

Long Term Care  
Intensive Train the Trainer Series

Managing Difficult Behaviors

# Putting the Person First In Dementia Care

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## Putting the Person First in Dementia Care

Teaching Cues	Content	Resources
<b>Title</b>	<b>Putting the Person First in Dementia Care</b>	<b>Putting the Person First in Dementia Care</b>
	<p>Module Overview: When we are caring for a person with dementia, do we really know who that person is? Not just their name or diagnosis, but where they came from? What their personal dreams and accomplishments were? Answers to these questions have a profound impact on the care of a person with dementia.</p> <p>In this module, we will explore what the experience of having dementia is like. It will help us to remember that the person is more important than the task to be accomplished. We will discuss the importance of focusing on the person's remaining strengths and abilities rather than what they cannot do. We will learn why a person's life story is so important when providing care.</p>	
<b>Objectives</b>	<p>The objectives for this module are:</p> <ol style="list-style-type: none"> <li>1. Recognize the needs and feelings associated with the experience of having dementia.</li> <li>2. Identify the elements of person-centered care.</li> <li>3. Describe the role of physical and social causes of dependence.</li> <li>4. Identify important factors for assessment.</li> <li>5. Identify common emotional reactions of families and the person with dementia to moving.</li> </ol>	<b>Objectives</b>
<b>Image Exercise by Tom Kitwood</b> <b>Have the group sit back and close their</b>	<p>You are in a swirling fog, &amp; in half-darkness. You are wandering around in a place that seems vaguely familiar; &amp; yet you do not know where you are. You cannot make out whether it is summer or winter, day or night. At times the fog clears a little, &amp; you can see a few objects really clearly. But as</p>	

<p><b>eyes while you read the following:</b></p>	<p>soon as you start to get your bearings, you are overpowered by a kind of dullness and stupidity, your knowledge slips away and again you are utterly confused.</p> <p>While you are stumbling in the fog, you have an impression of people rushing past you, chattering like baboons. They seem to be so energetic &amp; purposeful, but their business is incomprehensible. Occasionally you pick up fragments of conversation, &amp; have the impression that they are talking about you. Sometimes you catch sight of a familiar face; but as you move towards the face, it vanishes, or turns into a demon. You feel desperately lost, alone, bewildered, frightened. In this dreadful state, you find that you cannot control your bladder or your bowels.</p> <p>This is the present reality. Everything is falling apart, nothing gets completed, nothing makes sense. But worse of all, you know it wasn't always like this. Behind the fog and darkness, there is a vague memory of good times, when you knew where &amp; who you were, when you felt close to others. When you were able to perform daily tasks with skill and grace. Once the sun shone brightly and the landscape of life had richness and pattern. Once you were a person who counted. Now you are a nothing and good for nothing.</p>
<p><b>Have the class open their eyes.</b></p>	<p>How did you feel with these things happening to you? Then ask: What actions would help to meet your physical and emotional needs?</p>
<p><b>Discussion questions: (10 minutes)</b></p>	

	<p>This imagine exercise and first person accounts from people who are in early stages of Alzheimer’s help us to understand the experience of having dementia. There are a number of books that have been written by people with Alzheimer’s Disease. A listing is included with this presentation.</p> <p>When we learn about the experience of dementia, we can be more understanding and patient. It helps us to think about care in a different way.</p>	
<p><b>The old culture of dementia care.</b></p>	<p>For many years, people who had dementia were called senile, or diagnosed with organic brain syndrome.</p> <p>Dementia was seen as an incurable disease, and nothing could be done for the person.</p> <p>The medical model of care focused on the disease process to explain a person’s behavior. A person could be labeled a feeder, a hitter, a wanderer, or a stage 7.</p> <p>A difficult behavior needed to be managed with skill. As the disease progressed, only physical care was needed until the person died.</p>	<p><b>The old culture of dementia care.</b></p>
<p><b>The new culture</b></p>	<p>A new culture of dementia care has emerged over the past several years. There are a number of authors who have written about person-centered care. Tom Kitwood from England wrote about person centered care in his book, <i>The New Culture of Dementia Care</i>.</p>	
<p><b>Person centered care</b></p>	<p>The new culture of dementia care has several characteristics.</p> <p>Persons with dementia are viewed as being alive and responsive.</p> <p>They are able to relate to the people they interact with and need to have meaningful activities and experiences.</p> <p>In the new culture, the caregivers are focused on empowering a person and creating an environment where there is respect for each person’s unique characteristics.</p> <p>We understand that the person with dementia has behavior changes. The</p>	<p><b>Person centered care</b></p>

	<p>behaviors we see are a result of damage to the brain.          The focus of care is on the remaining strengths and abilities of the person with dementia.          We recognize that ongoing assessment and brainstorming of solutions are important.          Solutions to problem situations must be customized to the unique needs of each individual.</p>	
<p><b>We can change our attitude</b></p>	<p>Sometimes there is a lot of pressure to get the job done.          We need to focus on the person rather than the task.          The person's life story will give us strategies for providing care.          We can encourage people with dementia to participate in their care if we know their remaining strengths and abilities.          The time spent sharing memories, providing a compliment or laughing together has great value.          We remember that people with dementia live in the moment. Holding hands, sharing a joke or a hug can mean a lot and promote feelings of well being.</p>	<p><b>We can change our attitude</b></p>
<p><b>Discussion Questions (10 minutes)</b></p>	<p>If you had dementia and someone was caring for you, what special things would you want your care providers to know? What personal preferences, accomplishments would you like incorporated into your care plan?          In your family or community, how are people with dementia viewed and treated?          These concepts of the new culture of dementia care may seem ideal. What factors in your setting would make it harder for you to incorporate these ideas?</p>	<p><b>Write answers on flip chart</b></p>
	<p><b>Assessment</b></p>	
	<p>When a person with dementia begins to receive services at home, or moves to another living situation, there is an assessment. The type and length of the</p>	

<p><b>Parts of the assessment</b></p>	<p>assessment will depend on the setting.</p> <p>There are several factors that may be included in the assessment.</p> <ul style="list-style-type: none"> <li>▪ A medical history.</li> <li>▪ A functional assessment to evaluate the person’s abilities to perform their activities of daily living, such as bathing, dressing and eating. This takes into account the person’s vision and hearing abilities, chronic illnesses and physical mobility.</li> <li>▪ A mental health assessment will provide information about a person’s cognitive abilities. There may be a Mini Mental Status Exam.</li> <li>▪ A screening tool may be used for dementia or depression. There is a high incidence of depression in older adults, and often it is undiagnosed. Sometimes a person with dementia is depressed, and medications can help.</li> <li>▪ The person’s medications and their ability to take them reliably will be evaluated. The side effects and interactions from multiple medications may affect a person’s ability to function.</li> <li>▪ A social history will provide personal information about the person with dementia.</li> <li>▪ The life story of a person can be explored, looking at past dreams, accomplishments, hobbies and preferences. Significant friends, family and pets can be identified. These provide clues about meaningful activities.</li> </ul>	<p><b>Parts of the assessment</b></p>
<p><b>Other parts of assessment</b></p>	<ul style="list-style-type: none"> <li>▪ Things such as photos or a familiar quilt that can be used to make a new setting more homelike and provide cues in the environment.</li> <li>▪ Spiritual background</li> <li>▪ Financial assessment</li> <li>▪ Coping skills of person with dementia and their family</li> </ul> <p>This information can be incorporated into the care of the person with</p>	<p><b>Other parts of assessment</b></p>

<p><b>When there is no family</b></p>	<p>dementia to provide meaningful activities and conversation topics. Each person should receive this information that will be providing care.</p> <p>Sometimes a person with dementia comes into our setting with no family or social history. This becomes a challenge when trying to provide person centered care. Some other sources of information can be explored:</p> <ul style="list-style-type: none"> <li>▪ Possible living relatives or friends may be located through the phone book or internet.</li> <li>▪ A distant contact may be able to provide information about significant individuals.</li> <li>▪ Old medial records may provide valuable information</li> <li>▪ A visit to the person's former living environment may identify significant support systems. Sometimes we can facilitate a visit from an old friend who has been out of touch.</li> <li>▪ Hospital discharge planners may have information from previous admissions.</li> </ul>	<p><b>When there is no family</b></p>
<p><b>What happened before move?</b></p>	<p>It is important to know the circumstances and dynamics surrounding the move.</p> <p>Did the person come willingly to their new setting?          What were the factors that contributed to the move?          What role did the family play in the move?          What are the emotions that are being expressed by the person and the family members?</p> <p>Sometimes a person is dropped off at the new setting because the family was afraid to tell them about the move.</p> <p>This can be very upsetting and caregivers are challenged to help the person deal with their loss of independence.</p> <p>Sometimes the admissions coordinator can help families think through the move to make it easier for the person with dementia.</p>	<p><b>What happened before move?</b></p>

<p><b>Why does a person have to move?</b></p>	<p>When a person with dementia moves to another setting, it is often as a result of some type of change is their independence. The inability to live alone, death or illness of a caregiver or spouse can be factors that make a move necessary. Many older adults have several chronic illnesses that affect their function and mobility. These include heart or lung problems, arthritis and osteoporosis. As a person ages, the incidence of dementia increases. A person over 85 has a 50% chance of getting dementia. Over half the people who live in nursing homes have dementia.</p>	<p><b>Why does a person have to move?</b></p>
<p><b>Why is Moving Hard?</b></p>	<p>A person with dementia depends on the environment for cues. Familiar surroundings and routines are very important. When a person with dementia moves to a new setting, there is a period of adjustment.</p> <p>Some common reactions person with dementia may experience may include:</p> <ul style="list-style-type: none"> <li>▪ Confusion and disorientation may be seen especially at first. If the person was ill before the move, they may have a hard time adjusting to their new surroundings. Familiar surroundings and predictable routines are very important for a person with dementia to function at their best.</li> <li>▪ They may be extremely anxious and become easily agitated because of the unfamiliar setting.</li> <li>▪ The person may deny that they have moved, and become angry if someone argues, or tries to use logic.</li> <li>▪ Some people become depressed or withdrawn because of the loss associated with the move and feelings of not belonging.</li> <li>▪ A person may feel extremely tired. Trying to figure out the new environment can be exhausting.</li> </ul>	<p><b>Why is Moving Hard?</b></p>



	<ul style="list-style-type: none"> <li>▪ Sometimes a person with dementia feels relief when they move. This may occur when a person has been isolated, or the previous living situation has been stressful, or hard on the family.</li> <li>▪ If a person with dementia is allowed to visit the new setting and is able to give input, the adjustment may be easier.</li> </ul> <p>It may take months for the person with dementia to adjust to the new surroundings. A person with dementia may experience some of these same emotions when they begin to attend an Adult Day Services program. When caregivers are patient and reassuring, they can help the person feel like they belong.</p>	
<p><b>Family Issues</b></p>	<p>It is stressful for families to look at issues related to bringing in services or helping a person with dementia move to a new setting.</p> <p>Many times they feel guilty for introducing new help or not keeping the person at home.</p> <p>They may feel that it is their duty to care for the person and that they have failed in their role as a caregiver, child or spouse.</p> <p>Sometimes it is admitting that the person is dependent and will not get better.</p> <p>Family members may have made a promise that the person would never go into a nursing home and they feel guilty.</p> <p>As caregivers, we have to be careful about making judgments about families.</p> <p>We may not be aware of all the dynamics and history surrounding their relationship.</p>	<p><b>Family Issues</b></p>
<p><b>Helping families</b></p>	<p>When we care for a person with dementia, we become partners with the family.</p> <p>It is helpful to let the family know how the person is adjusting.</p>	<p><b>Helping families</b></p>

	<p>When family members come to visit a person in a new setting, they may feel uncomfortable.</p> <p>We want the families to feel like they were able to share a pleasant moment or memory with the person.</p> <p>Family and friends can be encouraged to share stories about the person. These can be incorporated into the person's care.</p> <p>Some families feel better having a structured activity with the person they are visiting. Caregivers can help identify meaningful activities such as looking at photos, sharing a snack, or reading the newspaper together.</p> <p>Sometimes the family stays too long or too many people visit at once. We can help families to understand that a shorter visit may be easier for the person with dementia. Smaller groups may be less overwhelming.</p> <p>Because of the brain changes from dementia, the person may tire easily, or have a short attention span. Shorter visits may be enjoyed by all.</p>	
<p><b>In Conclusion</b></p>	<p>In this module, we have examined the new culture of dementia care. We have explored the role of the life story, and the importance of putting the person first before the task.</p> <p>The brain changes that happen as a result of dementia are often the source of challenging behaviors. We recognize that when a person with dementia moves to a new setting, it can be challenging for the person and their families to adjust.</p>	<p><b>In Conclusion</b></p>

## Resources

- Bell, V., and Troxel, D., *The Best Friends Approach to Alzheimer's Care*. Baltimore: Health Professions Press, Inc. 1997
- Bell, V., and Troxel, D., *The Best Friends Staff, Building a Culture of Care in Alzheimer's Programs*. Baltimore: Health Professions Press, Inc. 2001
- Fazio, S., Seman, D., Stansell, J., *Rethinking Alzheimer's Care*. Baltimore: Health Professions Press, 1999
- Kitwood, T., and Benson, S., (eds) *The New Culture of Dementia Care*. London: Hawker Publications, 1995
- Kitwood, T., *Dementia Reconsidered: The Person Comes First*. Philadelphia: Open University Press, 1997
- Robinson, A., Spencer, B., *Developing Meaningful Connections with People with Dementia, A Training Manual*, Ypsilanti, MI Eastern Michigan University, 2002
- White, L., and Spencer, B., *Moving a Relative With Memory Loss, A Family Caregiver's Guide*, Santa Rosa, California, Whisp Publications, 2000

## **A SELECTION OF BOOKS WRITTEN BY PERSON WITH ALZHEIMER'S DISEASE**

- Davis, R., *My Journey Into Alzheimer's Disease*. Wheaton, IL Tyndale House Publishers, Inc. 1989
- Henderson, C, S., and Andrews, N., *Partial View: An Alzheimer's Journal*. Dallas; Southern Methodist University Press, 1998
- McGowin, D, F., *Living in the Labyrinth*. New York: A Delta Book, Dell Publishing 1994
- Rose, L., *Show Me the Way to Go Home*. Forest Knolls, CA: Elder Books, 1996
- Simpson, R. and A., *Through the Wilderness of Alzheimer's: A Guide in Two Voices*, Minneapolis, Augsburg Fortress, 1999

## Managing Difficult Behaviors

Putting the Person First in  
Dementia Care

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### Objectives:

1. Recognize the needs and feelings associated with the experience of having dementia.
2. Identify the elements of person-centered care.
3. Describe the role of physical and social causes of dependence.
4. Identify important factors for assessment
5. Identify common emotional reactions of families and the person with dementia to moving.

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## Old Culture of Dementia Care

In the Old Model of Dementia Care

- Dementia incurable-no hope
- Dementia care focused on medical model
- Disease explained the actions and behaviors
- People labeled as hitters or feeders
- Behaviors managed with skill
- Physical care until death

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### Person-Centered Care

- Person alive and responsive
- Able to participate in meaningful activities
- Focused on empowering a person and creating an environment where each person is unique and respected
- Behaviors are related to brain changes
- Focus on remaining strengths/abilities
- Ongoing assessment needed

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### We Can Change Our Attitudes

- Pressure to get job done
- Focus on person, not the task
- Learn the life story of the person and incorporate into their daily care
- Encourage person to participate in care
- Time spent connecting has value
- People with dementia live in the moment

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### Parts of the Assessment

- Medical history
- Functional assessment
- Mental health assessment
- Medications and side effects
- Social history
- Life story/meaningful activities

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**Other Parts of Assessment**

- Familiar objects to enhance the environment
- Spiritual background
- Financial assessment
- Coping skills of person with dementia and their families

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**When There Is No Family**

- Locate possible living relatives or friends through phone book or internet
- Distant contact may provide info about significant people
- Old medical records
- Visit to former living environment
- Hospital discharge planners

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**What Happened Before Move?**

- Look at circumstances and dynamics around the move.
- Did the person come willingly to the new setting?
- What factors contributed to the move?
- What role did the family play?
- What emotions are being expressed?

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### Why does a Person with Dementia Have to Move?

- Change in independence
- Unable to live alone
- Death or illness of a caregiver or spouse
- Chronic illness
- Increase in incidence of dementia as person gets older
- Over 50% of nursing home residents

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### Why is Moving Hard?

- Confusion and disorientation after move
- Loss of familiar surroundings and routines
- Anxiety and agitation
- Denial that move has occurred
- Depression and withdrawal
- Fatigue

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### Family Issues

- May feel guilty about bringing in services or a move
- May feel they have failed in caregiving role
- Admitting person is not going to get better
- May have promised that the person would never have to move out of their home
- Take care not to judge families

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## Helping Families

- Become partners in care
- Help families share a pleasant moment in time
- Encourage family to tell stories that can be incorporated into the person's care
- Help them to plan a structured activity
- Shorter visits may be easier for the family and for the person with dementia

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## In Conclusion

- New culture of dementia care
- Importance of life story
- Person more important than task
- Brain changes cause of challenging behaviors
- Move to new setting hard for person with dementia and their families

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