your face," pointing to the face. Take through all steps.	Verbal, visual, and tactile cues (pick up washcloth, hand it, say, "Wash your face." Point to or touch face.	Simple verbal cues with emphasis on visual and tactile. Communicate what is being done.

### Getting dressed in the morning

Stage	Early	Early-Middle		Late-Middle		Late
Level/ activity/ role	5	4.5	4	3.5	3	2.5
	Should be able to dress by self—able to choose own clothes and put them on without error or assistance.	Should be able to dress self—able to put on clothes—may make poor choices (e.g., want always to wear the same thing).	Can perform the physical activities involved in dressing, but may lose track likely to lose track of the task.	Should perform discrete actions (put on items) but won't understand or keep goal in mind; will need help: what goes on when.	Should be able to perform gross actions (putting on clothes) but may be ineffective (e.g., trouble with button or zipper).	Might perform some gross task by self (e.g., putting on garment)—will need direct help (buttoning, etc.).
set-up	No set-up really necessary.	Might have begun to simplify closet to limit choices and avoid confusion.	Focus on clothes in closet. Simplify; possibly order outfits to limit choices (put outfits together).	Set out the clothes in order of putting on. Remove or greatly limit choice.	Set out the clothes in order of putting on. Probably best if no choices.	Set out the clothes in order of putting on. Hand each in order.
assistance	Should be able to do by self; check back.	Give overall direction, check back more than once to redirect if necessary.	Set stage (it's time to dress), be ready to give directions (put on your pants, etc.); return frequently to check and prompt.	Focus on the individual actions that make up the task of dressing. Remain with person to cue.	Each sub-task is an end in itself. Hand the garment, start on task, refocus and redirect as needed.	Each sub-task is an end in itself. Allow person to take part, as able. Likely these are done primarily by caregiver.
cues and communication	Normal greeting and general direction: "Time to get dressed now." However, person may not need cue at all.	Specific direction (no big context): "It's time for you to dress." Then specific cues: "Are you dressed yet?"	Might need to have clothes laid out and in sight; provide reminders to stay on track; may need to direct for each part of getting dressed.	Verbal and visual cues (pick up garment, hand it, and say, "Put this on," perhaps mimic the action. Take through all steps.	Verbal, visual, and tactile cues (pick up garment, hand it, say, "Put this on," mimic action. Take through all steps for each sub-activity.	Simple verbal cues with emphasis on visual and tactile. Communicate what is being done.



*The next exercise focuses on a major management issue facing caregivers—helping the person to be content and involved in things during the day.* The issue is straightforward. There is just so much of the day that is given over to basic personal activities, like dressing, grooming, and eating. After that, what does the person with dementia do with the rest of his/her day? This issue is important for two reasons. The first is that, as the disease progresses, getting their persons involved in activities or tasks falls more and more on them. This is important because being involved will help keep the person focused, and that may help to keep Confusion—and the adverse effects of Confusion—at bay. In addition, keeping the person involved in things may improve the person's quality of life. Doing things can be enjoyable. The second reason is more self-serving but no less important—if caregivers can get their person's involved in things, there is a greater chance that the caregivers will find some time and space to do things that they (the caregivers) want or need to do.



In the first part of the exercise, have participants brainstorm about all of the things that go into a meal. What are the preparation tasks they do in the kitchen and in the dining area? What are the specific tasks they do to actually prepare—cook—the meal? What has to be done to clean up after the meal is over?

Keep a list of the things participants say and then refer to the list below as a way to illustrate the kinds of activities involved in mealtime.

#### *Meal Preparation*

- Mixing ingredients together
- Measuring ingredients
- Stirring
- Peeling—carrots, potatoes, fruit, etc.
- Shredding—e.g., tearing lettuce for a salad
- Chopping and dicing—cutting things up for a salad or to prepare for cooking
- Rewashing things (already washed in kitchen)
- Rolling (cookies)
- Pouring—e.g., water or juice into glasses
- Buttering bread/toast
- Putting sandwiches together
- Putting food in containers
- Shelling peas
- Preparing string beans
- Helping to cook things (e.g., spaghetti sauce; chili, bacon (?))
- Cracking eggs into a bowl
- Pouring syrup into containers
- Frosting cakes or cookies

### *Preparing and Cleaning the Dining Area*

- Getting things from the kitchen and other areas (e.g., the laundry room for tablecloths and napkins)
- Arranging tables and chairs
- Folding napkins
- Setting the table—putting on tablecloth
- Putting silverware on tables
- Putting napkins on tables
- Putting condiments on tables
- Putting water/juice on the table
- Putting flowers into vases for centerpiece (e.g., one rose into a small bud vase for the table)
- Putting flowers/other centerpiece on table
- Bringing things from the kitchen
- Taking things from the table
- Sponging down the table
- Sweeping or carpet sweeping under and around the table
- Rearranging the room
- Doing and/or drying dishes
- Taking things back to the kitchen

Now have the group members focus on their own persons (as above, you may want to create sub-groups whose persons have similar stages of the disease). Have them say—for the specific stage—what kinds of mealtime tasks they might try to involve their person in and what kinds of Structure and Support help they would give.

Make the point that this isn't about what they are currently doing but about what they might do. Get them to try to loosen up here—even if the person doesn't help now (and even if s/he never helped) what might the person do?

After the group has brainstormed about what they would do to involve their person (at a specific Level of Thinking) in mealtime activities, have them report back. Use the report back as an opportunity to make a list of activities and corresponding Structure and Support strategies. As each person or stage-specific small group reports back, have the other group members chime in with additional suggestions both for activities and for Support and Structure ideas. Once every sub-group has reported back in, use the grid on the previous page to provide additional feedback and suggestions in response to the exercise. Also, use the grid to look at ideas about stages not covered in the group exercise.

Using the mealtime example gives you an opportunity to deal with an issue that often comes up when trying to get caregivers to try to involve their person in various activities—the idea that certain activities are “off limits.” Caregivers may say, for example, that a male affected with dementia had never done certain household tasks (like cooking or laundry) or that a female had never done other kinds of chores (for example, yard work). While these kinds of activities might not reflect a strong association with the Person anchor (these were not things in which they had shown much if any interest in their lives), there might be another element of the Person anchor that they can tap into—the interest in helping and/or being with the caregiver. Urge caregivers not to be too quick to dismiss an idea for an activity just because it was something “s/he never did.” A wife caregiver might, for example, at least try to see if her husband could get involved in a food preparation task or a cleaning task just to be of help to her.

## Meal Preparation

Stage	Level	Structure and Support Consideration	Suitable Mealtime Tasks
Early	5	<ul style="list-style-type: none"> <li>• Should be able to perform tasks involving moving about the home</li> <li>• Should be able to do 4–5 step tasks</li> <li>• Will likely keep the purpose of task in mind</li> <li>• Provide clear verbal direction</li> </ul>	<ul style="list-style-type: none"> <li>• Getting things from other areas</li> <li>• Arranging an area</li> <li>• Measuring and mixing things together</li> <li>• Taking things back to the kitchen and other areas</li> <li>• Helping to cook</li> </ul>
Early-Middle	4.5	<ul style="list-style-type: none"> <li>• Should be able to perform tasks involving moving about the home</li> <li>• Should be able to do 3–5 step tasks</li> <li>• Will likely keep the purpose of task in mind</li> <li>• Provide clear verbal direction</li> <li>• Check a few times; may have to remind</li> </ul>	<ul style="list-style-type: none"> <li>• Getting things from other areas</li> <li>• Arranging an area</li> <li>• Taking things back to the kitchen and other areas</li> <li>• Measuring and mixing things together</li> <li>• Sweeping/carpet sweeping under/around the table</li> <li>• Doing and drying dishes</li> <li>• Helping to cook; making sandwiches</li> </ul>
	4	<ul style="list-style-type: none"> <li>• Needs a more contained area of work (e.g., the dining room)</li> <li>• Can do a 2–4 step task; repetition is good</li> <li>• Make sure materials are ready and out</li> <li>• Give directions and visual demonstration; show end product if possible; help to start on task</li> <li>• Check regularly; provide reminders to stay with the task; correct positively</li> </ul>	<ul style="list-style-type: none"> <li>• Putting silverware and condiments on tables</li> <li>• Making sandwiches</li> <li>• Putting food in containers</li> <li>• Preparing string beans; shelling peas</li> <li>• Putting on napkins and/or tablecloths</li> <li>• Putting water/juice on the table</li> <li>• Putting flowers/other centerpieces on tables</li> <li>• Taking things from the table</li> <li>• Sponging down the table; drying dishes</li> <li>• Rearranging the room</li> </ul>
Late-Middle	3.5	<ul style="list-style-type: none"> <li>• Needs a task that is right within reach—a sit down task is best</li> <li>• Can manage a 1–3 step task—needs repetition; likely won't recall purpose</li> <li>• Demonstrate; visual directions; show end product; start on task</li> <li>• Will need frequent checks to redirect and keep going on the task</li> </ul>	<ul style="list-style-type: none"> <li>• Wrapping silverware in napkins</li> <li>• Putting flowers into vases</li> <li>• Peeling, shredding, chopping, and dicing</li> <li>• Rewashing things</li> <li>• Stirring; rolling (cookies)</li> <li>• Cracking eggs into a bowl</li> <li>• Buttering bread/toast</li> </ul>
	3	<ul style="list-style-type: none"> <li>• May like made up 1–2 step tasks—don't worry about quality, only involvement</li> </ul>	<ul style="list-style-type: none"> <li>• Rolling (cookies)</li> <li>• Simple folding (napkins in half)</li> <li>• Stirring</li> </ul>
Late	2	<ul style="list-style-type: none"> <li>• Likely can only enjoy passive activity</li> <li>• May do single step task, if simple</li> </ul>	<ul style="list-style-type: none"> <li>• Wiping surface in front of him/her</li> <li>• Spreading butter already placed on bread</li> </ul>

The final exercise of this part of the session will be to involve participants in a brainstorming exercise.

Have the participants brainstorm as many tasks or household activities as they can come up with that they might try to involve their persons in. Note that these “activities” may not always result in a “useful” outcome. The goal is to engage the person, not to make him/her productive.

Keep track of the responses and use the list below as a stimulus for additional ideas.\*

- making the bed
- straightening up around the home
- hanging up clothes in the closet
- folding their own clothes
- putting clothes back into draws
- rinsing and drying dishes and glasses
- watering plants
- dusting
- polishing
- setting up and cleaning before and after various activities
- using a carpet sweeper and broom
- helping with personal laundry
- helping with specific tasks in the kitchen
- filling birdfeeders
- tending plants and flowers—including a vegetable garden
- weeding
- raking leaves and grass clippings and sweeping walkways
- keeping the outside clean
- mowing the lawn



### OOVL Decision-Making Guide for Family Caregivers

Caregiving for a person with Alzheimer’s disease and other dementias includes both the day-to-day caregiving tasks and a full range of decisions that need to be made. These decisions relate to everyday concerns such as how much help to provide in daily activities like bathing or dressing, to long-



\*Point out that the discipline of Occupational Therapy offers many insights into keeping persons with dementia contented and involved in tasks and activities. It might be helpful to refer participants to work done by Jitka Zgola, an Occupational Therapist. Two of her books, *Doing Things* and *Care That Works* are published by Johns Hopkins University Press. Dr. Laura Gitlin has done considerable research involving home instruction of caregivers by OTs; she has a book on the topic, and a recent article: Maintenance of Effects of the Home Environmental Skill-Building Program for Family Caregivers and Individuals with Alzheimer’s Disease and Related Disorders in the *Journals of Gerontology Series A: Biological Sciences and Medical Sciences* 60:368–374 (2005).

term decisions such as how best to use financial resources, whether or not to use a day care center or to remain in the family home. When people are faced with making decisions day in and day out, they may feel burdened, frustrated, and even in conflict with other family members.

For some 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 Alzheimer's and the caregiving spouse takes on more and more of the decision making, issues/problems can arise. For some people, major decision-making is a new experience, an added role and responsibility. 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 training describes an approach that includes the four major aspects of decision making: Options, Outcomes, Values, and Likelihoods (OOVL) which are further described below. The *OOVL Decision-Making Guide (OOVL Guide)* was developed to assist caregivers in the decision-making task. The *OOVL Guide* is a tool to help caregivers think about the various aspects of a decision situation to break down the decision into more manageable parts and combine them to make a decision. The *OOVL Guide* was developed to enhance people's decision making skills in general. Therefore it is applicable to many decision-making situations and can be used independently. As you introduce the topic of decision-making, and as you teach this segment, keep pointing out to participants that decision-making is not just about big, long-range decisions like selling a house or moving a person to a more protected environment. Caregivers have to make decisions every day. They have to decide about how to involve the person in activities, and they have to decide how much to involve their care recipients in those decisions. Every part of caring for a person whose cognitive powers are eroded by illnesses like Alzheimer's involves making decisions. So this segment of the program is about both big decisions and smaller, everyday decisions. Decision-making is a tool for day-to-day management.

The *OOVL Guide* provides caregivers with a structure and procedure for making choices for themselves or others. The procedure is a series of questions—presented in Table 1—for working through the decision-making process. You can use the instructional video (Dr. Lewis guiding caregivers through the OOVL model) in conjunction with your own presentation of this material. The video uses the same example (Mrs. Murphy) as the Trainer's Manual and the Caregiver's Manual, so the elements should reinforce each other. It works best if participants have their manual during this segment so they can follow along with the examples as they are presented.

If time permits, it is optimal if you can use the video to take participants through the OOVL grid and how it works, having them walk through the

example provided. Following that, it is very helpful if you can draw from the group at least two examples of decisions they are facing. Search for an example of a long-range issue but also search for an example of something that is more short-term and day-to-day. Again, if time permits, have the participants work through both examples. This will provide them with confidence that they can use the grid, and it might actually demonstrate the utility of the grid to caregiving. If participants have blank copies of the decision grid, it makes it easier for them to work through the examples, so provide these as a handout.

**Table 1. Questions to guide Decision-Making Procedure**

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

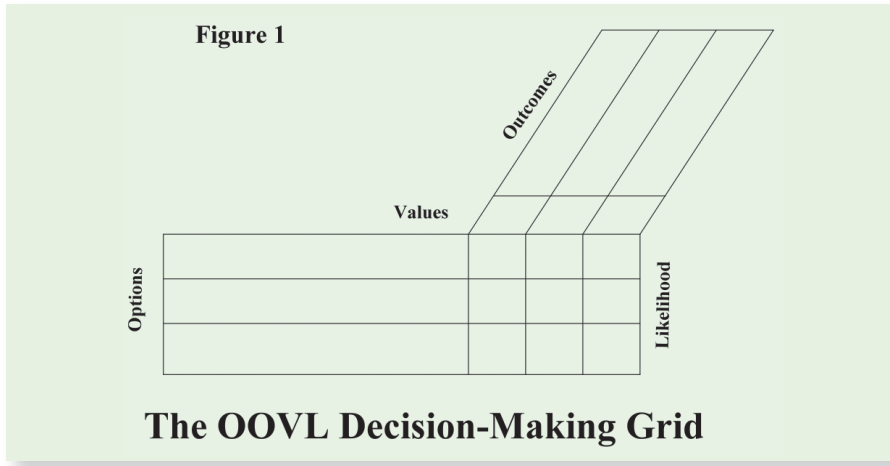
**Options** are defined as the various actions being considered in making a decision. **Outcomes** are the expected results or consequences of each option. **Values** are defined as the importance assigned by the decision maker to the outcomes. Finally, **likelihoods** are the probabilities that outcomes will occur.

The structure is a grid representing options, outcomes, values and likelihoods (see Figure 1, slide 66).

**Note to Savvy Trainers:** The OOVL grid is optional. Consider whether this type of learning tool is useful for students in your class. If it does not seem appropriate, then skip slides 66–69 and proceed to Session 6.



INDIAN  
COUNTRY



The grid and questions enable the decision maker to work through different scenarios associated with the options under consideration. In order to keep the process manageable, it is recommended that persons limit the number of options and outcomes under consideration. An example of a decision situation that a family caregiver might encounter illustrates the structure and procedures of the *OOVL Guide*.

#### **Illustration**

Mrs. Murphy works every morning at a florist shop. She enjoys the work and the time away from home, and the extra money helps. Mr. Murphy, who has Early-Middle stage dementia (level 4.5), has remained at home alone. Lately, Mrs. Murphy has become concerned about Mr. Murphy's ability to stay by himself after an incident in which she came home to find the front door unlocked and the gas stove on. Mrs. Murphy feels that she must decide what she is going to do about her husband when she is at work.

#### **Questions to Guide the Decision-Making Procedure**

##### **1. What 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:

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



**Figure 2. OOVL Grid for Work-Related Decision**

		Values			
		+++	-	++	
Options	Outcomes				Likelihood
	Mr. M.'s Safety				
	Mr. M.'s Hurt Pride				
				Mrs. M.'s Well-Being	
	Stay alone with phone calls	Low	Med	Low	
	Daughter stays with Mr. M.	High	Med	Med	
	Mrs. M. quits her job	High	Med	Low	

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

Any option that Mrs. Murphy chooses will have some outcomes. She needs to think about what she wants to have happen for herself and her husband, and what she wants to avoid happening. In this situation, Mrs. Murphy identifies three important results she wants to consider in choosing an action:

- She wants Mr. Murphy to be *safe* while she is at work.
- She 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 listed on Figure 2.

### 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 to both kinds of outcomes is to use one or more plus or minus signs. For example, positive outcomes can be assigned a value of +++ (most important positive outcome), ++ (second in importance), or + (third in importance). Likewise, the negative outcomes can be assigned a value of --- (most important negative outcome),

— (second in importance) or – (third in importance). Another way to represent the different values is to rank order the outcomes.

Mrs. Murphy considers the three outcomes she has listed.

- She ranks Mr. Murphy’s *safety* as the most positive outcome, assigning it +++.
- She ranks her *sense of 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 negative 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 2.

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

Decision making also involves looking at each option and determining, to the best of one’s ability, the **likelihood** that the option will lead to the outcome. In the context of caregiving, determining likelihoods is based primarily on personal experience as a caregiver, as well as information available from other resources, such as family health care providers, written materials, and community agencies. Having a sense of the person’s stage in the disease is linked importantly with the likelihood that an action will achieve a desired outcome. For example, persons in the Late Middle stage of the disease will most likely not be very self-aware. As a result, issues of self-esteem might no longer be pertinent for them, so outcomes involving promoting or retaining self-esteem are not likely to be accomplished—because the disease will have made them no longer relevant.

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

- When Mrs. Murphy thinks about the likelihood of Mr. Murphy being safe at home if he is allowed to stay alone, she knows that he has left the stove on and the door unlocked. Therefore, she rates the chance of him being safe at home alone as **low**.
- When considering the likelihood of her husband’s pride being hurt if she quits work, she remembers some information she learned about persons with dementia: they become less able to understand the meaning of events happening around them. Therefore, she speculates

that he won't understand that her being around more means that she quit her job to care for him; consequently, he won't be as upset as he might have been in the past. So, she rates the chance of his pride being hurt if she quits her job as **medium**.

- Mrs. Murphy continues this process of rating the likelihood of a chosen outcome occurring for each of the options she is considering. The likelihood ratings are found in the cells on the decision grid in Figure 2.

### **What option is most likely to achieve the best outcomes?**

Once the decision grid is completed, the decision maker chooses an option by relating the information about each option and then comparing the options. The grid serves as a guide in the process. Mrs. Murphy ponders the grid. She quickly eliminates option 1 (allowing Mr. Murphy to stay alone with hourly phone calls) because it has a low probability of keeping Mr. Murphy safe, 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 making as shown in the decision grid (see Figure 3).

**Figure 3. Simplified OOVL Grid for Work-Related Decision**

		Values		Outcomes	
		++	-	Mr. M.'s Hurt Pride	Mrs. M.'s Well-Being
Options	Daughter stays with Mr. M.	Med	Med		
	Mrs. M. quits her job	Med	Low		
					Likelihood

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 *OOVL Guide*. Mrs. Murphy's situation and her values influenced her decision making. Other people may face more complex decision situations and may think of different options and outcomes, assigning different values and likelihoods because of their unique situations and perspectives.

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

The *OOVL Guide* can be useful in situations where the decision makers and family members' values or preferences differ. This approach promotes systematic and consistent evaluation of options. Share the decision grids with other family members. One of the benefits of the grid is that families can discuss a decision situation, see where they may differ in their desired outcomes or the value they place on outcomes, and develop greater tolerance for each others' views.

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

Caregivers are faced with numerous decisions about what to do in the daily care and management of their person. Used in conjunction with the information they are learning about dementia and Savvy Caregiving, caregivers can use the decision grid to process care management strategy decisions.

Mrs. L is caring for her husband who has been assessed to be in the Early-Middle stage of the disease, 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.

Have the group use the five questions as a way of applying the things they've learned (including what they've learned about the decision guide) to this problem.

#### 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 Thinking Level into account and use the Structure and Support guidelines to select portions of the task that he could help with.

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

**(OUTCOMES)**

- Not have Mr. L lose self-esteem
- Not have the extra work and mess
- Get the laundry done

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

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Option 1: Mr. L. continues

High for self-esteem

Nothing will change and he will continue to feel as good as he currently does.

Low for extra work

Mrs. L. will continue to have to clean up.

Medium for getting laundry done

It will continue to take extra time.

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Option 2: Mr. L. doesn't help at all

Medium-low for self-esteem

Even though his dementia has progressed, he may well notice that he is no longer involved and this may affect him.

High for extra work

Mrs. L. will be able to do laundry faster.

High for getting laundry done

Mrs. L. will be able to do laundry faster and there will be no extra work to do.

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Option 3: Mrs. L. designs things; Mr. L. helps with parts\*

High for self-esteem

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.

Medium for extra work

It won't be as efficient as if she were doing it herself, but not as much as if he were doing it alone.

High for getting laundry done

Slower, but not the extra work of cleaning up after him—and it gets done.

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

\*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.

		Values		
		+++	+++	++
Options	Mr. L Continues to help with laundry	High	Low	Med
	Mr. L no longer helps with laundry	Low	High	High
	Mrs. L selects laundry tasks for him	High	Med	High
		Likelihood		
		Outcomes		
		Mr. L's Self-Esteem		
		No Extra Work		
		Laundry gets done		

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 in 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. Make the point that, as caregivers make choices about what to involve their persons in and what limits to impose, the issue of self-esteem fades as the disease progresses. So they should be less and less concerned about it.

So when Mrs. L. looks at the completed grid, she can see that the option of designing limited involvements for Mr. L. with the laundry 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.

Conclude by making two points:



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

- Work on management issues. Try an activity—food preparation or household chore—during the morning and afternoon. Think about the evening time and what they might do to involve the person after dinner and before bedtime. Use the Performance Level to help you design appropriate Structure and Support strategies.
- Continue to work on getting more control over a behavior you find troubling. Again, use the Savvy Caregiver techniques (Thinking, Structure, and Support), section 5 of the CD-ROM—management techniques—plus what you know about losses due to dementia to design a strategy for changing or settling (or living with) the troubling behavior.
- Read Caregiver Manual chapter on Families and Caregiving, pp. 156-164.
- Perform at least one act of Self-Care. Check in with your feelings and, if they are too heavily in the lower left-hand quadrant, do something to change the balance. Or spring free and dip into your free-time list and do something for yourself.
- Practice with the decision making grid. Perhaps you could use it as you design an engaging task or with work on a behavior.




HOMEWORK



# 6

## Savvy Caregiver Program American Indian / Alaska Native Trainer Essentials

### SESSION 6: STRENGTHENING FAMILIES AS RESOURCES OF CARE

<b>Homework Review</b>	60 minutes	 SESSION AGENDA
<ul style="list-style-type: none"><li>• Work on Issues of Behavior and Daily Management</li><li>• Strengthening Family Participation in Caregiving</li><li>• Continued Use of CD-ROM</li><li>• Self-Care</li></ul>		
<hr/>		
<b>Family Resources</b>	30 minutes	
<ul style="list-style-type: none"><li>• Strengthening Families as Resources of Care</li></ul>		
<hr/>		
<b>Review Savvy Caregiver Course</b>	30 minutes	
<ul style="list-style-type: none"><li>• Brief Review of Main Areas of Content</li></ul>		
<hr/>		

AI/AN families come in many different varieties and forms that can produce a uniquely Indian caregiving group.

Many AI/AN households have elders, adult children, their children, and even a “great grandchild” group. Many times, adults or children may live in a certain household for a limited time. Any kind of household membership makes a family that can be helpful with caregiving.

Family members, no matter how long they stay at one household, need to be taught about the symptoms of dementia and the need to continue honoring the elder with dementia by proper and loving treatment.

Family members, no matter how long they stay at one household, can be asked to help with caregiving, especially when accompanied by Savvy information delivered by a caregiver trainee.



INDIAN  
COUNTRY

AI/AN “households” or “family groups” do NOT all have to live in one house in order to be considered a caregiving group.

The history of AI/AN life includes today’s life in which some people are on small or large reservations, small villages, or in rural or urban non-reservation settings. However, many times, a caregiving group may be comprised of several houses that are very near each other and fosters good access to caregivers and the site of caregiving.



INDIAN  
COUNTRY

## Session 6: Objectives

- **Participants will appreciate that they have developed/strengthened their caregiving skills (as with Session 5)**
- **They will consider ways to strengthen their family resources for caregiving**
- **They will review the content of the entire program and appreciate and acknowledge that they have acquired more knowledge and skills -- and have altered their attitude about caregiving**

This is the last week of the workshop. You will present one piece of new material this session, but most of the time will be spent reviewing participants' efforts to apply what they've learned in the program to their own circumstances at home. The main thrust of your facilitation efforts should be on pointing out participants' successes—at home and throughout the program.\* The only “classroom” piece in this session will involve a segment on family issues in caregiving. You will also review the material covered in the whole program—a sort of closing or summary piece meant to remind participants about what they learned (or, at least, were exposed to).

As usual, the focus of the opening segment will be to have caregivers describe what their efforts at Savvy Caregiving have been like this week. There are a number of home assignments to review. Two of them involve the caregivers' efforts to put the Savvy Caregiver behavior management principles into practice. Reporting on these should form the majority of the segment. The third home assignment involved their attempting to improve family caregiving.

They were also expected to work on a self-care issue and on the decision grid. Check to see if there are any questions about the grid and to see what experiences participants had in using the grid. During this last session, check on their continued interaction with the CD-ROM.



INFORMATION



EXERCISE

Work on Issues of Behavior. The main assignments were to continue to use the Savvy Caregiver strategies to try to work on issues of daily behavior. There were *two* assignments—work to change some behavior that was bothering them and try to design food-related and evening activities the person would enjoy.\*

As usual, have the caregivers volunteer to describe what they did. Those who tried and met with success will usually want to step forward to talk about their experience. You may find that you will need to prompt caregivers' participation, so it may be useful to remind them of the homework (work on a behavior that bothers you and work on finding a food-related task or activity that the person gets involved in and likes doing). Then try asking them (for example):

- Did anybody work on trying to change some behavior of your person last week?
- Did you think about something that was bothering you and try to use what you know about the stages and performance levels and the ideas of Structure and Support to do something with the person about that?
- Did you try to design a food task the person might enjoy?
- Did you try to design an evening activity the person might enjoy?
- Did anybody try things but find they didn't work?

Be sure to “call on” all of the participants, even those who do not volunteer. Call on them—ask them to tell the group what they tried—or at least thought about trying. This is your “last shot” at any members of the group who have not taken the opportunity to speak up. By now they should be comfortable with everyone. It may be that they are just too shy to volunteer or they may feel that they have not accomplished much—or at least not as much as they feel others have. According to your assessment of the group dynamics, encourage them to share what they have done or even considered doing.

*Throughout this session, make note of the ways in which caregivers speak about their person.* In particular, how accurate are they in taking the disease into account when describing the person. For example, caregivers are often concerned that if they do something—take over a job or part of a job—the person might resent or feel diminished by that. The savvy caregiver—one who has recognized the impact of the disease on the person—will recognize

\*Be sure to get participants to report on both parts of this assignment.

that, as the dementia increases, the person's need to feel connected to the caregiver will likely grow. This will likely come to be a stronger feeling than one associated with a judgment or feeling that s/he is no longer able to do something or that something is being taken away. Similarly, those who recognize the implications of the declines in performance through the stages of the disease will use stages as a basis for adjusting the options they specify in a situation. For example, a caregiver for a person whose stage is estimated a Early-Middle (e.g., a Level 4) will not list as an option an activity that involves the person taking independent action or engaging—without prompting or supervision—in a complicated sequence of actions. In other words, this debriefing provides you with the opportunity both to check on caregivers' understanding of the decision grid and to hear again the manner in which they apply other Savvy Caregiving principles.

Keep in mind the principles you used in the last session while debriefing participants about this part of the assignment:

- Some participants will have tried the assignment in a way that suggests they really understood a lot of the principles and ideas that the Savvy Caregiver program is teaching, and they will have met with success. That is, they will:
  - Describe what they did in terms that reflect the content of the workshop (applied, for example Structure and Support strategies appropriate to their person's stage and performance level)
  - Report that their person's behavior changed in ways they (the caregivers) both anticipated and appreciated,
  - Report that they tried some kind of food and/or evening activity and that they were surprised about how well it worked (be sure to ask how they set the task up, what kind of support they provided and why), and
  - Demonstrate a sense of pride or accomplishment in what they did.

Keep in mind that this expression—that they feel good about having taken what they have been learning, put it into practice in their caregiving, and met with success—is Mastery. This is a key goal of the workshop—that the caregiver feels more in control, more skilled, and more confident that his/her skills and knowledge make him/her more able to handle the caregiving they have undertaken. If/when you hear such expressions, reinforce them; point out that the person has become more masterful—or is expression a greater sense of mastery.

- Other members of the group may have tried to apply the principles and ideas of the workshop, but they will seem not to have worked—

again, ask what they did and why—have them (and the group) try to analyze the situation through the framework of the stages—was the task of an appropriate size? Was the mode of communication appropriate? Did the person seem to understand what was being asked of him/her? Might the estimate of the person’s stage be too high or too low?

- The others will report that they did not try to do the assignments (change behavior or develop an activity)—then see above.

Think of each report—whether of success, failure, or not trying—as an opportunity to teach the savvy caregiving model. As with Session 5, you will have a number of different kinds of opportunities as the caregivers report in:

- **Reinforcement.** Praise those who put the principles into play and met with success and give them an opportunity to talk about how they feel about the success they met with. Their success also provides you with an opportunity to review how they approached the task. Take this chance to review the steps the caregiver took—to go back over the ground s/he covered in putting together the stage estimate with Structure and Support steps to achieve the end s/he achieved.
- **Clarification.** The Savvy Caregiver material is not always easy or easily understood. Listen carefully to how the caregivers talk about what they did and how they used the materials of the program. Make sure that their understanding of the ideas and principles is correct. If it is incorrect in any way, take this opportunity to review the material and make them clearer on it. Remember, too, that even if the effort didn’t yield the desired effects, the caregiver should be praised and encouraged for making the effort. The “experimental attitude” is very important and should always be encouraged.
- **Encouragement.** This portion of the workshop should be used to encourage participants to continue to try to apply the ideas and principles of the program even after the sessions are over. This is also an opportunity to draw the “non-doers” out—to get them to talk about what they did do during the past week to put some of the Savvy Caregiver principles into effect. Some participants will just be too shy to report to the group until they have what they define as a clear success. Until that time comes, they may report that they didn’t do anything—or at least not anything very much. Probe to get them to talk about what they did do. It may be they really did not try anything, but there is a good chance that they did make some attempts. Again, take this opportunity to reinforce them for their analysis and to encourage them for their efforts.



Decision-Making Exercise. Revisit the Decision video, and have group members review any decisions they made or worked on over the last week. Encourage caregivers to try using the decision-making grid.

Ask those who have tried using the grid what they liked or found helpful about it. In particular, ask them how easy or hard it was to identify the relative values of the outcomes they had specified and to estimate the likelihood of attaining the outcomes, given the various options available.

One of the best outcomes of the group regarding the decision making exercises will be if caregivers find them a handy tool. For some, even the idea that they can think in terms of options or that their decisions may involve potentially competing values (especially when one value has to do with the well-being of their person and another value has to do with their own well-being) are important realizations. The phrase, “what can I do?” raises the question of what options do I have in a situation. Ask caregivers whether, when they were working on the two behavior-related parts of their homework, a phrase like “what can I do?” or the question “what options do I have?” ran through their mind. In other words, did they, when doing the behavior assignment, use all or part of the decision grid model to help themselves think through the issues facing them? Take this opportunity to remind participants that the grid can be very useful in thinking through day-to-day management questions as well as longer range decisions they may face.

Debrief the group on their continued use of the CD-ROM

They were to have used section 5—on management principles—as part of their assignment to work on behavior and management issues. As with last week, try to find out if they found this section useful and understandable. You also want to use this as an opportunity to reinforce the CD-ROM as a resource they will be able to continue using even after the workshop is over. By way of debriefing, you might ask:

- What was your experience using section 5 of the CD-ROM? Were you able to navigate up and down the levels? Did you find the information helpful? Did you use any of it in caregiving over the last week?
- Did you have any difficulties with the CD-ROM?
- Have any other members of your family been able to view the CD-ROM? If so, has that had an effect on relationships in the family?

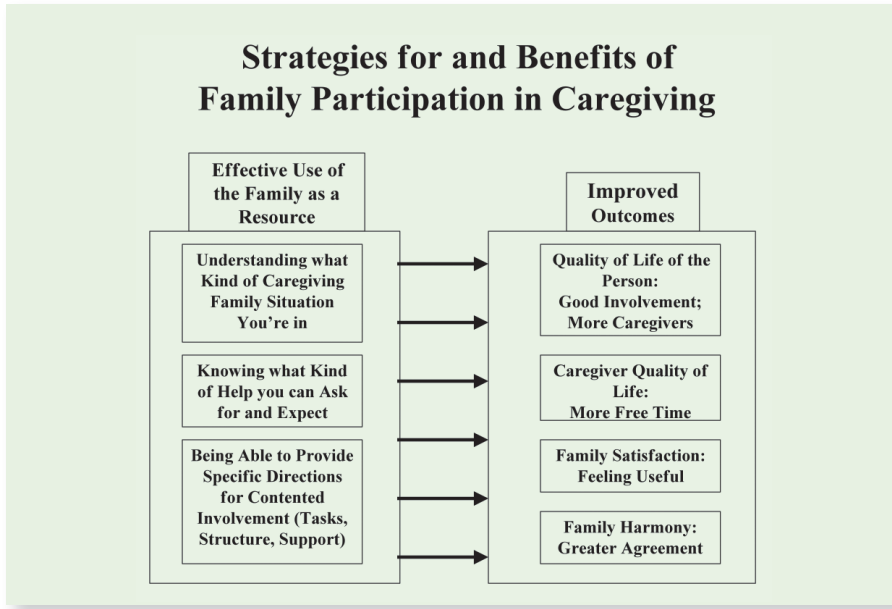
### Debrief on Self-Care Activities

Ask the group to report back on their efforts to work with their feelings about caregiving and to allow themselves a self-time activity.

At this point we switch our focus from daily management to families and family issues that may arise in caregiving. The present exercise is meant to shed light on families. In particular, it offers a way for caregivers to characterize the kind of family situation in which they find themselves. Ultimately, this exercise is related to the fourth basic task of the caregiver, the management of the family as a resource. The diagram below may be useful in explaining why it is important to manage the family resource effectively—and what is involved in doing that.



*INFORMATION*



The way to explain this slide is to point out that the improved use of the family as a resource can lead to a number of positive outcomes (as specified). The key to those outcomes is knowing what kind of help the caregiver can reasonably expect (hope) to get from his/her family and how to ask for that help. This, in turn, begins with having a basic understanding about the kind of family that is involved. And that is the point of the rest of this section of the workshop.

The objectives for this portion of the session are to:

- 1) Facilitate caregivers' explicit understanding of how their family works together;
- 2) Educate caregivers about different types of caregiving families; and
- 3) Prompt caregivers to think what type of caregiving family caregivers would like their families to be at this time and how they might go about creating the necessary changes.
- 4) Help caregivers to link this new knowledge—what kind of family type they're in—with what they have already learned about designing appropriate tasks or activities for their person to develop a strategy for asking for specific kinds of help from the family.



INFORMATION

The exercise above should have put participants in the mood to think about how their family works. Now you want to give them a framework that will help them to think about factors that help and hinder families working together and to characterize their family’s style of working together (or not). This framework will be useful in the final exercise of this session (and in the homework)—developing strategies for making better/fuller use of the help a family might provide in caregiving.

Following is a list of common types of caregiving arrangements families have. Families often find that, at any given time, they fit into more than one type of caregiving arrangement. It is important to stress that one type is not necessarily better than are the others. There are no “bad” types. In addition, families need the flexibility to change how they mobilize around caregiving as the dementia progresses. Caregiving is always changing and families may need to change from one type of caregiving family to another to adapt to the chronic illness.



*BRIEF TALK*

## **Five Types of Caregiving Families**

**Solitary Caregiving**  
**Observed Caregiving**  
**Tag Team Caregiving**  
**Uneasy Caregiving Alliance**  
**Collaborative Caregiving**

### **Solitary Caregiving**

In solitary caregiver families, one person does all the work of caregiving. Other family members may live in the area, but the responsibility of care rests almost solely on the caregiver.

**EXAMPLE:** Tina married Paul 6 years ago. About 4 years ago, Paul started showing signs of dementia. Now she can no longer leave him alone. Her two daughters from her first marriage, who live in the area, have offered to come and watch Paul while Tina goes out. She does not take them up on their offers because she feels that Paul is not their father and therefore they should not have to deal with his dementia. Paul's two children live out of state. They usually visit once a year and call weekly. Both of them also have jobs and families and very busy lives. While they stay in touch, they do not offer to help.

### **Observed Caregiving**

The observed caregiver, like the solitary caregiver, does all the work of caregiving. In the case of the observed caregiver, however, the family members are vocal about how they think care should be given.

**EXAMPLE:** Ron is the husband of Agnes, who was diagnosed with dementia two years ago. Ron has health problems of his own, and their daughter, Susan, is worried about them both. As a result, she keeps insisting that Ron and Agnes should move into assisted living. Ron does not want to move because the house is paid for and he knows the people in the neighborhood. What he would really like is for Susan to come and clean the house for him, but he does not feel right asking Susan to help him. Their son, John,

is also concerned, but for a different reason. He knows that if the parents move to an assisted living facility, their assets will soon be used up and he and his sister will be expected to assume some financial responsibility. He is encouraging his father to “hang in there.” and keep taking care of mom at home.

### Tag Team

The tag team caregiving family shares the work of caregiving—sequentially. Rather than all members helping at once, tag team families have one family member at a time take care of the family member with dementia. The responsibility of caring for the demented relative rotates among family members.

EXAMPLE: Randy, the father of three children, has dementia. He can no longer take care of himself, and his wife died two years ago. Therefore, his children take turns caring for their father. They have arranged it so that Randy stays a month at each child’s house. During that month, each child is responsible for getting Randy to daycare, and taking care of him at night, and the other two siblings are not expected to help, except in the case of an emergency.

### Uneasy Caregiving Alliance

These families have more than one member at a time caregiving for their relative with memory problems. In uneasy allies families, members share the work but family members do not necessarily have the same goals, or similar styles of providing care.

EXAMPLE: Sara and Martha are both caring for their mother, Midge, who lives in an assisted living apartment. Sara believes that Midge should do as much for herself as possible. Sara has Midge help her make dinner and do little chores around the house when she brings her mother home to visit. Martha feels Midge is too frail to leave her apartment at the assisted living center. She is afraid that while she is helping Sara cook her mother will cut herself or burn herself on the stove. Martha has repeatedly asked Sara not to let their mother help cook. Sara believes that Midge enjoys helping and that she is not in danger when she helps.

### Collaborative Caregiving

In this type of caregiving family, everyone in the family takes part in caring for the person with dementia. The family has a common goal for caregiving, and members perceive help as supportive. Everybody pitches in to help, but each person does not necessarily have to do the same amount of caregiving.

EXAMPLE: Sharon cares for her husband, Ray, who has had dementia for about 5 years.

Though Sharon lives with Ray, she gets a lot of help from her three children, Ray Jr., Paula, and Tim. Tim takes care of the outside work on the house—he mows the lawn and repairs things around the home. Paula does the shopping and helps her mother clean the house. Both Tim and Paula visit frequently. Ray Jr. lives 10 hours away and can't give the same consistency of help. One week each year, Ray Jr. comes and stays with Ray so Sharon can go to visit her sister in Nebraska. Ray Jr. also comes home during long holiday weekends and does what he can. All family members want to keep Ray at home as long as they are able.

After this brief talk on the types of caregiving families, ask each caregiver into which type they would place their family. They will most likely say a combination of types. If so, ask them when—under what circumstances or during what kinds of situations or events—they see their family falling into the types they mentioned. After the caregivers have done that, ask them what type(s) they would like their families to be. Have them brainstorm about how they would know when their family was a certain caregiving type, for example “We would be a Tag Team family if my sister would take care of Mom every other week” or “We would be a Collaborative Team family if my brother took charge of mowing the lawn” or “We would be a Collaborative Team family if my sister, who lives in Florida, would call Dad every week to ask him how he is doing”. This exercise will conclude after you give a brief talk—on barriers and aides to successful family caregiving. So once the participants have identified where they would like their families to be among the caregiving categories, have them hold that thought.

Sometimes, the reason one person is doing the caregiving is because the caregiver will not ask or let others help. This could be because the caregiver feels the members of his/her family are too busy, or that it is only the caregiver's responsibility. One reason parents don't ask their children to help is because they feel it is not the children's job to take care of their parents, it is the spouse's job. One way to get caregivers to consider asking/letting others help is to ask them what they would do if they fell and broke their hip, or something else that incapacitates them for a while. Point out that it is better to have plans in place than to have to figure them out in an emergency.

Sometimes a caregiver will say his/her family is a collaborative family because they think that is the “right” thing to say. You, as the instructor, need to be able to question the caregiver if the examples you heard do not fit the

collaborative description. You can say things such as “Gee, from what I’ve heard you say (give an example) sounds more like a tag team family.”

It is very important to emphasize that there is no “bad” kind of family. What is important is that the family type is working for the family, especially the family member with dementia and the primary caregiver.

### **Barriers and Aides to Successful Family Caregiving**

The next slide lists common barriers and aides to successful caregiving. These barriers and aides are helpful to keep in mind when talking with the caregivers about the types of caregiving families. You will find that caregivers often mention the barriers listed below when discussing the reasons they feel unable to take time for themselves. It is especially helpful if you

are able to point out how caregivers can use the aides to help overcome the barriers they are experiencing. One example, frequently on a caregiver’s mind but perhaps not said out loud, is that other family members will not do as good a job at caregiving as does the primary caregiver. Giving family members information about dementia, and details on how best to interact with the person with memory problems (communication) helps to overcome the reluctance to be alone with the relative with memory problems others face (lack of experience). Not knowing what to do if their family member gets agitated, or asks the person who they are, keeps many people from volunteering their help.



*INFORMATION*



## Five Types of Caregiving Families

- Solitary Caregiving
- Observed Caregiving
- Tag Team Caregiving
- Uneasy Caregiving Alliance
- Collaborative Caregiving

You will now give a brief talk on the barriers and aids to successful family caregiving. The participants have all of this material in their manual, so you can refer them to that and just hit the highpoints. This talk is a set-up for the final part of the exercise about improving the family as a resource for caregiving, so, as you give the talk, encourage participants to share anytime they feel you have spoken about something that describes their family situation. As you proceed through the talk, ask participants at the end of each small section if there is anything familiar about what you've just talked about—anything that reminds them of their family or of some family member in it.

**Barriers.** There are three main barriers that get in the way of a family successfully coping with having a family member with dementia: denial, lack of role flexibility, and lack of experience.

**Denial.** Denial is the result of the inability to deal with the losses associated with dementia—losses that the person is experiences and losses that family members feel (or don't want to feel) is seeing the person experience these losses. Denial that a family member has a disease like Alzheimer's is very common, especially around the time that some members of the family are seeking or considering a diagnostic work-up. Both the person with dementia and his/her family members can be in denial. Some people are not ready to confront the reality of how the disease will affect the lives in the family. Fear that they may get Alzheimer's when they get older, or the inability to face the loss of their relative as they once were, are both important issues that get in the way of coping. Unfortunately, families cannot mobilize to cope successfully with the disease if members cannot admit there is a problem.



BRIEF TALK

Denial is frequently the cause of friction within families. Family members in denial are likely to resist the primary caregiver's efforts to seek their help or to use outside help, such as moving the person to assisted living or using daycare. Denial by other family members also puts additional pressure on the primary caregiver. S/he cannot turn to those who are denying the reality of the situation for any comfort for his/her own situation of loss and increased workload.

If family members realize that denial is a result of fear, rather than laziness or an inability to care, it might be easier for them to deal with the person in denial. Rather than getting frustrated and angry because the person "refuses" to see the dementia, members could talk about the underlying fear the person in denial feels that keeps him/her from accepting the truth. Providing information about the disease and having the person spend significant time with the person who has the disease are both powerful tools for getting someone to face his/her denial.

**Lack of Role Flexibility.** A second barrier for families coping with dementia is the inability to adjust and change roles. This is often necessary when a family member has a disease like Alzheimer's. When a family member gets dementia, s/he gradually loses the ability to perform tasks for which s/he was previously responsible (like driving, paying the bills, cooking, and making major decisions, like whether to buy a car). In addition, the caregiver often finds that doing all the things s/he accomplished before the onset of the disease is more difficult.

Lack of flexibility can lead to a disorganization within the family. If members of a family are flexible regarding who can perform certain roles, the family's transition into caregiving will be smoother and the family will continue to be a resource in caregiving. Take the example of a mother of a large family who used to prepare elaborate holiday dinners for everyone in the extended family, but is no longer able to because of her memory problems. If roles are flexible within the family someone else can take over the role of hosting holiday dinners or the other members can share the role. In families that have a lack of role flexibility, the family may stop having holiday dinners together because that was always Mom's job, and nobody else 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 be responsible for—or assist the caregiver in some of his/her roles in order to lighten his/her load.

In many instances, it is the caregiver who fosters or supports role inflexibility within the family—they cannot or will not ask others in the family for help. Many caregivers feel their relatives, especially their children, are too busy to help. This is an example of lack of role flexibility. Parents frequently see their role as a provider of assistance rather than as someone

in need of help. Therefore, they believe their children are too busy with their own lives to assist in caregiving. This is not to say that children do not have busy lives with work and children of their own. However, the fact remains that the caregiver will need help at some point, especially if s/he can no longer be the primary caregiver. In this instance, it is the caregiver who has to recognize his/her own need for help and who has to bend in the situation—and ask the family to reorganize itself around the reality of the situation brought on by the dementing disease.

**Lack of Experience and of a Caregiving Repertoire.** Lack of experience is just that—members in the family do not know what to do regarding caring for a person with dementia. They have never been in this situation before and have no models for how to deal with it. Lack of experience may show itself in at least two ways. First, a person may not want to spend any time with the person with dementia because they don't know what to expect. The disease is a mystery to him/her. The behavior of a person with dementia is beyond his/her experience. S/he might feel fear about what the person with dementia might do and how s/he (the family member) might handle anything that came up. Second, family members do not know how much work is involved in caregiving or how to do the work of caregiving. To the extent that the disease remains a mystery—and a frightening one at that—or that they feel inadequate about how well they could provide care or in the dark about what to do if they were to be “in charge” of the person, they are less likely to offer help and understanding.

A third important barrier to getting help from family—and friends—is their not knowing what to do with the person. Someone who doesn't spend a lot of time with a person who is demented may be very unsure about how to fill the time, how to help the person with things, how to keep the person calm and in control.

**Aids.** Below are five ways to break through the barriers to successful coping. These are tools that can help families cope with having a member with a dementing illness. The tools help in everyday life, but are more crucial when an illness invades a family.

**Knowledge and Skill.** As the Savvy Caregiver program has emphasized, it is important to know about the condition—what to expect as the dementia progresses—but it is even more important to know what to do—how to manage things—as the condition progresses. It is also important to know about the resources that exist to help ease the work and stress of caregiving. This knowledge and skill can help prepare a caregiver for the task of ongoing caregiving. Sharing this knowledge and skill can also help families to organize

successfully to aid in the care of a person with dementia. If individual members have information about know the types of losses the person with dementia will face, and know how best to interact with their family member to give him/her the best quality of life possible, both the caregiving family and the person with dementia will benefit. Many organizations exist to help family members dealing with dementia. Knowing of the available resources can offer caregivers help in a variety of ways. For example, volunteer respite programs and professional day care centers can give caregivers a break from caregiving and time to do other things. Again, when the family understands the disease and the community resources for it, the family is more likely to promote and support the use of such resources.

**Having a Plan.** Successful caregiving requires a plan. A plan can include: who assists in caregiving for certain activities, or at certain times; how to handle a certain problematic behavior; or how to keep the person with dementia meaningfully occupied. Plans can also include decisions about caregiving in the future. For example, will the family decide to place their member in a nursing home? If so, how will they know when it is time? Family members have a better chance to organize and work together effectively if a common goal exists. If family members are each doing what they feel is important, but the members are working toward different goals, then help will not feel supportive. (See the “Uneasy Caregiving Alliance” type of caregiving family for an example.)

**Provide a Menu.** Have a list of answers ready for when someone in the family or among friends says, “Let me know if I can help in any way.” Be ready to give the person a number of specific options from which s/he can choose. A list might include: specific times (and durations) when a person could come to the house to stay with the person; times when transportation is needed; help with specific chores around the house that the caregiver can’t get to; help with other household affairs; bringing over meals. Have caregivers generate their own lists.

**Providing “Recipes.”** Helpers need some tips from the caregiver’s strategies. If the help that is provided involves direct care, then caregivers should provide a list of things that the helper could do with the person with dementia. A description of the schedule of activities that is typically done at that time of day would alert the helper to the routine. Descriptions of what the helper can expect of the person in those activities, what kinds of set-up the helper is likely to need to provide, good distracters, things that help the person focus, and things the person especially likes to do.

**Communication.** Communication helps to break down the barriers to successful coping. Communication is also a necessary component of the two other aides—Knowledge and Having a Plan. Talking about the disease, and how it affects all members of the family, including the person with dementia, can help family members let go of denial. Communicating about day to day caregiving to family members and friends enables them to comprehend the effect of dementia on the person and the caregivers. Communication about what works for the caregiver in his/her interactions with the person with memory problems helps others feel more comfortable around the person with dementia. If caregivers are able and willing to let family members know what they need, and what works in day to day caregiving, other people will be more able to assist with, or take over, the tasks that need to be accomplished. Families cannot create a plan for successful caregiving without exchanging information on what individual members need and what goals each individual has regarding caregiving and the future of the member with dementia. Communicating emotions, which certainly are plentiful, can also foster feelings of support and understanding. The bottom line is that talking with one’s family helps get over barriers most families face when struggling with a long-term progressive disease such as Alzheimer’s. When family members truly understand, they are more likely to pitch in and offer support.

This final exercise is meant to bring to the surface concrete steps that caregivers could take to improve the family resource for caregiving—that is, to get more help from his/her family and to get them more—or more effectively—involved in caregiving. Point out how this exercise ties into the idea of Savvy Caregiving. Emphasize the positive. Taking part in this exercise shouldn’t imply that participants’ families aren’t helping. Rather it means that even the most helpful and collaborative of families could be even better at what they are doing. And in those cases where the help is less than optimal, strategies can be developed to improve the situation.



EXERCISE

Previously, participants had identified their ideal—what kind of family caregiving situation they wished they had. In this part of the exercise, ask caregivers to use the Barriers and Aides handout (see next page) first to work through what they see is preventing their family from more effective family caregiving. Have them work for 3-4 minutes, individually, on the barriers section. Ask them to consider whether and, if so, how each of the barriers is at work in their family situation. Once they have had time to do so, have each report—briefly—back to the group what they have come up with. When all have reported, ask participants whether what others said stimulated any other thoughts.

Next have the participants work individually—again for 3-4 minutes—on the Aids section. Ask them to indicate what kinds of knowledge and skill they wish other members of the family would have. Ask how they might convey this to their family members. Finally, ask them to describe what they would say to help another family member take care of the person with dementia. As above, have individuals report back and then have the group consider whether these reports prompted additional thoughts. Since caregivers will be encouraged to apply this information to their own situation at home in the coming week, tell caregivers that they should just provide an outline of what they would do.

### **Barriers and Aids to Successful Family Caregiving**

**Denial.** Is there anyone in the family who does not believe that the person has a dementing illness? Or that the problem isn't as serious as you see it to be?

**Lack of Role Flexibility.** Are you willing to ask your family for help? Are there reasons why they cannot help? Are there reasons why you haven't asked for help?

**Lack of Experience.** Are there members of your family who don't understand what dementia looks like or what your person is like? Do you think any family members are frightened by your person (or too sad to be around him/her)?

**Knowledge and Skill.** What kinds of information –about the disease or how to care for the person—would help family members to be more a part of the situation and more able to help?

**Having a Plan.** Can you think of two or three caregiving tasks that you could export to family members? Given the family situation and the person's condition, what are a couple of ways in which you could ask for specific help?

**A Menu of Activities.** Can you think of 2-4 tasks or activities that you could tell a helping friend or family member to do with the person over a 2-3 hour span?

**Recipes for Helpers.** Take one of the activities from the menu and describe how you set it up for the person, how you get him/her involved with it, what kind of help you expect to give, and how you give that help.

**Communication.** Think about one of the tasks you feel you could ask for help from the family. Now develop a specific plan for communicating this to that family member. Tell him/her: what you want him/her to do with the person, what kind of Structure and Support to provide (and how to do that), what to expect and look for. Give the person specific advice on what to do if the person becomes distracted or distressed.

Since this is the last session of the workshop, you will not be providing participants with Home Assignments, but you can tell them that, if you were providing assignments, this would be the assignment related to strengthening the family resource for caregiving:

Design a change strategy to improve family caregiving. This should be based on what you see to be the barriers at work in the family.

You might choose to assign a task to a family member (in which case, provide a detailed plan) or to provide information (your manual, the CD-ROM, etc.) to someone to help him/her better to understand the situation.

**One Final Word.** The emphasis in the section above was on engaging family members in care and on understanding family dynamics as a way of seeing different kinds of helping and conflict that occur in families. What is not covered in the section is friends.

Friends can provide great support and help to a caregiver, and the techniques described above apply to friends as well as families. But caregivers often report that, as the disease progresses, friends—even long-time friends—seem to fall away and disappear. Caregivers report that when friends “go away” it is painful and it also makes them feel angry or disappointed.

For some people, the onset and progression of a disease like Alzheimer’s in a friend signals the end of the friendship. The connection is lost, and the friends go away. It’s likely there’s not much that can be done with or about these kinds of friends. They have pulled away, and the best thing for the caregiver is to let go of them.

Others may feel that the disease signals a time when family circles closely and friends have to stand back and let the family take over. Some encouragement to the friends to stay close might be helpful to such people—and may be all that’s needed for them not to go away.



Still others may be just like many family members: they may want to do something but not know what or how. In this kind of situation and the one above, being specific about possible ways to help and providing very detailed descriptions of activities and ways to help the person through them may be very helpful.



*TRANSITION*

This is the last part of the Savvy Caregiver program. This part of the session should be spent reviewing the content of the program. The slide below can serve as an overall summary of the six-week curriculum. The four bulleted items are those covered by the sessions, the reading, the CD-ROM, and the efforts caregivers made to apply the material to their home situation.



*INFORMATION*

### Major Areas of the Savvy Caregiver Program

- **Improving Your Caregiver Skills and Knowledge -- and Outlook**
- **Developing Skills for Self-Care**
- **Strengthening Family Resources**
- **Strengthening Decision-Making Skills**

The principal focus of the Savvy Caregiver program was on the first of these bullet points—developing skills for self-care. The program advertises itself as a course designed to give caregivers the training they haven’t had, but that they need, to carry out the very difficult work they have undertaken. We have tried to make it clear that caregiving is more than the day-to-day dealing with the person. Taking care of oneself, being able to draw on other resources in the family, and feeling equipped to manage the longer-term realities of being the household leader are all integral to the role. The training program has also been built on the idea that caregivers will not only learn the information we are teaching and be able to put the skills into practice, they will come away from the workshop with a different sense about themselves, a sense we have termed “mastery”. This sense combines an appreciation both that they know and are able to do more things but, more fundamentally, that they feel more confident about their ability to carry out the role they have undertaken.

*Use the next four slides to review the main points of the program. Use this as an opportunity to draw caregivers into the discussion. The review should be a “bragging session” for them. It should give them a chance to show off—as individuals and as a group what they have gained and what they have become as a result of the program.*

*As you begin to review the material—really just the main topics—keep the following probes in mind:*

- Have any of you found that you are using this (information, skill, technique, tool—whatever is appropriate) in your caregiving?
- How do you find it is working for you?
- How does it feel for you? How do you feel about yourself using this in your caregiving?

### Skills for the Savvy Caregiver

- **Understanding the reality and meaning of losses in dementia; the impact of Confusion**
- **Clarifying an appropriate goal for caregiving—Contented Involvement**
- **Mastering Savvy Caregiver Skills**
  - ⇒ **using the Stages (levels of performance)**
  - ⇒ **linking Stages to Structure and Support strategies**
  - ⇒ **seeing troubling behaviors as part of Confusion**
  - ⇒ **developing a caregiving routine**
  - ⇒ **improving communication**

Go over each point and sub-point of the slide and remind caregivers—briefly—of the main points covered in the program

#### ***Caregiving requires savvy***

Over time, dementia changes everything. As the person changes, everything about the relationship between the person and the caregiver—and the rest of the family—changes as well. The expectations of normal life can no longer be assumed, and it falls on the caregiver to make changes and adjustments in his/her manner of relating to the person with the disease. The caregiver gradually assumes more and more responsibility for communication, decision making, structuring daily life, and thinking through the moment to moment actuality of the day. Understanding cognitive losses and the impact of confusion are important starting points for the caregiver to make this shift to greater responsibility and to begin to adopt a more deliberative and calculating—a more savvy—approach to how s/he deals with the person with dementia.

#### ***Caregiving should have a reasonable goal***

The person cannot be cured by caregiving, no matter how good and selfless. Nor should the person's every need and want trump all other concerns, including the caregiver's own well-being. Nor does dementia take away the person's ability to zero in on things and take pleasure in them. So helping the person to become and remain reasonably enjoyably involved in things is a reasonable goal for caregivers. And caregivers are allowed to be enjoyably involved too—either along with the person or on their own.

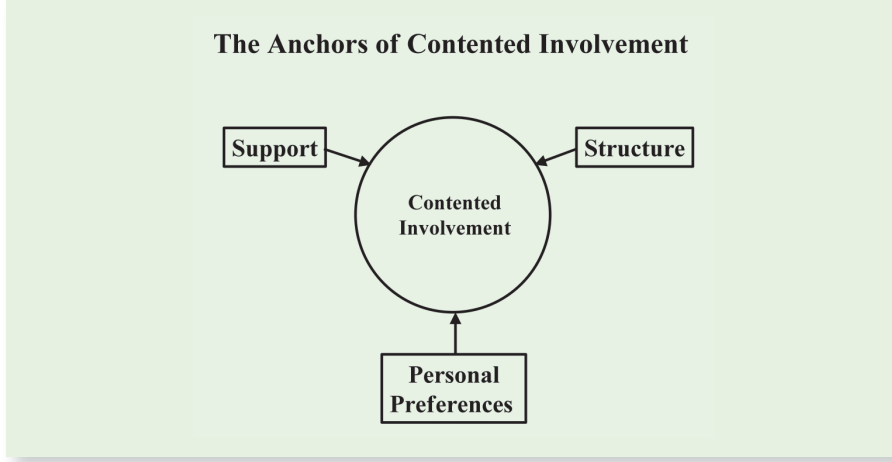
***Caregivers can get good at—and feel good about mastering— a basic set of caregiving skills***

**Understanding the Stages and the effect of the disease on performance**

The participants have learned that the global losses can be described in a staging system that they have learned (linked to the Allen Levels). They have seen that the stages link to important elements of performance (Purpose, Order, and Use) and to the key elements of tasks (size/complexity, geography, etc). Finally, they have used the CD-ROM and Personal Task Worksheet to estimate their person's stage and performance level.

**Linking to Structure and Support Strategies**

The main part of the workshop has been spent teaching a simple model of developing strategies for maintaining a person in a condition of Contented Involvement, represented next.



Recall for participants the various handouts linking structure and support to stages. Remind them, too, of section 5 of the CD-ROM which provides detailed guidance for how to design appropriate involvements for their person.

#### Linking Confusion to Troubling Behavior

Many of the behaviors caregivers report as most troubling—like repetitive questioning and shadowing—relate to the fear the person feels from the confusion that is characteristic of the disease. Recall the section of the readings on dealing with troubling behaviors. Remind participants that they have worked on this at home, that the CD-ROM has parts of section 6 that deal with these issues, and that the principles of Structure and Support can be applied to these situations.

#### Developing a caregiving routine

The program has tried to emphasize the value of a regular routine for the person with dementia. Although s/he may not remember what will happen, repetition will develop a sense of familiarity, and familiarity provides comfort. Having a routine—for the day and for what to do (how to respond) in difficult or bothersome situations—will also help the caregiver. It will save the energy of having always to create each day anew.

#### Improving Communication

Several parts of the program dealt with communication between the caregiver and their person. The section on cognitive losses should have helped to clarify for the caregiver what s/he could expect in an exchange with the person. The section on Thinking and Support dealt directly with the kinds of

communication that are most appropriate for persons at various levels of the disease. Section 5 of the CD-ROM deals with this issue extensively, and there is a video in section 6 that also deals with it. Beyond this, there is a section in the readings on communication techniques.

Use the next slide to remind participants of the main content related to the second major theme of the program, taking care of their own well-being.

## Caregiver Self-Care

- **Recognizing and Dealing with Feelings -- Using the Quadrant Model**
- **Developing a Repertoire of Self-Time Activities**

Use the slide to remind them of the two main topics covered;

### Caregiving can produce great emotional stress

Early in the program caregivers learned a technique for sorting their feelings into quadrants and for working on moving to a more positive feeling state. Their homework and some of the video clips in section 6 of the CD-ROM should have helped them to check in more regularly with their feelings and to work on moving them to a more positive state.

### Caregivers can—and should—have satisfying and rich lives

The program worked on helping caregivers specify—or recall—interests they might like to pursue, if they had the time. They developed a list of things they would like to do. In later exercises—particularly those related to the family as a resource—they tried to create time to pursue some of these activities. The notion of a daily routine also works in the direction of caregivers pursuing some of their own interests.

Use the next slide to remind participants about the workshop's third main theme—that families are (or can be) important resources for caregiving.

## Family as a Caregiving Resource

- **Understanding Family Caregiving Strategies and Types**
- **Overcoming Barriers to Stronger Family Caregiving**
  - ⇒ **Schedules**
  - ⇒ **Specific Plans (tasks and activities with Structure and Support strategies)**

### Families have Different Styles

Help participants recall the session and the homework on identifying the kind of caregiving family type that they are a part of—and of working through identifying the kind of family type they want to have.

### There are Barriers and Strengths in Every Family

Remind participants of the major barriers to stronger family caregiving (Denial, Lack of Role Flexibility, and Lack of Experience). Remind them of the class exercise and home application in which they worked to design a strategy for improving the family resource for caregiving. The two particular strategies they were to work on were: develop agreement within the family about others' doing specific tasks at specific times, and provide to family members a detailed plan for how they can provide care to the person during the agreed upon times. Successfully implementing this plan depends on other family members' appreciating and acknowledging that the care receiver has a disease (dementia) that seriously affects daily life. It also depends on strengthening communication within the family.

Finally, use the slide below to review the main points of a final theme of the program—the caregiver as key decision-maker.



## The OOVL Decision-Making Model

- **Options**
- **Outcomes**
- **Values**
- **Likelihoods**

⇒ **Impact of Dementia on the Person and its impact on possible outcomes**

The key points to make here:

- Caregivers have been given a simple and flexible tool to help them with decisions. They can ask and come up with answers to six basic questions to help themselves arrive at a level of comfort with most decisions. In many cases, just thinking about a portion of the model—for example, what options are there or what’s really important here—will be enough to clarify a caregiver’s decision.
- These decisions may be large and long-range (selling the house, getting rid of the car, etc.) or they may be more day-to-day, relating to how to take care of the person.
- Dementia plays a part in thinking through decisions. Many of the person-centered outcomes that caregivers worry about (his/her feelings will be hurt or self-esteem damaged) need to be considered in light of the disease. Dementia dulls many feelings in the person, and issues like these—while still important—are increasingly less important as the disease progresses.

*One of the central goals of the Savvy Caregiver Program is that participants acquire a sense of mastery about their caregiving.* Before this session, think about the gains and progress you have seen in each of the participants—especially as they relate to material covered in the sessions. Point out the successes you’ve seen—the progress you have seen them make toward becoming or improving themselves as Savvy Caregivers. This will reinforce their sense that they have become more knowledgeable, more skilled, and more able as caregivers.



TRANSITION

Below are some things you might consider as you compile a list of successes you want to comment on among the caregivers;

- They have changed something of the way they deal with their person, based on what they learned in the workshop
  - Accepting and dealing more realistically with the losses
  - Handling difficult behaviors better
  - Finding new things for the person to do
  - Changing the way they relate to the person—different language and speech patterns; more control; more directive; etc
  - Creating more routine and structure
  - Using external resources—day care, etc.
- They have reported that they are thinking and/or doing more to take care of themselves
  - Using the quadrant tool to manage their feelings
  - Taking some time for themselves—and feeling okay about that
- They are involving their family in caregiving in various ways
  - Asking for more help
  - Helping the family to get involved
- They have used the decision grid, or think about decision making in a new way
- They have used the CD-ROM—perhaps using a computer for the first time ever

## THE END

At the end of this last session, caregivers appreciate it if you can make their completing this training as much of a celebration as possible. It is a kind of “Graduation.” Some group leaders/trainers have given out “diplomas” that they make on a computer. Encourage participants to keep in touch—and if they are in a support group, encourage them to share what they have learned. Remind them that they are leaving with new skills and have acquired new knowledge and a more masterful outlook on their own work. In addition, they have materials they can keep referring to as their caregiving continues; the manual, the CD-ROM, and each other.



INFORMATION