

A Telehealth Education Program for  
Caregivers of Veterans with  
Dementia

Participant Workbook



Printed for your use by the VISN 2  
Center for Integrated Healthcare



Do not quote without permission.

## **Telehealth Education Program for Caregivers of Veterans with Dementia Participant Workbook**

---

The preparation of this manual was made possible through grant # IIR 03-076-1 from the VA Health Services Research & Development.

Laura Wray, Ph.D. – Director of Educational Operations, VISN 2 Center for Integrated Healthcare, Assistant Professor of Clinical Medicine, State University of New York at Buffalo.

Ronald Toseland, Ph.D.- Professor and Director, Institute of Gerontology, School of Social Welfare, University at Albany, State University of New York.

Mollie Shulan, M.D.- Principal Investigator, Telehealth Education Program, Director of Geriatric Fellowship Program and Geriatrician Upstate New York VA Medical Center at Albany, Assistant Professor at Albany Medical College, Albany New York.

## Table of Contents

Session #1 – Basic Dementia Education	
▪ Worksheet 1.1 – Contact Information.....	4
▪ Worksheet 1.2 – What is Dementia?.....	5
▪ Worksheet 1.3 – Weekly Worksheet.....	6
Session #2 – Stages of Dementia	
▪ Worksheet 2.1 – Stages of Dementia.....	7
▪ Worksheet 2.2 – Seven Steps to Problem Solving .....	8
▪ Worksheet 2.3 – Weekly Worksheet.....	9
Session #3 – Behavior Management Part I	
▪ Worksheet 3.1 – Challenging Behaviors.....	10
▪ Worksheet 3.2 – The ABCs of Behavior Management.....	11
▪ Worksheet 3.3 – Behavior Observation Sheet #1 .....	13
▪ Worksheet 3.4 – Weekly Worksheet.....	14
Session #4 – Behavior Management Part II	
▪ Worksheet 4.1 – Applying the ABCs of Behavior Management.....	15
▪ Worksheet 4.2 – Behavior Observations Sheet #2.....	17
▪ Worksheet 4.3 – Weekly Worksheet.....	18
Session #5 – Improving Communication Part I	
▪ Worksheet 5.1 – Communication and Dementia.....	19
▪ Worksheet 5.2 – Three Stages of Communication Deterioration in Dementia .....	20
▪ Worksheet 5.3 – Communication Strengths Remaining in the Three Stages of Dementia.....	21
▪ Worksheet 5.4 – Deep Breathing.....	22
▪ Worksheet 5.5 – Weekly Worksheet.....	23
Session #6 – Improving Communication Part II	
▪ Worksheet 6.1 – General Communication Guidelines.....	24
▪ Worksheet 6.2 – Communication Strategies – Early Dementia Stage.....	25
▪ Worksheet 6.3 – Communication Strategies – Moderate Dementia Stage.....	26
▪ Worksheet 6.4 – Communication Strategies – Late Dementia Stage.....	28
▪ Worksheet 6.5 – Building a Personal Memory.....	30
▪ Worksheet 6.6 – Building a Personal Memory Chart.....	31
▪ Worksheet 6.7 – Weekly Worksheet.....	32
Session #7 – Caregiver Coping Strategies Part I	
▪ Worksheet 7.1 – Caregiver Self Care.....	33
▪ Worksheet 7.2 – My Resources and Supports.....	34
▪ Worksheet 7.3 – Weekly Worksheet.....	35
Session #8 – Caregiver Coping Strategies Part II	
▪ Worksheet 8.1 – Coping with Stressful Situations.....	36
▪ Worksheet 8.2 – My Stress Triggers.....	38
▪ Worksheet 8.3 – Tips for Relaxation.....	39
▪ Worksheet 8.4 – Weekly Worksheet.....	40

Table of Contents (cont.)

Session #9 – Planning for the Future – Part I

- Worksheet 9.1 – Planning Ahead..... 41
- Worksheet 9.2 – New York State Healthcare Proxy Form..... 42
- Worksheet 9.3 – New York State Healthcare Advanced Directive Form..... 43
- Worksheet 9.4 – More Steps to Help You Prepare..... 45
- Worksheet 9.5 – Crisis Management..... 46
- Worksheet 9.6 – My Emergency Telephone Numbers..... 47
- Worksheet 9.7 – Weekly Worksheet..... 48

Session #10 – Planning for the Future – Part II

- Worksheet 10.1 – Long Term Plans..... 49
- Worksheet 10.2 – My Strengths and Accomplishments as a Caregiver..... 50

TEP Worksheet 1.1: **Program Contact Information**

---

The TEP Telephone **Group Facilitator is:**

**Katherine Schaffer, LCSW-R** (Canandaigua) 585 393-7660

Toll Free 800-204-9917

Program Supervisor:

**Laura Wray, Ph.D.** (Buffalo) 716-862-8598

If you, or the veteran you care for, are having thoughts of harming yourself call:

**National Suicide Hotline 1-800-273-TALK  
(8255)**

## TEP Worksheet 1.2: **What is Dementia?**

---

The word dementia refers to any condition where there is a loss of memory AND changes in at least two of the following areas of thinking:

- Language
- Perception (understanding visual information)
- Organization
- Reasoning
- Judgment

Dementia is defined as a progressive decline that causes cognitive (thinking) and functional deterioration leading to changes in the person's ability to continue to work or socialize as they had in the past.

- Dementia is not the name of a single disease. It is a word to describe the results we see from many different diseases of the brain.
- Dementia affects many areas of the brain and so we see changes in many thinking abilities AND behaviors.
- Some dementias (like Alzheimer's) will get progressively worse. Others may be fairly stable for a time or may even improve temporarily in response to medications. Most diseases that cause dementia are progressive, that is, they get gradually worse over time.
- Dementia is NOT normal aging
  - The likelihood of dementia increases with age. For example, it is estimated that 10% of people over the age of 65 have some form of Alzheimer's Disease. (That means 90% DO NOT have Alzheimer's Disease).
  - People used to think that memory loss was simply the result of normal aging. We do experience a mild decline in our new learning abilities. Normal aging DOES NOT bring a decline in general knowledge or the ability to function independently.
- Causes of Dementia
  - Alzheimer's Disease: Most common cause of dementia. Alzheimer's causes changes in the brain cells and affects memory and other thinking.
  - Vascular Dementia: Second major cause of dementia. In this case, losses in memory and thinking occur because of damage to circulation in the brain. People who have had strokes, mini-strokes, TIAs, and/or hypertension are at risk for this type of dementia.
  - Less Common Diseases: Other diseases that cause dementia can include (but are not limited to) Pick's Disease (also called Frontal Lobe Dementia), Parkinson's disease, and Lewy-Body Dementia.
  - Multiple Causes: It is possible for people to have more than one type of disease causing the change in their abilities. For example, a person who has Alzheimer's may also have mini-strokes causing vascular dementia and further lessening their abilities.
  - My loved one's diagnosis is: \_\_\_\_\_

TEP Worksheet 1.3: **Weekly Worksheet**

---

**Action Plan**

This week my **Action Plan** is: \_\_\_\_\_

---

---

---

---

**Week 1 Homework**

Read about the **Stages of Dementia** in Worksheet 2.1. My notes or questions:

---

---

---

---

One thing I would like to do better for myself or for the person I care for is:

---

---

---

---

**Notes/Questions for Next Week**

---

---

---

---

## TEP Worksheet 2.1: **Stages of Dementia**

---

There are many different ways to break down the changes that a person with dementia experiences. Here is one way to break down the stages:

**Level 0:** No Impairment. There is no evidence that the disease has begun to damage the person's brain.

**Level 0.5:** Questionable Impairment. Only a very mild change in day-to-day functioning may be seen. Recent memory, judgment, reasoning and planning begin to be affected. There may be slight confusion about time. You may notice small changes in the person's conversation style. He or she is beginning to have difficulty with the most complex tasks and may be having difficulties with hobbies or community activities. He or she may seem self-centered.

**Level 1.0:** Mild Impairment. All areas of thinking are now impaired. These include orientation, memory, perception, attention, concentration, language, and coordination. Changes in thinking may cause problems like suspiciousness or paranoia. Conversation is becoming difficult. Despite these changes, a casual observer who does not know the patient may think that he or she is normal. The person can no longer be completely independent. Behavior problems may arise when the person does not have enough support. He or she needs complex tasks, such as cooking, done for them, but can still do many simpler tasks. He or she may need reminding to bathe, or have intermittent difficulty with these simpler daily tasks.

**Level 2.0:** Moderate Impairment. The person may be confused or disoriented much of the time. However, he or she can still enjoy socializing and being with others. Memory is severely impaired and new information is rapidly lost. Older memories may still be available and the person may often talk about events from his or her distant past. Spontaneous speech may be infrequent, fragmented or make no sense. The person may need step-by-step instructions for simple tasks. He or she may still go to events outside the home but will be completely dependent on others for guidance. Only simple chores such as wiping the table are still possible and the person will need some prompting to do these. Assistance is needed for dressing and grooming. He or she can be easily overwhelmed by complex tasks or activities around them. Tasks that are too difficult or too much stimulation can cause restlessness or agitation. As the person's attention span shortens, distraction can be used more easily when events or thoughts upset them.

**Level 3.0:** Severe Impairment. At this stage, memory loss is severe and only fragments may remain. The person may no longer recognize common objects and what to do with them. Spontaneous speech may be garbled, infrequent, or not make sense. This person appears too ill to be taken to events outside the home. This person is likely to be incontinent. He or she may be able to cooperate with care but needs to have all activities performed for them. Repetition and showing the person what to do may help him or her follow simple commands. The person may resist care when he or she does not know what is happening.



**TEP Worksheet 2.2: Seven Steps to Problem Solving**

---

1. State the Problem



5. Implement the plan



2. Brainstorm



6. Re-evaluate



3. Evaluate the possible solutions



7. Keep trying till you find the missing piece!



4. Choose ONE solution to try



TEP Worksheet 2.3: **Weekly Worksheet**

---

**Action Plan**

This week my **Action Plan** is: \_\_\_\_\_

---

---

---

---

**This Week's Homework**

One problematic behavior I have notice in my spouse that I would like to work on next week is:

---

---

---

---

**Notes/Questions for Next Week:**

---

---

---

### TEP Worksheet 3.1: **Challenging Behaviors**

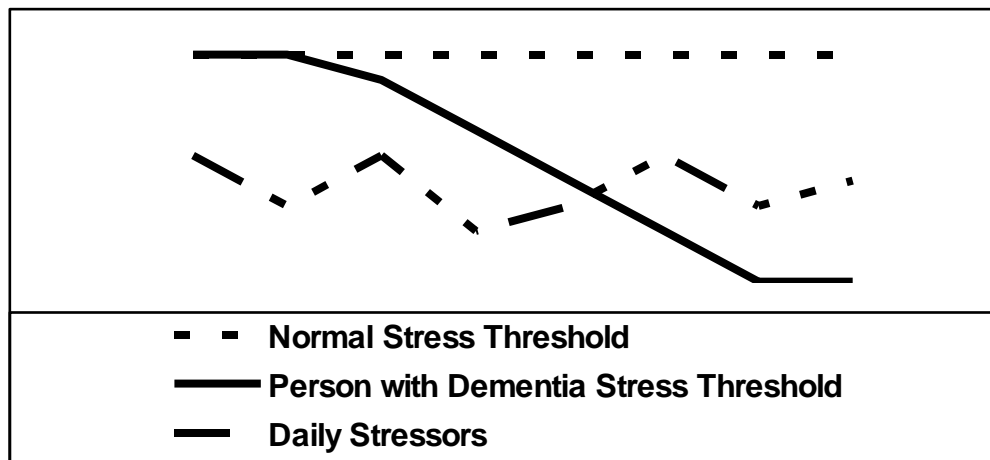
#### **Challenging Behaviors are:**

- Behaviors that may endanger the patient, such as wandering.
- Behaviors that may endanger others, such as aggression.
- Behaviors that make life more difficult for the patient, the caregivers, and the family such as inappropriate comments.

#### **Challenging Behaviors may be different over the course of the illness.**

Stage	Common Challenging Behaviors
Early	<ul style="list-style-type: none"> <li>▪ Apathy</li> <li>▪ Difficulty with initiating, or starting, desired behaviors</li> <li>▪ Irritability</li> </ul>
Middle	<ul style="list-style-type: none"> <li>▪ Wandering</li> <li>▪ Agitation (especially during confusion)</li> <li>▪ Refusal to cooperate with care</li> <li>▪ Sleep disturbance</li> <li>▪ “Shadowing” the caregiver (following the caregiver even around the house)</li> </ul>
Late	<ul style="list-style-type: none"> <li>▪ Agitation may worsen as confusion increases</li> <li>▪ Sleep disturbance may worsen</li> </ul>

**The Progressively Lowered Stress Threshold:** Everyone has his or her own tolerance for stress. The person with dementia’s ability to tolerate stress decreases over the course of the illness. Even minor stressors can be too much and cause the person with dementia to be upset or agitated.



## TEP Worksheet 3.2: **The ABCs of Behavior Management**

---

Before we can help someone to change a behavior we need to understand three important types of information.

**Antecedents** are the things that come before the behavior. They are signals or cues as to how someone may behave. They may be external: tone of voice, (child knows his mother may give a punishment when she calls him using his middle name), knowledge of a police car. They may be internal: hunger, emotions, and illness. When thinking about antecedents we need to consider:

- **WHO:** *Sometimes we see that specific people cause a person with dementia to be upset. We believe that this may happen when a person looks like someone from earlier in the patient's life who the patient did not like. Other times, it may be the tone of voice the person uses or it may be that person speaks too quickly.*
- **WHAT:** *We need to think about what was happening when the behavior started. One of the most common difficulties for caregivers of dementia is trying to help with bathing or grooming. Another common "what" is when family is visiting and there is too much activity for the person to tolerate.*
- **WHEN:** *We should look for patterns in the time of day. Often when a person seems agitated at a certain time of day there is a biological reason. He may be hungry or need to go to the bathroom. He may have arthritis and the pain medication may be wearing off. Or maybe, something is happens regularly at that time of day. For example, your loved one may be getting upset when you are trying to help him dress or bathe. So, think about what is happening at that time of day. You then might try a different way of approaching him to get the task accomplished, for example, slower and with more verbal reassurance, or you might wait a little while and try again.*
- **WHERE:** *Sometimes a certain place can cause difficulty. Some patients become anxious when they need to go to the VA for an appointment. They might think that their family is going to leave them there. Or the place may be too stimulating (have too much activity) for the patient to tolerate. Imagine that you suddenly found yourself in another country where you could not understand what people were saying to you. That might be frightening and overwhelming! So if there is a place that seems to cause trouble, you can think about what might be causing the person to feel uncomfortable.*

**Behavior**: It's important to look at the exact form of the behavior and think about the meaning within the context of what you know about the person. For example:

- **Constantly following someone** may mean that the person is seeking security, or seeking attention, or does not know what else to do.
- **Wandering** may be an effort to escape or go to a specific place, or seeking stimulation.

In both examples, the comments that the person is making can give helpful clues.

**Consequences** are what happen after the behavior. They are the “paycheck” for the behavior. They may be planned, for example, a promised reward for getting an ‘A’ on a report card or getting paid for working. They may be unplanned, such as kids getting attention from Mom every time they quarrel.

**TEP Worksheet 3.3: Behavior Observation Sheet #1**

---

<b>The behavior I am keeping track of this week is:</b>			
<b>When</b>	<b>A: Antecedents (What came before the behavior)</b>	<b>B: Behavior</b>	<b>C: Consequences (Anything that happened after the behavior)</b>

TEP Worksheet 3.4: **Weekly Worksheet**

---

**Action Plan**

This week my **Action Plan** is: \_\_\_\_\_

---

---

---

---

**This Week's Homework**

Record my Behavioral Observations on the sheet provided.

---

---

---

---

**Notes/Questions for Next Week:**

---

---

---

---

---

---

**TEP Worksheet 4.1: Applying the ABCs of Behavior Management**

Last week we talked about the ABC's of Behavior Management and you took notes about one specific behavior. This week we will use the information you noted over the week to find ideas about avoiding or managing the challenging behaviors you selected. Look over the notes you took during the week and think about the ABC's.

**A = Antecedents:** These are the things that come BEFORE a behavior. It helps to look for patterns in who, what, when, or where behaviors happened.

**WHO:** Did the behavior occur only when a certain person or people were present?

---

---

---

**WHAT:** Think about what was happening when the behavior started. Did the behavior tend to occur during or after certain activities?

---

---

---

**WHEN:** Look for patterns in the time of day. Does the behavior seem to happen around the same time of day? Is it a time when you tend to do something specific? Might the person be hungry or tired?

---

---

---

**WHERE:** Did the behavior tend to occur in a certain place? Might that place have been frightening or confusing to the person?

---

---

---



**B = Behavior:** We defined the behavior last week. Do you notice any difference between the way you described the behavior and what you noticed happening? Sometimes we think we are looking at one behavior but there turns out to be two different behaviors. Did you notice any differences between the behavior you described last week and the behavior you observed? Make note of any differences between your original description and what you observed:

---

---

---

---

---

---

---

---

**C = Consequences:** Think about what happened AFTER the behavior. You can ask yourself the same questions as you did when you considered the things before the behavior. Who, what, where, when? Is the behavior helping the person to escape from something frightening? Remember, even simple things can be frightening or confusing when the person has dementia. Is the person gaining attention because of the behavior?

---

---

---

**Making a new plan:** Now that you have considered all the possible antecedents and causes of the behavior, it's time to ask yourself, "What could I do differently to help avoid this situation?" You may need to ask for help from the group or use problem-solving strategies to think of a new plan. List your ideas here:

---

---

---

---

---

---

---

---

TEP Worksheet 4.2: **Behavior Observation Sheet #2**

**The behavior I am keeping track of this week is:**

**This week I am going to do the following:**

<b>When</b>	<b>A: Antecedents (What came before the behavior)</b>	<b>B: Behavior</b>	<b>C: Consequences (Anything that happened after the behavior)</b>	<b>Results: How is my plan going?</b>

TEP Worksheet 4.3: **Weekly Worksheet**

---

**Action Plan**

This week my **Action Plan** is: \_\_\_\_\_

---

---

---

**Week 1 Homework**

Record my Behavioral Observations on the sheet provided.

---

---

---

---

Record the results of the new plan on the sheet provided.

---

---

---

---

**Notes/Questions for Next Week:**

---

---

---

---

---

## TEP Worksheet 5.1: **Communication and Dementia**

---

Communication becomes more challenging as dementia progresses. Age related sensory changes occur for all people of advanced old age. It is important not to ignore the impact of age-related sensory changes on the ability of persons with dementia to communicate.

In addition to age-related sensory changes there are changes in the brain of persons with dementia that impede the processing of information and their ability to communicate. It is important to understand that these changes are not merely cognitive. Profound changes in the brain can lead to mood abnormalities, impaired thought processes, and physical health problems (particularly late in the disease process). For example, there may be hallucinations when dementia is severe. Brain changes also cause progressive deterioration in ability to conduct daily activities such as managing money and driving a car, and in later stages of the disease, the performance of basic self care activities. There is also frequently a negative impact on social skills and social interest, including willingness and interest to engage in activities. Frequently, there are also behavioral changes such as wandering and agitated behavior that are challenging to cope with. All of these impairments can interfere with communication.

Communication problems differ depending on the progression of the dementia. In early dementia conversational ability is still largely intact. However, words may become harder to find and naming difficulties may be noticed. There may be more frequent requests for clarification and confirmation. More frequent conversational turns may be needed to hold the person's attention. Vocabulary begins to be limited but this may not become apparent until later stages of the disorder.

As the disease progresses there are breakdowns in proper sentence structure and increased difficulty in finding words. Speech becomes vague with increasing use of indefinite references, and a decrease in topic maintenance. Missing words and phrases become more common with poor noun choices and incorrect verbal tenses. Still, the person with dementia is still able to maintain communication if they have a patient and understanding person with whom to communicate.

In late stages of dementia, people have more difficulty maintaining any conversation. The person still tries to communicate verbally. Gradually, however, there is more difficulty in forming words and the person may become mute. People at this stage may understand more than they are able to convey. Even in the very late stage, people with dementia still send and receive non-verbal messages and they respond to touch.

Here are some basic tips to help with communication:

- **Address sensory deficits:** Is the person able to see and hear adequately? Does he or she need to see the doctor to have their vision or hearing checked? Is he or she wearing their eyeglasses and/or hearing aids?
- **Ensure that environmental stimulation and physical comfort are not interfering with communication:** Is the environment too noisy? Is it well lit? Is the person hungry or uncomfortable? Are they in pain?
- **Be aware of the demands of the environment:** The person may not be able to process information at the same speed as before. Are we slowing down enough so that they can understand us?
- **Understand communication deterioration as dementia progresses:** Worksheets 5.2 and 5.3 describe changes and strengths that remain.

**TEP Worksheet 5.2: Three Stages of Communication Deterioration in Dementia**

---

	Early State Dementia	Moderate Stage Dementia	Severe Stage Dementia
Rules of Communication	Breakdowns in cohesion/coherence. Frequent confirmation / clarification requests. More frequent conversational turns. Need for conversational partner to be more directive to maintain dialogue.	Vague speech. Increasing confusion and lack of cohesiveness. Poor topic maintenance. Increasing use of indefinite References ( <i>it, they, them</i> ).	Difficulty maintaining any conversation. Mutism. Difficulty maintaining eye contact.
Knowledge & Meaning of Words	Vocabulary progressively more limited. Some naming difficulty.	Vocabulary progressively more limited. Increased naming difficulty. Increased empty speech.	Vocabulary progressively more limited. Frequent naming difficulty. Poor comprehension. Echolalia.
Sentence Comprehension	Breakdowns in proper tense use.	Missing phrases more common.	What is expressed by the person may seem incomprehensible Person does not understand what others are saying. Poor comprehension and use of grammar.
Ability to Produce Words	Still relatively intact.	Difficulty finding words.	Increased difficulty in forming words.

**TEP Worksheet 5.3: Communication Strengths Remaining in the Three Stages of Dementia**

<b>Early Stage Dementia</b>	<b>Moderate Stage Dementia</b>	<b>Severe Stage Dementia</b>
<ul style="list-style-type: none"> <li>• Conversational ability is still largely intact.</li> </ul>	<ul style="list-style-type: none"> <li>• Person responds to visual and non-verbal aids to communication.</li> </ul>	<ul style="list-style-type: none"> <li>• Person responds to touch.</li> </ul>
<ul style="list-style-type: none"> <li>• Prompts, cues, and structuring of conversation by the family member enables the person to maintain verbal communication.</li> </ul>	<ul style="list-style-type: none"> <li>• Given patience and understanding the person is able to maintain verbal communication.</li> </ul>	<ul style="list-style-type: none"> <li>• Person understands more than she or he is able to convey.</li> </ul>
<ul style="list-style-type: none"> <li>• Writing things down helps the Person maintain independence.</li> </ul>	<ul style="list-style-type: none"> <li>• Established, habitual activities will continue to be performed.</li> <li>• Memories of less recent events remain strong.</li> <li>• Long-term memories remain strong.</li> </ul>	<ul style="list-style-type: none"> <li>• Person may still try to communicate verbally.</li> <li>• Person receives and sends non-verbal messages.</li> <li>• Familiar activities may still be enjoyed.</li> </ul>

## TEP Worksheet 5.4: **Deep Breathing**

---

It is often hard to maintain a calm tone of voice. This is particularly true for people who are busy and being frequently interrupted for repetitive questions. People often will say, “I had to take a deep breath and count to ten to keep my temper.” This is actually a very good strategy. Deep breathing can be very helpful when you are trying to stay calm. Here’s how to do it.

This is a method of breathing for relaxation. This technique should not take more than approximately two minutes.

- *Concentrate on one spot in your stomach*
- *Concentrate on the flow of your breath as you inhale*
- *Concentrate on the flow of your breath as you exhale*
- *Focus on your breathing as you repeat this procedure several times slowly*
- *Visualize your breath going in through your nose, into the center of your body, and out again*

If you practice this, or any other, deep breathing method, you will find that it becomes easier to use. You will be able to take a few deep breaths to maintain your temper whenever you need it.

TEP Worksheet 5.5: **Weekly Worksheet**

---

**Action Plan**

This week my **Action Plan** is: \_\_\_\_\_

---

---

---

---

**This Week's Homework**

I practiced using **Deep Breathing** and a **Calm Tone Of Voice** and this is what happened:

---

---

---

These are the **Barriers To Communication** I found in my home:

---

---

---

**Notes/Questions for Next Week:**

---

---

---

---



**TEP Worksheet 6.1: General Communication Guidelines**

---

1. Begin all communications by first ensuring that you are relaxed and are conveying that you are relaxed. One technique to get rid of stress has been called deep breathing which we already reviewed. Turn to Worksheet 5.5 for a review.
2. Reduce background noise and other distractions and stimuli.
3. Ensure that there is adequate lighting for the person with dementia or move to a brighter location.
4. If the person with dementia usually wears glasses or a hearing aid, try to have the person with dementia use them. However, do not argue if the person with dementia does not want to wear them.
5. Speak in a slow, calm, respectful manner and keep the pitch of your voice low.
6. Avoid speaking to the person with dementia like a child.
7. Even when the person with dementia has severe language problems never assume that he or she does not understand you. Always assume that he or she will understand at least some of the information you are attempting to convey.
8. Do not talk about the person with dementia with others as if the person with dementia is not there.
9. Sit at the same eye level as the person with dementia to show that your attention is focused on him or her.

**TEP Worksheet 6.2: Communication Strategies – Early Dementia Stage**

---

1. Use simple direct language.
2. Let the person with dementia teach you the limits of his or her attention span.
3. Encourage the person with dementia to use different words or provide other information when they can't remember something.
4. Avoid talking for the person with dementia and filling in missing words.
5. Allow the person with dementia time to process what you are saying.
6. Structure conversations from general to specific topics.
  - a. Introduce the topic
  - b. Summarize what you want to convey
  - c. Fill in the details
7. Keep the conversation on track by summarizing and rephrasing.
8. Let the person with dementia reminisce – talk about favorite memories and concerns from the past, visit familiar places, re-experience old routines.
9. Allow the person with dementia to express feelings including those of frustration and anger.
10. Express your support, caring, and encouragement.
11. Repeat important messages.
12. Encourage the person with dementia to write down appointments and other information.
13. Give information and instructions immediately before they are needed. This will help lower the level of anxiety of the person with dementia.
14. Use memory aides. Encourage the person with dementia to write down appointments and other information. Have clear places such as a tray or a small box to leave keys, wallets, etc.

**TEP Worksheet 6.3: Communication Strategies – Moderate Dementia Stage**

1. Speak only when you are visible to the person with dementia.
2. Begin by addressing the person with dementia by name and give your own name or a visitor's name if the person with dementia does not recognize you or a visitor. Avoid saying "Do you know who I am?"
3. Face the person with dementia when speaking so that he or she can benefit from the visual cues of your facial expression and mouth movements.
4. Use overemphasis, gestures, facial expressions and pointing to familiar objects or photos to support the message expressed in your words.
5. Make sure you have been understood by the person with dementia. Give the person with dementia time to listen, think, and respond.
6. Wait for the person with dementia to respond. What seems like a long and unproductive silence to you may instead be time needed by the person with dementia to concentrate, comprehend, and make a response.
7. If the person with dementia does not respond in one or two minutes, repeat the question using the same wording or very similar wording.
8. If the person with dementia appears to be having difficulty understanding some particular phrase or word, use a different, simple way of saying the same thing rather than repeating the original words.
9. Use people's names, not "he," "she," etc.
10. Establish a basic vocabulary of words and phrases that you use with the person with dementia.
11. Keep communication simple. Use short phrases. Repeat if necessary but remember to pause first, giving the person with dementia plenty of time to respond.
12. Use yes or no rather than open-ended questions.

13. When giving directions break down tasks into simple steps. Use short simple sentences (four to six words). Then wait for the person to complete each step before explaining the next one.
14. If the person with dementia has trouble finding a word, encourage him or her to “talk around” the word or describe the words to you.
15. Develop a predictable routine for personal care activities.
16. Choose familiar activities to do together that the person with dementia enjoys. These activities might include planting seeds, simple crafts projects, folding laundry, easy baking, raking leaves, or taking a walk.
17. If the person with dementia is still able to read and understand, label everything in the room.
18. Try not to take it personally when the person with dementia sometimes forgets aspects of your relationship or other close family and friends.
19. Provide the person with dementia with encouragement and praise for trying to communicate or engage in activities.
20. Use every available clue. Words, gestures, expressions, and memory aids can all help you to understand what the person with dementia is saying.
21. If you are giving specific information, ask the person with dementia to repeat it back.
22. Avoid sudden changes in topics. If the subject is changed, say to the person with dementia, “Now we are talking about...”
23. Use reminiscence. Encourage the person with dementia to talk about favorite memories. Provide pictures or other memorabilia that will stimulate reminiscence.
24. Visit old familiar places.
25. Use familiar routines for personal care and other daily activities. Allow the person with dementia more time to complete daily activities.

**TEP Worksheet 6.4: Communication Strategies – Late Dementia Stage**

1. Speak only when you are visible to the person with dementia.
2. Begin by addressing the person by name and give your own name if the person does not recognize you.
3. Smile.
4. Keep your voice calm and affectionate. Talk in a normal voice. Do not whisper or yell.
5. Face the person with dementia when speaking so that he or she can benefit from the visual cues of your facial expression and mouth movements.
6. Use overemphasis, gestures, facial expressions, and pointing to familiar objects such as photographs to support the message expressed in your words.
7. Take twice as long to form your words, and make the effort to shape your words very clearly.
8. Always assume that the person with dementia is hearing what you are saying and understanding some of it.
9. Keep talking, even if there is no response.
10. Gently and reassuringly touch the person with dementia while talking.
11. Respond to seemingly meaningless communication attempts by the person with dementia with verbal reassurance. Try to understand what is being said. If the person with dementia uses a word that seems to have no apparent meaning, such as “tebra,” explore with him or her what the meaning might be. For example, ask: “tebra?” or “tell me more about the tebra.”
12. Look for nonverbal messages from the person with dementia.

13. Listen to music together, read aloud and modify activities that the person with dementia was able to enjoy in the past. For example, the person might not be able to garden any longer, but might be able to pot a plant with assistance from you.
14. Go slowly during personal care activities. Talk to the person with dementia about the next steps in the process and give the person time to process that information.
15. Use reminiscence. Point to an old photograph and say a few words about it. Use a memory album or a memory board.
16. Audio and video tapes of familiar voices describing important memories can be comforting to people with advanced dementia.

**TEP Worksheet 6.5: Building a Personal Memory**

---

To build the Personal Memory Album:

1. Find old photographs, postcards, or take pictures of familiar places, persons, or things. Try to pick items that are particularly meaningful to your spouse and that will remind your spouse of events from the distant past.
2. Place a photo on one side of the memory album. Try to place it so that there is room at the top for writing.
3. On an index card, write down in big letters a short statement of a few words only describing the photograph. Try to convey only one piece of information. For example, you could write “THIS IS YOUR BROTHER” or “THIS IS THE FACTORY WHERE YOU WORKED.”
4. Cut up the index card and place the written portion of it at the top of the photograph and paste it in using some glue
5. If the writing is too long to fit, try to shorten it. If you still can't get it to fit you can try placing it on the opposite page of the memory album.
6. Try using the memory album especially when your spouse becomes agitated or restless.

**TEP Worksheet 6.6: Building a Personal Memory Chart**

---

Get a poster board. You can get them at any office supply place.

To build the Personal Memory Chart:

1. Find old photographs, postcards, or take pictures of familiar places, persons, or things. Try to pick items that are particularly meaningful to your spouse and that will remind your spouse of events from the distant past.
2. Divide the poster board up into several sections by using a marker and a ruler.
2. Place a photo in one section. Try to place it so that there is room at the top for writing.
3. On an index card, write down in big letters a short statement of a few words only describing the photograph. Try to convey only one piece of information. For example, you could write “THIS IS YOUR BROTHER” or “THIS IS THE FACTORY WHERE YOU WORKED.”
4. Cut up the index card and place the written portion of it at the top of the photograph and paste it in using some glue.
5. If the writing is too long to fit, try to shorten it. If you still can’t get it to fit you can try placing it next to the photograph.
6. Place the poster board in an area where your spouse spends time such as in the family room or living room.



TEP Worksheet 6.7: **Weekly Worksheet**

---

**Action Plan**

This week my **Action Plan** is: \_\_\_\_\_

---

---

---

---

**This Week's Homework**

Create a **Memory Album or other Memory Tool**.

When I used the Memory Album, I noticed that:

---

---

---

---

**Notes/Questions for Next Week:**

---

---

---

---

---

---

## TEP Worksheet 7.1: **Caregiver Self Care**

---

Self-care is what we do to help ourselves be physically, emotionally, and spiritually healthy. Caregivers are often so busy caring for their loved one that they forget to take care of themselves! You may not even notice that gradually you may be giving up activities that help you feel good. It's easy to put aside social activities and hobbies because you are so busy providing care. If you give up everything, though, eventually YOUR health will begin to suffer. Your loved one depends on you, but you won't be able to provide him with care if you have exhausted all of your own physical and emotional resources. Have you noticed that you have given up things that used to make life more pleasant? What types of things are you still doing to help take care of yourself? Write some of these things down here. \_\_\_\_\_

---



---



---

One form of self-care is taking care of your physical health. We often hear about caregivers who have neglected their own doctor's appointments or medication refills in order to provide care for their loved one. Do any of you fall into this category? What do you do to take care of yourself physically?

Another self-care area that you may neglect is maintaining your own emotional health. Caregiving is a stressful undertaking and it can wear away on your nerves. Caregivers can also become depressed. If the depression is serious, that is, it interferes with sleep, eating, is limiting your activity, or is causing the person to think about suicide, you should seek medical help from your doctor as soon as possible. Medications for depression can be helpful. Even if you do not think you are depressed enough to take an anti-depressant medication, it can be helpful to talk about how you feel in this group and to use the problem solving portion of the session to figure out what you might do to overcome the blues and to feel happier despite all the responsibilities you face. You may also want to talk with your family physician. There are many good treatments for depression that do not affect your alertness or ability to provide care.

Fortunately, although caregiving is difficult at times, most caregivers do not become that seriously depressed. Many of you have already found ways to help yourself cope. What do you do to help yourself stay emotionally healthy? \_\_\_\_\_

---



---



---



---

**TEP Worksheet 7.2: My Resources and Supports**

---

Fortunately, most of us have people or groups that can be helpful to us as caregivers. These people might be someone who will lend a hand, watch your husband while you go out, or just someone that you know you can talk to when you are feeling down. You may also know of community agencies or religious or civic organizations that can help you. Let's take a minute now to list those resources and their phone numbers if you know them. If you don't have the phone number handy right now, leave that space blank until after our group session.

**Resources and Supports**

**Telephone Number**


TEP Worksheet 7.3: **Weekly Worksheet**

---

**Action Plan**

This week my **Action Plan** is: \_\_\_\_\_

---

---

---

---

**This Week's Homework**

The **pleasant thing** that I am going to do for myself this week is:

---

---

This week I visited \_\_\_\_\_ (**day care or community agency**) and I found out:

---

---

I **practiced relaxation** and it made me feel:

---

---

**Notes/Questions for Next Week:**

---

---

---

## TEP Worksheet 8.1 Coping With Stressful Situations

---

Learning appropriate coping strategies for caregivers with dementia is important. We all have different ways that we cope with stressful situations. Sometimes these coping strategies are effective, and sometimes they are not so effective. When coping strategies are not effective it is usually because we do not perceive “triggers” or things that “push our buttons” and instead act automatically and respond out of frustration, anger or some other negative emotion.

There are several steps that you can take to improve the way you cope with stressful situations:

- **Be more aware of your bodily reactions to stress triggers:** When you feel yourself becoming distressed you can do something about it – but when you are not aware of what is triggering your distress you react without thinking. Therefore, make a point of thinking about the most common triggers for your stress and be prepared to change the way you react when these occur. Sometimes simple awareness is all that is necessary to keep you in control.
- **Use stress reduction strategies such as deep breathing to calm yourself down:** When you perceive stress triggers take a moment out to take some deep breaths before proceeding. Pay attention to your inner dialogue. We all talk to ourselves. Some things that we say to ourselves can increase our stress, while other things we say to ourselves reduce our stress. For example, are you saying things to yourself like, “Why does he do this to me?” or “He does this on purpose to make me mad.”
- **Change your inner dialogue:** Think of things that you can say to yourself that give you a new, more positive perspective on the situation. For example, you might say to yourself “it’s not him, it’s the disease” or “he is not doing this on purpose.”
- **Take his perspective:** Consider aspects of the situation that might have caused his reaction which, in turn, heightened your stress. For example could you have approached your spouse too abruptly? Could he be confused or unable to go as quickly as you would like? Could he be uncomfortable or in pain? By taking his perspective you might be better able to understand his reaction, and de-escalate the situation.
- **Change the situation:** For example, sometimes when people with dementia are physically uncomfortable they pace constantly. They might be in pain, too hot or too cold, or need to go to the bathroom, but they can no longer figure that out or tell you why they are uncomfortable. If you can figure out what might be bothering them, you can change the situation. Are you feeling cool? Maybe you can help him put on a sweater. Is there something else about the situation you can change that might make him more comfortable?
- **Remove yourself from the situation:** If you can’t think of anything right at the moment, try removing yourself temporarily from the situation until you can calm down and approach the situation with a new perspective. For example, you can say you will be right back and go into another room. You could go to the bathroom. You might be able to take a walk within your home or outside.

All of these steps are meant to help you take better control of yourself during stressful situations. Start by recognizing stress triggers. Then interrupt automatic “hot” responses (like raising your voice or snapping at the patient) by using relaxation strategies such as deep breathing, by changing your inner dialogue from negative self-talk to positive self-talk, and by deliberately trying to remain calm and positive. Next “reappraise” the situation by taking his perspective and by viewing his reaction as disease related. Think about how you might approach the situation differently. If this does not work, remove yourself from the situation until you can calm down and re-approach the situation.

TEP Worksheet 8.2: **My Stress Triggers**

---

**My Stress Trigger:**

Write down something that your spouse does that triggers stress for you.

---

---

---

---

**My Thoughts:**

What do I say to myself that increases my stress? (Ex: "He's doing this on purpose.")

---

---

---

What could I say to decrease my stress?

---

---

---

**My Reaction:**

A way I can change or interrupt the situation to gain control of my stress:

---

---

---

---

**TEP Worksheet 8.3: Tips for Relaxation**

Decide how long you will relax. It can be two minutes or ten. Whatever the length of time, make that be your special time and don't let other things interfere.

Make yourself a pleasant, quiet place. Take the phone off the hook. Turn off unnecessary noisemakers like the TV. You may choose to put on some soothing music. You may want to burn a fragrant candle or spray your favorite fragrance in the air.

You may want to take a few minutes of relaxation when you have someone over to distract the person for whom you are caring. You may want to practice relaxing when he or she is taking a nap, asleep for the night, or before he or she gets up in the morning.

Be at a comfortable temperature. It's hard to relax when you are cold. Sit in a warm room. Use an afghan or blanket.

Make your body comfortable: Sit in a favorite recliner, or lay down on the bed. Make sure all of your body is supported. Don't cross your legs or arms.

Breathe deeply, in through your nose and out through your mouth. Find a slow comfortable pace.

With each inward breath, imagine that you are breathing in the relaxation. With each outward breath, imagine that you are breathing out the tension.

Once your breathing is slow and regular, focus on your muscles. Are you feeling tense in one area such as your neck, shoulders, jaw or forehead? Concentrate on that area and imagine the warmth of relaxation seeping in. If you are having trouble letting a muscle group relax, you can try gently tensing the muscle, holding the tension for a second or two, and then relaxation. Practicing tensing and relaxing can help you "get the feel for" letting muscles relax by simply concentrating.

If worries or thoughts pop into your mind while you are trying to relax, you can tell yourself that you will think about them when you are done relaxing. Don't try to block all thoughts, but if they come, imagine them floating on by. You will only be relaxing for a few minutes and you have the whole remainder of the day to think about those things!

You may want to visualize a special or happy place such as a favorite vacation spot. Use your imagination to conjure up as many details as possible. The more details, sights, smells, sounds, the more you will feel like you are actually there.

Before ending your practice session, take a few more minutes to focus on your breathing and to let go of any remaining tension. Tell yourself that you can take this nice feeling with you when you go back to your day. You may want to count backwards slowly from 10 to 1 as you gradually "wake-up."



TEP Worksheet 8.4: **Weekly Worksheet**

---

**Action Plan**

This week my **Action Plan** is: \_\_\_\_\_

---

---

---

**This Week's Homework**

I said these things to myself to help myself feel less stressed:

---

---

---

---

I changed the following situation so that I would feel less stressed.

---

---

---

---

**Notes/Questions for Next Week:**

---

---

---

---

## TEP Worksheet 9.1: **Planning Ahead**

---

It is important for you to start planning ahead so that you can be prepared to meet your husband's needs in the future, and so that you can involve him in future plans to the extent that that is possible now. One of the many ways that you can do this is by considering developing a Health Care Proxy, and an Advance Directive.

It's a good idea for all of us to discuss our health care wishes with those that may someday have to make a decision for us. For example, if you could not speak for yourself, would you want to be kept alive on a machine that breathes for you? When a person is diagnosed with dementia, having taken care of these plans in advance becomes more important because we know there will come a time when he cannot make his own decisions. For some of your loved ones, that time may have already arrived. For others, you may still be able to involve them in medical decision-making.

In the healthcare system, we try to encourage everyone to appoint a "Health Care Proxy." The proxy is the person who will make medical decisions for your husband if he is unable. This only goes into effect when your husband is not capable of making his own decision. Often, the person will appoint their spouse, but it is a good idea to have a backup as well. For example, what if the spouse were to die before the patient with dementia? If your loved one was in later stages of the disease, he would not be able to appoint a new proxy. Therefore, many people chose to appoint a son or daughter or a close family member or friend as well. This may be particularly important for you if you have some children who have differing opinions.

Some people chose to make specific statements about their wishes for future medical decisions. These statements are called "Advanced Directives" because they tell your healthcare providers ahead of time what you want them to do. For example, people often feel that they do not want to be kept alive by machines that breathe for you or by inserting a tube down your nose or directly into your stomach to provide liquid nourishment when you can no longer eat. Others may feel strongly that they want to be fed, no matter what. It is important for you to talk to your healthcare provider and family about your loved ones wishes.

Knowing that they have dementia or other chronic illnesses, some people do not want their heart to be resuscitated if it stops. They might feel that when it is "their time to go" that doctors or emergency medical professionals should not interfere. This type of Advanced Directive is called a "Do Not Resuscitate Order" or "DNR" order. It means that if a person's heart stops, the doctors and nurses will not do CPR to try to revive them.

It's important to know that making a statement that limits treatment, like DNR or tube feeding, does not mean that you will not be cared for. Your health care providers will continue to do everything possible to provide the right care including keeping your loved one comfortable. We have included both New York State Health Care Proxy and Advance Directive forms in your workbook. Let's take a look at these forms. Do you have questions about the things I've been talking about or about the forms? If you have not already filled out a Health Care Proxy or an Advance Directive, I would like you to try to do that this week before our next meeting. This may involve talking with your husband or recalling what he has said to you about what kind of care he would have wanted at the end of his life. It may also involve talking with family members or close friends that might know what kind of medical care he would want if he becomes very severely ill.

TEP Worksheet 9.2: **New York State Healthcare Proxy Form**

---

# New York State Health Care Proxy Form

**1. I,** \_\_\_\_\_ hereby appoint \_\_\_\_\_

(name, home address and telephone number)

as my health care agent to make any and all health care decisions for me, except to the extent that I state otherwise. This proxy shall take effect when and if I become unable to make my own health care decisions.

**2. Optional instructions:** I direct my agent to make health care decisions in accord with my wishes and limitations as stated below, or as he or she otherwise knows. (Attach additional pages if necessary.)

---

---

---

(Unless your agent knows your wishes about artificial nutrition and hydration (feeding tubes), your agent will not be allowed to make decisions about artificial nutrition and hydration. See instructions on reverse for samples of language you could use.)

**3. Name of substitute or fill-in-agent** if the person I appoint above is unable, unwilling or unavailable to act as my health care agent.

---

(name, home address and telephone number)

---

**4. Unless I revoke it, this proxy shall remain in effect indefinitely, or until the date or conditions stated below. This proxy shall expire (specific date or conditions, if desired):**

---

**5. Signature** \_\_\_\_\_

Address \_\_\_\_\_

Date \_\_\_\_\_

Statement by Witnesses (must be 18 or older)

I declare that the person who signed this document is personally known to me and appears to be of sound mind and acting of his or her own free will. He or she signed (or asked another to sign for him or her) this document in my presence.

Witness 1 \_\_\_\_\_

Address \_\_\_\_\_

Witness 2 \_\_\_\_\_

Address \_\_\_\_\_

**TEP Worksheet 9.3: New York State Healthcare Advanced Directives Form****New York Living Will**

This Living Will has been prepared to conform to the law in the State of New York, as set forth in the case *In re Westchester County Medical Center*, 72 NY2d 517 (1988). In that case the Court established the need for "clear and convincing" evidence of a patient's wishes and stated that the "ideal situation is one in which the patient's wishes were expressed in some form of writing, perhaps a 'living will.'"

**[PRINT YOUR NAME]**

I, \_\_\_\_\_, being of sound mind, make this statement as a directive to be followed if I become permanently unable to participate in decisions regarding my medical care. These instructions reflect my firm and settled commitment to decline medical treatment under the circumstances indicated below:

I direct my attending physician to withhold or withdraw treatment that merely prolongs my dying, if I should be in an incurable or irreversible mental or physical condition with no reasonable expectation of recovery.

These instructions apply if I am (a) in a terminal condition; (b) permanently unconscious; or (c) if I am minimally conscious but have irreversible brain damage and will never regain the ability to make decisions and express my wishes.

I direct that my treatment be limited to measures to keep me comfortable and to relieve pain, including any pain that might occur by withholding or withdrawing treatment.

**[CROSS OUT ANY STATEMENTS WITH WHICH YOU DO NOT AGREE]**

**While I understand that I am not legally required to be specific about future treatments if I am in the condition(s) described above I feel especially strongly about the following forms of treatment:**

**I do not want cardiac resuscitation.**

**I do not want mechanical respiration.**

**I do not want artificial nutrition and hydration.**

**I do not want antibiotics.**

**However, I do want maximum pain relief, even if it may hasten my death.**

**[ADD PERSONAL INSTRUCTIONS (IF ANY)]**

**Other directions:** \_\_\_\_\_

**These directions express my legal right to refuse treatment, under the law of New York. I intend my instructions to be carried out, unless I have rescinded them in a new writing or by clearly indicating that I have changed my mind.**

**[SIGN AND DATE THE DOCUMENT AND PRINT YOUR ADDRESS]**

**Signed:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Address:** \_\_\_\_\_

**[YOUR WITNESSES MUST SIGN AND PRINT THEIR ADDRESSES]**

I declare that the person who signed this document is personally known to me and appears to be of sound mind and acting of his or her own free will. He or she signed (or asked another to sign for him or her) this document in my presence.

**Witness #1:** \_\_\_\_\_

**Signed:** \_\_\_\_\_

**Address:** \_\_\_\_\_

**Witness #2:** \_\_\_\_\_

**Signed:** \_\_\_\_\_

**Address:** \_\_\_\_\_

## TEP Worksheet 9.4: **More Steps to Help You Prepare**

---

Another thing you can do to plan for the future is to have accurate information about the financial implications of care, whether this means care at home or in an institutional setting. You can get information about current New York State Medicaid limits for income and assets on the internet, from your local State legislators or your county Office for Aging. This information will help you decide if you would benefit from talking to an attorney about your rights under Medicaid law.

Another important step you can take in planning for the future is to consider making a “**Power of Attorney (POA)**.” Sometime people confuse the Health Care Proxy and the Power of Attorney. A POA is for financial and legal matters and does not automatically give you the authority to make health care decisions for a person. The POA form allows you to follow the person’s direction and do things like withdraw money for his banking account or sign a paper for him. The POA can be used, for example, if you are in the hospital and you need your son or daughter to do banking for you before you are discharged. It can be very helpful for a caregiver to have a POA because it can help you to more easily take care of accounts or legal items for your husband. You can arrange a POA through your bank, but this would be limited to financial transactions.

You can also have what is called a “**Durable Power of Attorney**” that covers all types of financial and legal transactions. You can arrange a Durable POA through an attorney. You can also purchase a Durable POA form at office stores (such as Office Max or other similar stores). You do not have to have an attorney to fill out that form but you must get it notarized. Any POA can be revoked at any point in time if the person who signed it changes his or her mind.

## TEP Worksheet 9.5: **Crisis Management**

---

There may come a time in your role as caregiver when you feel that things are out of control. Hopefully, your participation in this group will help you manage things so that that time never comes, but just in case, it's very helpful to be prepared ahead of time. Many of us have had experienced some type of emergency in our lives and you may have noticed that in a crisis it can be hard to think straight. If you have thought out your "emergency plan" ahead of time, you may become less anxious or confused about what to do and you won't need to rely so much on your wits to resolve the crisis.

You may be wondering what I mean by the word crisis. For example, if the person you are caring for has been very agitated in the past, you may already know the feeling. Perhaps the person is so upset that they are threatening verbally, or striking out. You know that you have reached that point when you do not feel physically safe or when you feel your loved one is in danger of harming himself, but because of his emotional state, you are unable to stop him. That can be a very frightening situation. For example, one caregiver described a situation where her husband was becoming increasingly threatening toward her. He was no longer able to speak much, but each time she tried to interact with him, he made an angry face and would shake his fist at her. (It may be that he was not recognizing her or could not understand what she was trying to do.) At one point, he put his hands around her neck and she was afraid that he would choke her. You can imagine how frightening that would be. Fortunately, these situations do not happen with everyone, and as I said, after being in this group, you have lots of good ideas about how to avoid problems or help calm your husband down if he gets upset. Let's talk about what you might do in the situation.

Get away from the situation -Caregivers may feel duty bound to stay with the person with dementia. While supervision is certainly important, if the caregiver is in danger you should always make sure that you maintain your own safety first. For example, you might go to their bedroom or bathroom and shut the door, or you might need to step out of the house for a few minutes until the situation has calmed down again. While you do that, it's a good idea to call someone for help. You can refer to your list of helpful people for ideas and numbers. Remember you made one list in during meeting 7 – see worksheet 7.2. On the next page of your workbook there is also a place that you can list emergency telephone numbers that you can use in a crisis.

## TEP Worksheet 9.6: **My Emergency Telephone Numbers**

---

It is a good idea to make a list of contacts and telephone numbers that you can use in an emergency. We have listed some contacts. During the week I would like you to add to this list and to fill in the telephone numbers for each contact. You may want to keep this list by the telephone. You might also consider keeping it or a separate copy in your purse so that when you go out you will have that with you in case you need it.

### Emergency Contact

### Telephone Number

Emergency Response System

911

---

Family Members

---



---



---

Friends/Neighbors

---



---



---

Mobil Crisis Team (if your area has one)

---

Hospital Emergency Room

---

Primary Care Provider (Physician)

---

Primary Care Social Worker

---

Poison Control

---

Alzheimer's Association

---



TEP Worksheet 9.7: **Weekly Worksheet**

---

**Action Plan**

This week my **Action Plan** is: \_\_\_\_\_

---

---

---

---

**This Week's Homework**

I filled in the **NY State Healthcare Proxy and Advanced Directive** forms.

---

---

I filled in the remaining emergency numbers on **Worksheet 9.6**. I am going to keep my emergency numbers:

---

---

**Notes/Questions for Next Week:**

---

---

---

---

---

---

---

## TEP Worksheet 10.1: **Long Term Plans**

---

One of the hardest decisions that caregivers make is the decision to place their loved one in a nursing home or assisted living facility. Many people have the goal of keeping the person with dementia at home throughout the course of the disease. The VA tries to support this goal by offering home care and other supports so your husband can remain at home for as long as possible. Unfortunately, there may come a time when he with can no longer stay in his own home. That time is different for every caregiver. Some people with dementia are easier to handle than others. Some caregivers have more resources, such as many children living near by who can help out. Whatever the situation, it's a good idea to give some thought to what would cause you to consider placement before you come to a crisis situation.

Some of the challenges that make it impossible for caregivers to manage may be:

- **Changing Sleep Cycles. If the person with dementia is up all night long and the caregiver is getting no sleep, you may not be able to manage him even with changes in activity routines or medications from his doctor.**
- **Incontinence. When the disease progresses to the point where he or she is no longer able to cooperate with bathroom routines diapers can be used. But there are situations where the sheer volume of laundry produced and care needed to clean the patient is more than one person can take on.**
- **Behavioral Symptoms. In most cases, you will able to either manage symptoms by changing your own reactions, by getting help from staff at the VA, by learning to avoid situations that cause behavior problems, or, if needed, with medications. There are times, however, when he puts himself in such danger by wandering off, or by violent behaviors, that he may need the safety of a structured environment.**
- **Caregiver Illness. Many caregivers have their own health problems. Sometimes, these health problems get worse and limit your ability to care for your loved ones.**

Fortunately, these severe situations are fairly infrequent and in most cases you are able to keep him at home long into the illness, or even until death. However, the wear and tear of caregiving, even in less stressful situations, adds up over the years and many caregivers find that their loved one needs more help than one person can provide. It's helpful to think ahead of time about what some of your own personal limitations might be. In that way you can use the skills and information that you have learned in this group to be better prepared and can keep your husband at home longer.

We also encourage you and your family to visit nursing homes in your area so that you can see first hand what they look like and what you feel comfortable with. Because there is often a long waiting list, you may want to begin the application process when you begin to feel like you may no longer be able to provide enough care on your own. By visiting nursing homes, you can get a sense of the application process and the waiting times. Being familiar with the process and which people can be most helpful can help you feel less worried. And the less worried you feel, the better able you will be to keep on caregiving!

TEP Worksheet 10.2: **My strengths and Accomplishments as a Caregiver**

---

All of us have strengths and weaknesses. Take a moment to list your inner strengths and assets that help you to keep going in your role as a caregiver. Also, list the things you have already accomplished as a caregiver.

My Strengths and Assets as a Caregiver

---

---

---

---

My Accomplishments as a Caregiver

---

---

---

---