

Knowledge and Skills Needed for Dementia Care



A Guide for Direct Care Workers

In Everyday Language

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Dementia Competencies Workgroup
2008

Mission

To help direct care workers provide excellent dementia care by identifying the skills and knowledge they need to succeed.

Vision

All direct care workers will have the knowledge, skills and compassion to provide great quality care when they work with people with dementia*, their families and other caregivers.

* Dementia is a group of symptoms, not a disease. It is a decline in the ability to think that persists long enough and is severe enough to interfere with routine daily activities.

2006 First Edition
2007 Second Edition with minor modifications
2008 Everyday Language Edition

Development of this guide was supported by funding from the Michigan Department of Community Health and included funding by the Alzheimer's Disease Demonstration Grants to States from the Administration on Aging, Department of Health and Human Services, Washington, D.C. 20201 (CFDA #93-051). Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Point of view or opinions do not, therefore, necessarily represent official Administration on Aging policy.

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Purpose of This Guide

**The purpose of this Guide is to empower you...
the direct care worker.**

Use this guide to identify the knowledge and skills you need to provide quality care for a person with dementia.



Knowledge and skills, along with your compassion, will help you in your work with people with dementia and their families.

A Direct Care Worker

- + (plus) special knowledge
- + (plus) good skills
- + (plus) compassion

= **Providing quality care for
someone with dementia.**

This Guide covers the special skills you need when working with a person with dementia. It does not address the general skills needed as a direct care worker, such as making transfers and assisting with eating.

An example of special skills for working with someone with dementia would be the ability to communicate with a person who is confused by his or her surroundings. Another example is hydration. It is a concern for all persons receiving care. However, when the person has dementia, hydration is an even greater concern since he or she is more likely to forget to drink fluids. So, the Guide identifies hydration as a special concern for individuals with dementia.

Some of the knowledge or skill items appear in more than one place in the Guide if they are important to more than one topic.

Philosophy and Values

Having quality relationships with the person you are caring for and their family gives meaning and purpose to your work. This guide provides an outline of the knowledge and skills needed to enhance caregiving relationships. These relationships are based on seeing each person as unique and respecting those differences.



As a direct care worker, you are an essential part of the caregiving team. Your work and how you care for people is valuable. You can help create a supportive and safe setting for each person.

The competencies in this guide are based on the belief that quality care must:

- Be person-centered (care that looks at each person as unique).
- Help the person grow and develop.
- Consider the importance of each person's needs.
- Create a supportive environment.
- Value your contributions.

The best care is given when decisions are made by the persons getting care, or by someone closest to them.

This is often you... the Direct Care Worker.

1.1.1.1 As a Direct Care Worker (DCW) you can do your best work when you have:

- Relationships that are meaningful.
- Opportunities to grow personally and professionally.
- Positive feedback for your accomplishments.
- Training that centers on you as an adult learner and helps you to be creative and problem solve.
- A feeling of "ownership" in your work and encouragement to try new ideas.

And when...

- High standards of care are a priority.

Best wishes with your continuing efforts to provide the best care possible.

How to Use This Guide

We suggest you look through all of the competency areas for:

1. Areas you are not familiar with or want to know more about.

2. Topics that really interest you.

- Check the *Suggested Resources section* in the back of the Guide for lists of books, articles, videos and DVDs.
- Read some of the books and articles or view the videos or DVDs to help you learn more.
- Check the *Reference section* which lists the same resources -- and more -- in alphabetical order.
- If you come across words you don't know, check the *Glossary* or the *Suggested Resources section*.
- To find a list of organizations that give training on specific skill or knowledge areas check in the *Dementia Education and Training Directory for Michigan* at: www.dementiacoalition.org. Classes and trainings are listed by county.



**The more you know
+ (plus) the more experiences you have
= Greater enjoyment while you give care**

Your Feedback is Valuable

We hope to continue to improve this guide. You can help by giving us your comments to the questions below:

1. How helpful was this Guide to you? VERY SOMEWHAT NOT VERY

2. What is most helpful about this Guide?

3. What would make this Guide better?

4. How has using this Guide changed how you care for persons with dementia?

**Please use this page (or additional paper) to send your responses to:
Michigan Public Health Institute Dementia Project
2436 Woodlake Circle, Suite 300; Okemos, MI 48864**

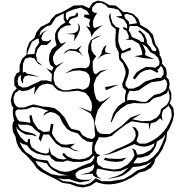
**You may also reply by Fax to # 517-381-0260 or email to: Lmassuch@mphi.org
If you have questions, please call # 517-324-7320**



Competency Areas and Objectives

A. Knowledge of Dementia Disorders

1. Identify the primary causes of dementia.
2. Know the differences between irreversible and reversible dementia.
3. Understand what delirium means and how it is different from dementia.
4. Describe how brain changes make a difference in the way a person functions and behaves.
5. Explain why it is important to personalize the care you provide to someone with dementia.



B. Person-Centered Care

1. Discuss the characteristics of person-centered care.
2. Describe how you can give care to help the person with dementia be comfortable and secure, as well as live a full and meaningful life.
3. Describe how knowing a person's background, culture and experiences can help you give them the best possible care.
4. Describe how *your* background, culture, experiences, and attitudes affect how you give care.



C. Care Interactions

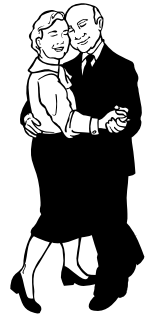
1. Provide help with physical care tasks that matches the needs and abilities of the person.
2. Identify and take care of safety needs of each person with dementia.
3. Consider the person's abilities, needs, desires and interests to ensure the greatest comfort, a sense of well-being, and the fullest life possible.
4. Get and use information about the individual's personal history; personal, religious, and spiritual preferences; and cultural and ethnic background.
5. Identify and support the feelings – whether spoken or otherwise expressed – of the person.



6. Show effective ways of listening to and communicating with someone who has dementia.
7. Discuss how a person's surroundings may affect them.
8. Understand why a person with dementia may be more vulnerable to abuse and neglect.

D. Enriching the Person's Life

1. Support and encourage the person to maintain their usual activities, social life, and community involvement.
2. Recognize how important it is for people to do things that give meaning and purpose. These activities are often part of their culture and background.
3. Recognize how important pleasurable activities are in a person's life. They may include sexual activity, intimacy and feeling close to others.



E. Understanding Behaviors

1. Understand that how a person behaves is a form of communication. Behaviors may reflect emotions or unmet needs.
2. Recognize that what a person thinks is acceptable behavior is their reality. It may be influenced by many things, including their cultural background and family dynamics. These influences can affect behavior related to gender roles, eye contact, and personal space.
3. Describe helpful responses to behaviors that you find "challenging" or "difficult."



F. Interacting with Families

1. Respond respectfully to the family's unique relationships, experiences, cultural identity, and losses.
2. Use a positive and accepting approach with family members or when talking about the family with other staff.
3. Recognize the family as part of the caregiving team.



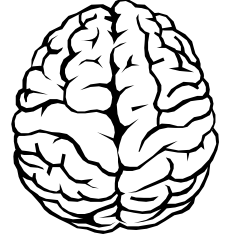
G. Direct Care Worker Self-Care

1. Identify your own feelings, beliefs, or attitudes that may affect your caring relationships.
2. Identify helpful ways to prevent and cope with your own stress and burnout.
3. Identify the ways you cope with grief and loss.
4. Explain helpful ways to talk with supervisors and co-workers to address differences and ideas about caregiving and what you believe is best for the person with dementia.



A. Knowledge of Dementia Disorders

As a DCW who is knowledgeable about dementia disorders, you are able to:



1. Identify the primary causes of dementia.
2. Know the differences between irreversible and reversible dementia.
3. Understand the definition and significance of delirium.
4. Describe how brain changes affect the way a person functions and behaves.
5. Discuss why it is important to personalize the care you provide to someone with dementia.



1. Identify the primary causes of dementia.

Explain that there are many causes of dementia. Understand that dementia itself is not a disease, but a group of symptoms (signs or changes) that vary.

Recognize the key characteristics (such as how they develop and the behaviors that people with the disease are likely to have) of diseases and disorders that are the primary causes of dementia, such as:

- Alzheimer's disease
- Vascular disease
- Lewy body disease
- Frontotemporal disorders
- Parkinson's disease
- Head trauma
- Huntington's disease
- Substance-induced disorders
- HIV-AIDS



Dementia is a group of symptoms (not a disease). It is a loss of mental function in two or more areas of the brain, such as language, memory, visual and spatial abilities, or judgment severe enough to interfere with daily life. Usually begins gradually and progresses over time.

Delirium describes a state of confusion that usually begins suddenly and ends fairly quickly. It may include agitation, anxiety, illusions, hallucinations, muddled speech, flawed perception, and being easily distracted, hyperactive, or disoriented.

2. Recognize the difference between irreversible and reversible dementia.

- 2.1 Understand that there are reversible types of dementia in which the symptoms can improve with proper treatment.
- 2.2 Recognize the primary symptoms and causes of reversible dementia.
- 2.3 Understand that treatment may delay the symptoms of dementia from becoming worse. Treatment may also improve quality of life for a person with an irreversible dementia.
- 2.4 Explain why it is important for a person with dementia to get an early and definitive diagnosis. A definitive diagnosis will include the primary cause of the dementia.

Definitive Diagnostic Tools: A simple diagnosis of *dementia* is not enough. Ongoing research is increasingly improving the diagnostic tools. A full diagnostic workup includes a complete, physical, mental and functional assessment.

3. Understand the definition and significance of delirium.

Understand that delirium is an acute medical condition that can be fatal if not treated.

Recognize the symptoms and causes of delirium.

4. Describe how brain changes affect the way a person functions and behaves.

- 4.1 Describe how dementia symptoms typically progress or worsen over time.
- 4.2 Recognize that different primary causes of dementia affect different parts of the brain.
- 4.3 Recognize that different primary causes of dementia have different stages or phases.
- 4.4 Recognize that different primary causes of dementia have different effects on behaviors.
- 4.5 Recognize that a person may have more than one cause of dementia.
- 4.6 Recognize that a person may have changes in more than one area of the brain.
- 4.7 Recognize the symptoms that may be a part of active dying.

5. Discuss why it is important to personalize the care you provide to someone with dementia.

- 5.1 Understand that each person's symptoms and progression through the different stages or phases are unique.
- 5.2 Understand that each person's symptoms and progression may be very different from what is typical.
- 5.3 Recognize how the care a person needs may be different depending on the primary cause or causes of dementia.

B. Person-Centered Care

As a DCW who is person-centered, you can:

1. Discuss the characteristics of person-centered care.
2. Describe how you can give care to help the person with dementia be comfortable and secure, as well as live a full and meaningful life.
3. Describe how knowing a person's background, culture, and experiences can help you give the best possible care.
4. Describe how *your* background, culture, experiences, and attitudes affect how you give care.



1. Discuss the characteristics of person-centered care.

- Identify ways to see each person with dementia as a special person.
- 1.2 Explain the importance of relating to all aspects of the person with dementia (physical, emotional, mental and spiritual; and past, present and future).
 - 1.3 Explain how the person's feelings are more important than completing a task.
 - 1.4 Recognize that people with dementia are able to make decisions and choices until the end of life.
 - 1.5 Identify ways to help the person make decisions.
 - 1.6 Identify how to offer choices in ways that match the person's ability.
 - 1.7 Identify ways to keep the power to make decisions in the hands of the person or those closest to her or him.
 - 1.8 Recognize that people with dementia should continue to have opportunities and risks in life.
 - 1.9 Explain the difference between *doing for* the person and *partnering with* the person.

Person-centered care is a widely used term with many meanings. Here we use the term to refer to care that takes into account that each person is unique. Person-centered care respects and honors individual differences. Each person with dementia has his or her own history, personality, needs, and wishes. Person-centered care offers the person with dementia choices within his or her ability to choose. Providing person-centered care means *taking the time* and *making the effort* needed to know the person as an individual so that her unique individuality is honored.

2. Describe how you can give care to help the person with dementia be comfortable and secure, as well as live a full and meaningful life.

- 2.1 Explain why it is helpful to learn a person's preferences for how you give care and interact with them.
- 2.2 Describe how the person with dementia may experience the world around them.
- 2.3 Recognize the importance of having routines that are familiar to each person.
- 2.4 Identify ways to set up familiar routines for each person.
- 2.5 Describe the importance of being flexible in meeting each person's needs.
- 2.6 Discuss ways to identify the person's current skills and abilities.
- 2.7 Describe ways you can encourage the person to use the skills and abilities they have.
- 2.8 Recognize that every person has a need for:
 - Relationships with others
 - Inclusion (being part of a group)
 - Occupation (having things to do)
 - Individuality (feeling unique)
 - Dignity
 - Feeling secure emotionally
 - Privacy
 - Intimacy and touch
 - Socialization (being with others)
 - Meaning
 - Physical comfort
 - Meaningful activities



2.9 Recognize and encourage each person's ability to:

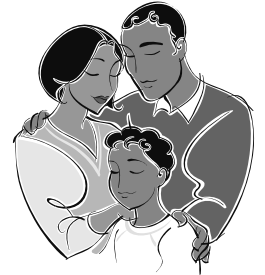
- Grow
- Connect
- Give
- Receive
- Teach



2.10 Identify ways to help the person be a member of a community.

3. Describe how knowing a person's background, culture and experiences can help you give them the best possible care.

- 3.1 Explain why it is helpful to you as a caregiver to learn information about the person's background, culture, religion and life history.
- 3.2 Recognize how a person's ethnicity and culture may affect how they view you as a caregiver.
- 3.3 Describe the importance of understanding and honoring each person's unique story without judgment.



4. Describe how *your* background, culture, experiences, and attitudes affect how you give care.

- 4.1 Describe the values, beliefs and attitudes you have because of your unique background, culture and life experiences that affect how you give care.
- 4.2 Identify how your background, culture and life experiences influence how you perceive the people you care for, especially those with different backgrounds, religions and ethnicities.
- 4.3 Recognize that differences in backgrounds can cause tension between you and the person with dementia; their families and other staff. Be open to working with their preferences.



C. Care Interactions

As a dementia-competent DCW, you are able to:

1. Provide help with physical care tasks in ways that match the needs and abilities of the person.
2. Identify and take care of the safety needs of each person with dementia.
3. Consider the person's abilities, needs, desires, and interests to ensure their greatest comfort, a sense of well-being, and independence.
4. Get and use information about:
 - the individual's personal history
 - personal, religious and spiritual preferences
 - cultural and ethnic background
5. Identify and support the feelings - whether spoken or otherwise expressed - of the person with dementia.
6. Show effective ways of listening to and communicating with someone who has dementia.
7. Discuss how a person's surroundings may affect them.
8. Understand why a person with dementia may be more vulnerable to abuse and neglect.



1. Provide help with physical care tasks in ways that match the needs and abilities of the person.

- 1.1 Understand that care needs are different for each person and that the care required may be different for the same person in different situations.
- 1.2 Provide help with eating in a way that matches the person's needs and abilities.
- 1.3 Encourage enough hydration.
 - 1.3.1 Recognize that the person with dementia may not feel thirsty.



- 1.3.2 Recognize that the person with dementia may not look like they are thirsty and may not tell you they are thirsty.
- 1.4 Use ways to help the person remain clean that cause the least amount of distress.
- 1.5 Recognize and respond to signs of pain or discomfort.
- 1.6 Prevent or reduce pain and discomfort when helping the person move.

2. Identify and take care of the safety needs of each person with dementia.

- 2.1 Identify ways to reduce risks and prevent injury.
- 2.2 Recognize that as dementia progresses, the person's abilities change.
- 2.3 Be creative in changing the environment to make sure the person is safe.
- 2.4 Recognize changes in the person that can affect safety. These include changes in judgment, physical ability, and senses (such as eyesight, hearing and touch).
- 2.5 Understand the risks of wandering and reduce these risks as much as possible.
- 2.6 Understand the risks of weapons. Take care of these risks, according to agency policies or as needed to make sure the person is safe.
- 2.7 Recognize that more help is needed when there is an emergency with a person with dementia.
- 2.8 Describe basic steps to take in an emergency.



3. Consider the person's abilities, needs, desires, and interests while providing comfort, a sense of well-being, and independence.

- 3.1 Recognize that independence is a goal as long as it helps the person feel better about themselves and gives them pleasure.
- 3.2 Understand that some challenges may be stimulating and add independence. Challenges can also overwhelm the person and make them tired.

- 3.3 Recognize the person’s ability to take part in activities.
- 3.4 Identify ways to help the person function as independently as possible:
 - simplify activities
 - break down tasks into steps
 - provide assistance
- 3.5 Recognize that the person’s abilities may go up and down.
- 3.6 Recognize that different types of dementia affect a person’s abilities in different ways.
- 3.7 Offer choices when you can in providing care.
- 3.8 Discuss how using prompts can help the person do more on their own.
- 3.9 Recognize signs that palliative or hospice care may be needed. Discuss what you’ve noticed with your supervisor.

4. Get and use information about the individual’s personal history; personal, religious, and spiritual preferences; and cultural and ethnic background.

- 4.1 Recognize that it is helpful to continue to gather information about the person’s history and preferences as you care for them.
- 4.2 Recognize that your role in sharing what you learn with family members and other staff is important.

5. Identify and support the feelings – whether spoken or otherwise expressed - of the person.

- 5.1 Understand that the person with dementia reacts to your emotions and to those of others around them.
- 5.2 Respond in a respectful way to the feelings expressed by the person.
- 5.3 Describe various ways a person with dementia may behave to show feelings.

Palliative care is sometimes called “comfort care.” It is care that focuses on making sure that a person is comfortable rather than on trying to cure. Palliative care seeks to ensure that remaining life is of the highest quality possible, but does not try to prolong life.

Hospice provides palliative care and supportive services that are covered by Medicare. People often wait longer than necessary to call upon Hospice services. Dementia and co-morbidities may support a person’s eligibility for hospice care.

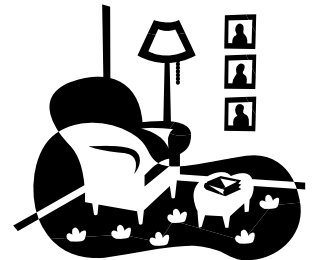


6. Show effective ways of listening to and communicating with someone who has dementia.

- 6.1 Recognize the various ways a person can communicate, whether by talking or in other ways.
- 6.2 Make sure you have the person's attention before asking a question or beginning a task with them.
- 6.3 Demonstrate good listening skills.
- 6.4 Demonstrate ways to change how you communicate with a person with dementia when their abilities change.
- 6.5 Describe ways to offer physical and emotional comfort to those experiencing loss or actively dying.

7. Discuss how a person's surroundings may affect them.

- 7.1 Recognize that a person's surroundings include social and physical aspects as well as how things are organized.
- 7.2 Recognize that the person's surroundings can help or hurt:
 - Autonomy (being able to do things on one's own)
 - Personalization (using own belongings or decorations)
 - Sense of well-being
 - Orientation and way-finding (understanding where things are and how to get around)
 - Privacy
 - Safety
 - Social interaction
 - Physical comfort
- 7.3 Discuss how to notice "triggers" in the surroundings that may create stress for the person.
- 7.4 Describe how to change the surroundings to support or improve the person's quality of life.
- 7.5 Discuss why it may be important to make ongoing changes in the surroundings to meet the person's needs.



8. Understand why a person with dementia may be more vulnerable to abuse and neglect.

- 8.1 Recognize that caring for a person with dementia may cause you to have feelings and thoughts that affect or interfere with your ability to give compassionate care.
- 8.2 Recognize the signs of physical, emotional, sexual, and financial abuse.
- 8.3 Recognize the signs of physical and emotional neglect.
- 8.4 Recognize when, how and to whom to report your concerns about signs of potential abuse and neglect.



D. Enriching the Person's Life

As a dementia-competent DCW, you can:

- 1. Support and encourage the person to continue their usual activities, social life and community involvement.**
- 2. Recognize how important it is for people to do activities that give meaning and purpose. The activities are often a part of their culture and background.**
- 3. Recognize how important pleasurable activities are in a person's life. These may include sexual activities, intimacy and feeling close to others.**



1. Support and encourage the person to continue their usual activities, social life and community involvement.

- 1.1 Assist the person to be involved in activities they find meaningful. These are critical because they help the person have good relationships, feel good about themselves, and preserve their personal identity and self esteem.
- 1.2 Recognize the importance of supporting and assisting the person in doing what they like to do to be a productive member in their community.
- 1.3 Recognize that the person may need to maintain their usual social life and community involvement for spiritual fulfillment.



2. Recognize how important it is for people to do activities that give meaning and purpose. The activities are often part of their culture and background.

- 2.1 Understand that activities can be simplified to meet the person's ability without being childish.
- 2.2 Encourage the person to do as much as they can for themselves. This helps to maintain their dignity and highest level of functioning.



- 2.3 Understand that activities should fit each person. Consider the person's history, experience, cultural background, and identity.
- 2.4 Understand that the person's abilities change. Recognize the importance of calmly adapting activities and tasks as the disease progresses.
- 2.5 Understand the importance of physical activity in maintaining the person's independence and abilities.
- 2.6 Identify reasonable expectations of the person's ability given how the disease affects them.
- 2.7 Understand the importance of moments of joy.
- 2.8 Describe how actively listening to the person with dementia reminisce and tell stories from their life can give them pleasure and enrich your relationship with them.
- 2.9 Understand the importance of the person reviewing their life – so they can identify remaining goals, tie up any loose ends, make peace, and leave a legacy.
- 2.10 Recognize that the person with dementia can continue to benefit from new experiences.
- 2.11 Recognize that all activities can be adapted to the person's ability.
- 2.12 Understand the importance of respecting the common routines and daily pleasures of the person.



3. Recognize how important pleasurable activities are in a person's life. These may include sexual activities, intimacy and feeling close to others.

- 3.1 Understand the person's need to be sexual and close to others.
- 3.2 Allow the person to express their sexuality when it does not harm or threaten others.
- 3.3 Discuss how the various forms of dementia may affect the expression of sexuality.
- 3.4 Recognize the difference between being sexual and being close to others.
- 3.5 Understand that people never lose the need for touch.
- 3.6 Be mindful to protect the dignity of every person.



- 3.7 Be creative and generous with non-sexual forms of appropriate touch. Examples include massage, manicures, pedicures, and hair combing.
- 3.8 Use ways that touch all the senses to create pleasure. Examples include music and aromatherapy.
- 3.9 Recognize the need of the person to feel attractive and desirable.
- 3.10 Recognize that the person with dementia can still enjoy humor.
- 3.11 Understand that everyone has a different idea of what is funny and appropriate.
- 3.12 Ensure that persons with dementia never feel that you are laughing at them.



E. Understanding Behaviors

As a DCW who understands the behaviors of persons with dementia, you can:

- 1. Understand that how a person behaves is a form of communication. Behaviors may reflect emotions or unmet needs.**
- 2. Recognize that what a person thinks is acceptable behavior is their own reality. It may be influenced by many things, including their cultural background and family dynamics. These influences can affect behavior related to gender roles, eye contact, and personal space.**
- 3. Describe helpful responses to behaviors that you find “challenging” or “difficult.”**



- 1. Understand that how a person behaves is a form of communication. Behaviors may reflect emotions or unmet needs.**
 - 1.1 Discuss common ways that people with dementia act out. Examples include shouting, cursing, hitting, slapping, shoving, wandering, and verbal or physical agitation or aggression.
 - 1.1.1 Understand common causes of acting out by people with dementia. Examples include physical pain, hunger, thirst, boredom, frustration and the need for assistance with a desired activity.
 - 1.2 Use positive words when describing behavior.
 - 1.3 Discuss why the words and behavior of a person with dementia need not be taken personally, even if they seem aimed at you.
 - 1.4 Understand signs of depression in a person with dementia.
 - 1.4.1 Understand the increased risk of depression.
 - 1.4.2 Understand the increased risk of depression not being recognized.

- 1.4.3 Understand the increased risk of depression not being treated.
 - 1.4.4 Explain the benefits of treating depression in a person with dementia.
 - 1.4.5 Recognize the signs of depression in a person with dementia.
- 2. Recognize that what a person thinks is acceptable behavior is their own reality. It may be influenced by many things, including their cultural background and family dynamics. These influences can affect behavior related to gender roles, eye contact, and personal space.**
- 2.1 Understand that a person’s perception is their reality.
- 3. Describe helpful responses to behaviors that you find “challenging” or “difficult.”**
- 3.1 Recognize that our personal views often lead us to decide whether behavior is challenging.
 - 3.2 Discuss how important it is to identify the need causing a behavior.
 - 3.2.1 Recognize how important it is to understand all the factors that contribute to the behavior. These include what happens before and after the behavior, as well as more long-term and invisible issues.
 - 3.3 Discuss how to identify the need causing a behavior.
 - 3.3.1 Identify needs that may lead to certain behaviors:
 - Physical comfort
 - Emotional well-being
 - Feeling competent
 - Desire to be social with others
 - Ability to find one’s way
 - Desire to be understood
 - Desire to communicate
 - Boredom
 - Depression



- 3.3.2 Understand how to problem solve to identify potential causes of behaviors.
- 3.3.3 Understand the importance of keeping track of and reporting changes in behaviors and mental status.
- 3.3.4 Demonstrate how to track and report changes in behaviors and mental status.
- 3.4 Respond in helpful ways when you believe that words and behaviors may express unmet needs.
- 3.5 Identify and meet the needs of the person to prevent or decrease “challenging” behaviors.
- 3.6 Adjust your approach, communication, and attitude to respond in ways that help the person.
 - 3.6.1 Assure the person.
 - 3.6.2 Redirect to a new topic.
 - 3.6.3 Ask for background information about the topic that the person is concerned about.
 - 3.6.4 Offer simple choices.
 - 3.6.5 Change the surroundings.
 - 3.6.6 Change the task or activity.
- 3.7 Demonstrate being flexible, creative, and able to try different ways to take care of causes of certain behaviors.
- 3.8 Identify when, how, and what information to seek from family and other caregivers.
- 3.9 Describe how to assess the person’s response to your actions to determine how effective the actions are.
- 3.10 Identify the possible results of medications and restraints.
- 3.11 Explain the importance of using the least amount of restraint needed.

F. Interacting with Families

As a DCW who is competent to interact with the families of persons with dementia, you can:

- 1. Respond respectfully to the family's unique relationships, experiences, cultural identity, and losses.**
- 2. Use a positive and accepting approach with family members or when talking about the family with other staff.**
- 3. Recognize the family as part of the caregiving team.**



1. Respond respectfully to the family's unique relationships, experiences, cultural identity, and losses.

- 1.1 Actively listen to family members to learn about the person's history, preferences, etc.
- 1.2 Recognize how the family's ethnicity and culture affect how family members understand dementia.
- 1.3 Recognize how the family's ethnicity and culture affect how family members view their roles and responsibilities.
- 1.4 Recognize the other responsibilities family members may have, such as caring for both children and parents. These may affect their role as caregiver for the person with dementia.
- 1.5 Recognize that feelings of guilt, grief, uncertainty, and stress may affect how family members communicate with each other and others.
- 1.6 Show a basic knowledge of how families commonly operate and how their relationships can affect caregiving.
- 1.7 Recognize that you may never know what a family member has experienced with the person. Avoid judgment and criticism.
- 1.8 Recognize that a person with dementia may be at risk of abuse or neglect by family members.



- 1.9 Recognize that individuals living with persons with dementia are more likely to be abused or neglected.
- 1.10 Respond to signs of depression or burnout in family caregivers.
 - 1.10.1 Understand the increased risk of depression or burnout for family caregivers.
 - 1.10.2 Explain the benefits of treating depression or burnout in family caregivers.
 - 1.10.3 Recognize the signs of depression or burnout in family caregivers.
 - 1.10.4 Understand when to discuss potential family caregiver depression or burnout with your supervisor.



2. Use a positive and accepting approach with family members or when talking about the family with other staff.

- 2.1 Understand that all families are different.
- 2.2 Recognize the effect of your own family values on caregiving relationships.
- 2.3 Recognize that families may show negative emotions and understand how to respond without taking it personally.
- 2.4 Show understanding of how your own ethnic and cultural values influence how you deal with others.
- 2.5 Understand how tempting it is to gossip, but recognize how hurtful and damaging it can be.



3. Recognize the family as part of the caregiving team.

- 3.1 Recognize each family member's understanding of the disease process.
 - 3.1.1 Recognize that family members may have valuable information about the person's condition and ability to function.
- 3.2 Provide information and support as appropriate. It is appropriate when the family requests it, or an offer is welcomed by the family.
- 3.3 Assist family members in learning more about dementia.

- 3.4 Model positive skills and approaches for family members.
- 3.5 Encourage family members to use new skills and approaches.
- 3.6 Discuss the important role families have in decision-making.
- 3.7 Identify issues that may affect the relationship between staff and family members.
- 3.8 Work with the family to create consistency for the person with dementia. Examples include keeping the same schedule, supporting the person in regular activities that are meaningful to them, and having everyone respond to a particular behavior in the same way.
- 3.9 Communicate promptly with the family about changes in mood or ability to function.
- 3.10 Explain why it is helpful to you as a caregiver to invite family members to share information about the history, culture, background and religion of the person with dementia.



G. Direct Care Worker Self-Care

As a DCW who cares for yourself, you will:



- 1. Identify your own feelings, beliefs, or attitudes that may affect your caring relationships.**
- 2. Identify helpful ways to prevent and cope with your own stress and burnout.**
- 3. Identify the ways you cope with grief and loss.**
- 4. Explain positive ways to talk with supervisors and co-workers to address differences and ideas about caregiving and what you believe is best for the person with dementia.**



1. Identify your own feelings, beliefs, or attitudes that may affect your caring relationships.

- 1.1 Recognize when you feel uncomfortable with certain qualities or differences in other people.
- 1.2 Identify qualities that make you feel uncomfortable or negative. These may include race, culture, ethnicity, sexual orientation, religious beliefs, lifestyle, weight or other qualities.
- 1.3 Understand how your own experience and history influence your beliefs and feelings about others.
 - 1.3.1 Recognize that if you have had very painful experiences, you may respond strongly to situations that remind you of them.
- 1.4 Explain how your beliefs and feelings about others may affect how you provide care.
- 1.5 Discuss your ethical responsibility, as a care provider, to respect others in spite of differences.
- 1.6 Describe positive ways to cope with situations when you have strong personal reactions to others.
- 1.7 Recognize when and how to seek help with your uncomfortable or negative feelings.

2. Identify helpful ways to prevent and cope with your own stress and burnout.

- 2.1 Recognize typical signs of stress, burnout, or depression.
- 2.2 Understand how you respond in stressful situations.
- 2.3 Identify specific caregiving interactions that have been stressful in the past.
- 2.4 Discuss your personal signs of stress or burnout.
- 2.5 Explain the benefits of addressing stress, burnout, or depression.
- 2.6 Identify ways to take care of yourself.
 - 2.6.1 Understand that learning about differences among people, as well as other issues, can be a way to cope with stress.
- 2.7 Identify coping strategies that work well for you.
- 2.8 Use those strategies when you feel stress, burnout or depression.
- 2.9 Recognize when and how to seek assistance for stress, burnout or depression.



3. Identify the ways you cope with grief and loss.

- 3.1 Recognize that over time persons with dementia experience many kinds of physical, emotional, and social losses. This can in turn create losses for those close to them, including family members and you.
- 3.2 Understand that it is healthy to feel grief and many other emotions in response to losses.
- 3.3 Identify positive ways to respond to losses that are personal and meaningful to you. These may include rituals, ceremonies, special clothing, etc.
- 3.4 Recognize that grief and loss can be stressful to you.
- 3.5 Recognize when and how to seek assistance for grief and loss.

4. Explain positive ways to talk with supervisors and co-workers to address differences and ideas about caregiving and what you believe is best for the person with dementia.

- 4.1 Recognize that your knowledge, experience, and insight can make a valuable contribution to the care team.
- 4.2 Recognize that others' knowledge, experience, and insight can make a valuable contribution to you and others on the care team.
- 4.3 Describe positive ways to share your knowledge, experience, and insights with supervisors and co-workers, even when you are stressed or disagree with them.



Glossary

Abuse: Misuse of power, funds or position. Abuse includes insulting or attacking a person with words, and the physical, mental and/or emotional mistreatment of one person by another.

Active-dying: This begins when it has been determined that a person has 72 hours or less left to live. Signs include deep congestion -- that is a “death rattle” or gurgling sound deep within the chest produced by air passing through mucus in the lungs and air passages of a dying person. Other signs can be mottled skin, with dark blue pallor from the toes to the knees and/or on the back, restlessness, picking the air, and frequently, seeing people who have gone before them.

Activities of Daily Living (ADL’s): Normal activities that include bathing, dressing, toileting, transferring, continence and eating.

Aggression: When a person acts in an apparently unprovoked way with physical or verbal attacks and threats. It includes hostile, injurious, or destructive behavior or outlook, especially when caused by frustration. A person may also show a readiness to be combative at any time. A more positive use of the term refers to a driving energy or willingness to take action.

Agitated: An unpleasant state of emotional arousal and increased tension. An agitated person may pace or move with abrupt, irregular, rapid motion.

Appropriate: An action that fits the situation in a positive way.

Autonomy: Independence or freedom. Making decisions for oneself.

Burnout: Fatigue, frustration, or apathy (lack of feeling) resulting from prolonged stress, overwork, or intense activity.

Care-assistance: To provide or give help or guidance to another. To aid or be helpful.

Caregiver: Someone whose job is to look after a sick or disabled person. An individual, such as a physician, nurse, social worker, or nursing assistant, who assists in the identification, prevention, or treatment of an illness or disability.

Care-partner: An individual, such as a spouse, significant other, friend or neighbor, adult child, parent, foster parent, or head of a household who attends to the needs of another person.

Care-plan: A specific document describing the plan of care. Usually involves information from many disciplines, (Nursing, OT, PT, etc.) and should be reviewed/reassessed as a person’s needs change.

Ceremonies: Procedures, acts or activities that have been defined by history and are done in a particular way.

Characteristics: A distinguishing trait, quality or property.

Cognitive functions: Means by which people think and engage in conscious activity, including learning, perceiving, decision-making, and remembering.

Compassionate: Sympathetic awareness of others' distress together with a desire to ease it.

Competency: A skill or piece of knowledge needed to perform well, or do something.

Cope: To deal with and attempt to overcome problems and difficulties. To have strategies and behaviors that aid in working with difficulties.

Culture: The behaviors, activities, beliefs, and characteristics of a particular social, ethnic, or age group.

Degenerative: Describes illnesses that are likely to become worse or deteriorate, or cause a person to become less functional.

Delirium: Describes a state of confusion that usually begins suddenly and ends fairly quickly. It may include agitation, anxiety, illusions, hallucinations, muddled speech, hyperactivity, flawed perception, and being easily distracted or disoriented.

Dementia: A loss of mental function in two or more areas of the brain, such as language, memory, visual and spatial abilities, or judgment severe enough to interfere with daily life. Usually begins gradually and progresses over time.

Dementia itself is not a disease but a set of symptoms that accompanies certain diseases or physical conditions. Other physical conditions may cause or mimic dementia, such as depression, brain tumors, head injuries, nutritional deficiencies, hydrocephalus, infections, drug reactions and thyroid problems.

Individuals experiencing dementia-like symptoms should undergo diagnostic testing as soon as possible. An early and accurate diagnosis helps to identify reversible conditions and gives persons a greater chance of benefiting from existing treatments, and allows them and their families more time to plan for the future.

Demonstrate: To show clearly. To prove, illustrate or explain by reasoning or evidence, especially with many examples.

Depression: Psychological disorder characterized by sadness, lack of energy and stamina, poor appetite, loss of interest in usual activities, withdrawal, and increased episodes of tearfulness. Disorder refers to periods when these characteristics last most days for more than two weeks and affect the person's ability to function.

Describe: To give a verbal or written account of a mental image or impression with words.

Direct care workers (DCW's): Caregivers who provide the vast majority of hands-on care within our long-term care networks. DCW's help care for people with physical, mental or emotional illness, or who are injured, disabled, or infirm who live in hospitals, long term care facilities, mental health settings, homes or residential care facilities. DCW's are also known as nursing assistants, certified nursing assistants, geriatric aides, unlicensed assistive personnel, home health aides, orderlies, or hospital attendants. Assigned tasks include assisting persons with dementia with meals, dressing, bathing, bathrooming, skin care, transferring (assisting clients move from one location to another), walking, recreation, socialization, and assisting with some health care procedures such as taking and recording vital signs. Because DCW's often have more contact with the person's they care for than other caregivers, it is important to have ongoing positive relationships with them.

Disorientation: Mental confusion or impaired awareness, especially regarding place, time, or personal identity. Loss of one's sense of direction, position or relationship with one's surroundings.

Empathic: The ability and sympathy to share another's emotions or feelings.

Environment: All of the events, space, things, conditions, people, and influences around someone.

Ethical: Acting in moral or principled ways that demonstrate an understanding of right and wrong in conduct. Acting according to the rules or standards for right conduct or practice, especially the standards of a profession.

Ethnicity: Pertaining to or characteristic of a people, especially a group that shares a common and distinctive culture, religion, language, etc, and usually from the same geographic region.

Explain: To define or make understandable. To offer reasons for or give a cause.

Family dynamics: A pattern or process of change, growth, or activity within a family. All the forces that are at work in any interactions.

Feeder: An inappropriate slang term used to refer to persons who require assistance with eating.

Fluctuate: To vary over time, such as to shift back and forth, ebb and flow, rise and fall, come and go, etc.

Gender roles: A term used in the social sciences and humanities to indicate a set of behavioral standards or norms associated with a given status for males and females. For example, in the past in American culture, men were not expected to do housekeeping, cooking, laundry or be caregivers, but these norms are slowly changing.

Grief: Deep and emotional distress caused by a loss. Bereavement.

Hitter: An inappropriate slang term used to refer to persons who are likely to physically strike out at others, especially during care.

Hydration: Adequate intake of fluid, particularly water. Needed to maintain the body's fluid level for good health.

Identify: To name or recognize the collection of characteristics by which a thing or person is distinctly known.

Inclusion: Allowing or inviting a thing or person to be accepted as part of the whole.

Individualize: To adapt to the needs or special circumstances of a person.

Instrumental Activities of Daily Living (IADL's): Normal activities that include using the telephone, shopping, food preparation, housekeeping, laundry, arranging or providing transportation, and handling finances and one's own medications.

Interpersonal: Relating to, or involving relations between two or more persons.

Intervention: A deliberate action taken to influence something that is happening so that it can be changed in positive ways. In dementia care, this may include taking steps to help a person with dementia recognize their circumstance and identify options available to them, overcome barriers, and stop actions or thinking that are harmful to them

Intimacy: A deeper level of understanding and feeling between persons in a relationship. It is not necessarily sexual.

Irreversible: Impossible to reverse or undo.

Legacy: A personal story, custom or thing handed down from an ancestor or a predecessor from the past.

Neglect: To fail to give the proper or required care to somebody or something.

Organize: To arrange or assemble in an orderly, structured, and useful way.

Overwhelm: To overpower in thought and feeling. To overcome completely; make helpless.

Palliative care: The active and total care of a person, including controlling pain and minimizing their emotional, social and spiritual suffering, at a time when their disease or condition is not responsive to medical treatment. Palliative care is also known as “comfort care”. It focuses on making sure a person is comfortable rather than on seeking a cure.

Paranoia: A tendency to excessively and/or irrationally distrust and suspect others.

Perceive: To understand or interpret something in a particular way. How a person with dementia perceives an event or activity *is* their reality.

Person centered care: Care in which you build a relationship with your client so you can see that each person is unique, and you respect and honor individual differences, skills and abilities. Providing person centered care means taking the time and making the effort to know the person so you can help them be successful, maintain their independence, and meet their needs for attachment, inclusion, occupation and comfort.

Philosophy: The set of core beliefs, principles and/or aims that underlies a person’s approach to work or life.

Potential: Having the capacity to develop, improve, or become more than is currently visible or obvious.

Primary: First in importance. First in order of time or development. Has to come before something else in a continuing process.

Progression: Process of going forward or continuing to develop, as in a disease or in healing.

Quality care: High degree of excellence in providing care to another.

Recognize: To identify or know from previous experience or knowledge.

Reminiscing: Informal chatting and storytelling with someone about feelings, activities, and events in their past.

Restraints: Any devices, such as lap belts or medications, used to keep someone from moving about freely.

Reversible: Capable of change, correction or improvement.

Rituals: An established and set pattern of activity that has meaning for the person(s) performing it. People may find rituals calming and soothing. Rituals may include religious observances, personal routines, bedtime activities, celebrations, etc.

Self-care: Performance of activities that maintain or regain one’s emotional, physical and spiritual health.

Sexuality: The physical makeup of an individual's body based on gender, including how it performs physical functions, its metabolic processes, and the manner and degree of its reactions to stimuli in relation to sexual attitudes or activity. The thoughts, feelings and perception an individual has about his or her gender and sexual activities.

Stimuli: Plural of stimulus. Anything that stirs, excites, or influences activity.

Symptom: A physical, emotional or other sign of an underlying cause. For example, a runny nose is a symptom or indication that a person may have a cold.

Typical: Common characteristics of a certain individual, class or group.

Understand: To know or comprehend. To grasp the significance of.

Unique: Being the only one of its kind. Unlike anything else.

Validate: To declare that something is in agreement with the facts or logically sound. To make somebody feel valued as a person, or feel that his or her ideas or opinions are worthwhile.

Various: Of different kinds. Diverse.

Vulnerable: Open to attack, hurt or injury, particularly due to weakness or disability.

Wandering: Walking, driving, or riding with or without a perceived destination. To go from place to place in an aimless way. A behavior frequently exhibited by persons with dementia.

Dementia and the Primary Causes of Dementia

Alzheimer’s Disease (AD): A degenerative disease that attacks the brain, begins gradually, and progresses at a variable rate, resulting in impaired memory, thinking and behavior. Is progressive and can last from 3 to more than 20 years. It is the leading cause of dementia-related illnesses and is irreversible and incurable. Warning signs are memory loss that affects skills, difficulty performing familiar tasks and activities of daily living, problem finding the right words, disorientation to time and place, poor or decreased judgment, difficulty with learning and abstract thinking, placing things in inappropriate places, changes in mood and personality, and marked loss of initiative. The person with Alzheimer’s generally requires direct caregiving for 8 to 12 years.

Creutzfeldt-Jakob Disease (CJD): A rare, fatal brain disorder that causes rapid, progressive dementia and other neuromuscular disturbances. A transmissible pathogen called a “prion,” short for “proteinaceous infectious particle,” is responsible for transforming normal protein molecules into infectious ones. Early symptoms of CJD include failing memory, changes in behavior, and lack of coordination. Involuntary movements appear and the person experiences severe difficulty with sight, muscular energy and coordination.

Dementia-Related Illnesses: Dementia itself is not a disease but a set of symptoms that accompanies certain diseases or physical conditions that damage the brain. Currently research has identified over 100 dementia-related illnesses. The well known dementia-related illnesses include Alzheimer’s disease, Vascular (or multi-infarct) dementia, Lewy body dementia, Parkinson’s disease with dementia, Huntington’s disease, Creutzfeldt-Jakob disease, and Pick’s disease. Some physical conditions may cause or mimic dementia, such as depression, brain tumors, head injuries, nutritional deficiencies, hydrocephalus, infections (meningitis, syphilis), drug reactions and thyroid problems. Individuals experiencing dementia-like symptoms should undergo diagnostic testing as soon as possible. The shortened term “dementia” is generally used in place of the more complete term dementia-related illnesses.

Early-Onset Alzheimer’s Disease: A rare form of AD that usually begins to affect people between the ages of 30 and 60. It is called Familial Alzheimer’s Disease if it has been diagnosed in other members of blood-line family.

Frontotemporal Dementia (FTD): A group of related dementias which begin in the brain’s frontal lobe, temporal lobe or both lobes together. The cluster of symptoms will vary according to the degree of involvement of the lobes and which side of the brain is affected.

Huntington’s Disease (HD): An inherited, degenerative brain disease that causes both physical and mental disabilities and usually begins in mid-life. Early symptoms can vary from person to person but include involuntary movement of the limbs or facial muscles, difficulty concentrating, and depression. Other symptoms include personality change, memory

disturbance, slurred speech, and impaired judgment. Children born to a person with HD have a 50% chance of inheriting the gene that causes HD.

Irreversible Dementias: Dementias that cannot be changed, corrected or reversed. Behaviors and symptoms can be improved with treatment and interventions, but the disease itself cannot be cured. Irreversible dementias include: Alzheimer’s disease, Vascular (or multi-infarct) dementia, Lewy body dementia, Parkinson’s disease with dementia, Huntington’s disease, Creutzfeldt-Jakob disease, and Pick’s disease.

Korsakoff’s Syndrome (alcohol-related dementia): Too much alcohol, particularly if associated with a diet deficient in thiamin (vitamin B1), can lead to irreversible brain damage. This dementia is preventable.

Late-Onset Alzheimer’s Disease: The most common form of AD. It occurs in people aged 65 and older.

Lewy Body Dementia: This dementia-related illness accounts for up to 15% of all diagnosed cases. It is associated with abnormal structures, called Lewy bodies, in the brain. Persons experience a gradual start of the disease and progression of cognitive decline. Symptoms also include paranoia and hallucinations in the early stage, often lasting throughout the disease process. The clinical term for this condition is “dementia with Lewy bodies”.

Parkinson’s Disease with Dementia: A progressive disorder of the central nervous system which causes deterioration of specific brain cells that produce dopamine, a substance that helps control muscle activity. Parkinson’s is often characterized by tremors, stiffness in limbs and joints, speech difficulties, and difficulty initiating physical movement. About 50% of persons with Parkinson’s will eventually develop dementia in later stages of the disease.

Phases or Stages of Alzheimer’s Disease: It is impossible to say how long each stage of Alzheimer’s will last for each person, but there is a general pattern. Most people have symptoms of AD 3 to 5 years before receiving an actual diagnosis. AD takes anywhere from 3 to 20 years to progress, but on average, people live about 8 to 13 years after diagnosis.

Pick’s Disease: A rare brain disorder characterized by shrinkage of the tissues of the frontal and temporal lobes of the brain and by the presence of abnormal bodies (Pick’s bodies) in the nerve cells of the affected areas of the brain. Pick’s disease usually begins between the ages of 40 and 60. The symptoms include a loss of language skills, physical movement and recognition of objects or people. Initial diagnosis is based on family history, symptoms, tests and ruling out other causes of dementia. This disease may be inherited.

Primary Causes of Dementia: The most common cause of dementia is Alzheimer’s disease. Other fairly common causes are: Vascular dementia, Dementia with Lewy bodies, Parkinson’s disease with dementia, Huntington’s disease, Creutzfeldt-Jakob disease and Pick’s disease. A recent report from

the Alzheimer's Association states that "anything that affects the heart or lungs most probably affects the brain," so many other causes are possible.

Reversible Dementias: Degenerative dementias that are caused by diseases or conditions that can be cured or reversed. Causes may include space-occupying lesions, trauma, substance-abuse, infection, some vascular disorders, endocrine disorders, toxic reactions, anoxia, and vitamin deficiency. Treating the underlying causes may stop the progression and symptoms may improve.

Vascular/Multi-Infarct Dementia: This is the second most frequent cause of dementia, accounting for up to 40 % of the diagnosed cases. A deterioration of mental capacity caused by multiple strokes (infarcts) in the brain. These events may be described as mini-strokes, where small blood vessels in the brain become blocked by blood clots, causing the destruction of brain tissue. The onset of vascular dementia may seem relatively sudden and it may take several strokes for symptoms to appear. These strokes may damage areas of the brain responsible for a specific function as well as produce general symptoms of dementia. Vascular dementia is not reversible or curable, but detection of high blood pressure and other risk factors can lead to a specific treatment that may modify its progression.

Top Ten Warning Signs of Alzheimer’s Disease and Other Dementia-Related Diseases

1. Loss of ability to remember recent events that affects job or performance skills
2. Difficulty performing familiar tasks
3. Problems with language, including finding words for familiar objects and people
4. Disoriented to present time and place
5. Poor or impaired judgment
6. Problems with abstract thinking
7. Misplacing objects
8. Changes in mood or behavior
9. Changes in personality
10. Loss of initiative

Structures of the Brain

Brain Stem: The brain stem connects the brain to the spinal cord. It controls automatic body functions such as breathing, heart rate, body temperature and blood pressure.

Brain Structure: The brain is comprised of right and left cerebral hemispheres, each made up of multiple lobes. The lobes are identified as: temporal, parietal, frontal, and occipital lobes. The brain structure also includes the hippocampus, cerebellum, and brain stem.

Cerebellum: The part of the brain that is responsible for maintaining the body's balance and coordination.

Cerebral Cortex: The outer layer of nerve cells surrounding the cerebral hemispheres that serves as a protective covering of the brain.

Cerebral Hemispheres: The largest portion of the brain, composed of billions of nerve cells in two structures connected by a fibrous bridge called the corpus callosum. The cerebral hemispheres control conscious thought, language, decision making, emotions, movement and sensory functions.

Frontal Lobe: A part of the brain that helps a person:

- Handle more than one thing at a time.
- Know or prioritize what to focus on.
- Sense how much time is passing.
- Switch attention from one idea or task to another.
- Keep focused on a task and know when it is done.
- Control impulsive responses to thoughts and desires.
- Identify and follow the order of steps for a task.

When the frontal lobe becomes damaged a person may:

- Have difficulty paying attention to what's going on around them.
- Be overwhelmed when a caregiver touches them and talks at the same time.
- Be unable to stop from striking or grabbing because they can't control impulses or switch gears quickly.

Hippocampus: A structure deep within the brain that plays a major role in learning and memory. It is involved in converting short-term memories, which can last as little as 30 to 60 seconds, to long-term memories. When the hippocampus has been damaged, persons may repeat questions or concerns, forget something someone just said, or forget that someone just visited.

Hypothalamus: A structure in the brain located under the thalamus that monitors activities such as body temperature and food intake.

Limbic System: A region of the brain that links the brain stem with the higher reasoning elements of the cerebral cortex. It controls one's emotions, instinctive behavior, and sense of smell.

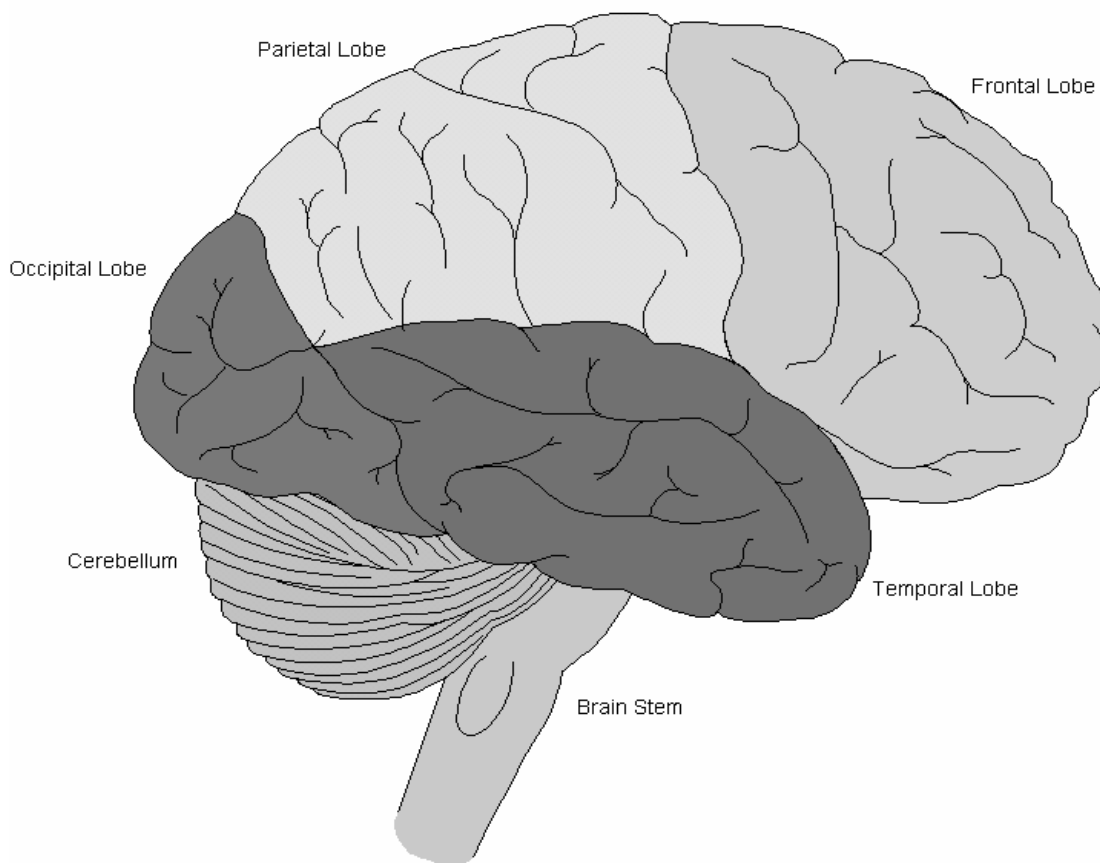
Parietal Lobe: A part of the brain that helps one locate and arrange objects in space and tells the brain to pay attention to everything in the visual field. When this part of the brain is damaged, a person has difficulty gauging distances and locating and arranging objects in the space around them. A person with parietal lobe damage may:

- Use excessive energy trying to complete tasks, such as putting on and buttoning a shirt or tying a shoe.
- They may have difficulty tolerating clutter or the movement of objects in the environment.
- Feel anger, frustration or fatigue when confusing or too much stimuli overwhelm them.

Temporal Lobe: A part of the brain that helps a person speak and understand language. When damage has occurred, a person may respond with nonsensical sounds, use the wrong words, substitute a similar word or use fewer words when trying to communicate. They may say yes when they mean no or use profanity without realizing it. They may not understand simple directions, what someone tells them, or what they read.

Ventricle: Cavity within the brain that contains cerebrospinal fluid. During AD, the brain tissue shrinks and the ventricles enlarge.

Right Hemisphere of the Brain



Dementia Assessment Education Program, Michigan Alzheimer's Disease Research Center, University of Michigan, Educational Session 1, by Shelly E. Weaverdyck, PhD; edited by Julie Wheaton, MSW & Sara Holmes, MPH, 3/14/02. Funded in part by the Long Term Care Innovations Grant from the Michigan Department of Community Health.

Resources

Listed below are some of the resources that work group members have identified as favorites. These are only a small number of the many good resources available. Including them is not a formal endorsement.

Check with your local library for any resource you would like to borrow. You may be able to place a special order at the library, bookstore or purchase an item via the Internet. If you would like assistance in locating or obtaining a resource, contact the **Mental Health & Aging Project (517-483-1529 or Email: beham@lcc.edu) or the Alzheimer's Association (800-272-3900).**

Resources by Competency Area

A. Knowledge of Disorders

Books

Lippincott, Williams & Wilkins, Inc. (1987 to Present). **Alzheimer's disease & associated disorders: an international journal.** Hagerstown, MD.

National Institute on Aging. (2002). **Alzheimer's disease: unraveling the mystery.** Bethesda, MD.

Powell, L. S. & Courtice, K. (2002). **Alzheimer's disease: a guide for families.** (3rd ed.). Cambridge, MA: Perseus Publishing.

Prime National Publishing Corporation. (2000 to Present). **American journal of Alzheimer's disease and other dementias.** Weston, MA: Prime National Publishing Corporation.

Radin, L. & Radin, G. (Eds.). (2003). **What if it's not Alzheimer's: a caregiver's guide to dementia.** Amherst, NY: Prometheus Books.

Shenk, D. (2003). **The forgetting: Alzheimer's, portrait of an epidemic.** New York, NY: Anchor Books.

Videos

Educational Media Services. (1998). **From here to hope.** [Video.] Durham, NC.

Films for the Humanities & Sciences. (2003). **Alzheimer's mystery**. [Video.] Princeton, NJ.

George G. Glenner Alzheimer's Family Centers, Inc. (1999). **Living in Alzheimer's disease**. [Video.] San Diego, CA.

Geriatric Resources. (1995). **Understanding Alzheimer's disease: an overview from A - Z**. [Video.] Radium Springs, NM.

Info Vision. (1996). **Alzheimer's disease: at time of diagnosis**. [Video.] Glenwood, IA

Long Island Alzheimer's Foundation. (1993). **Living with Alzheimer's**. [Video.] Port Washington, NY.

Terra Nova Films. (2001 b). **String worms at Budd Terrace**. [Video, 71 minutes.] Chicago, IL.

Terra Nova Films. (1990). **Alzheimer's disease: pieces of the puzzle**. [Video.] Chicago, IL.

Twin Cities Public Television, Inc. (2003). **The forgetting**. [Video.] St. Paul, MN.

Fact Sheets

Alzheimer's Association Fact Sheets*

- (a) **Alzheimer's disease**
- (b) **Basics of Alzheimer's**

Weaverdyck, S. **Caring sheets: thoughts & suggestions for caring**, edited and produced by EMU Huron Woods Alzheimer's Research Program for the Michigan Department of Community Health. Available on the Mental Health and Aging Project webpage: <http://www.lcc.edu/mhap/>

- # 1: **The Healthy Brain and Cognition**: S. Weaverdyck
- # 2: **Brain Changes and the Effects on Cognition**: S. Weaverdyck
- #21: **Questions about a Person's Cognition: An Assessment Checklist**: S. Weaverdyck

* Alzheimer's Association fact sheets are frequently updated. Check for current editions on the website at www.alz.org or call 1-800-272-3900.

B. Person-Centered Care

Books

- Amado, A. & McBride, M. (2001). **Training person-centered planning facilitators: A compendium of ideas.** Minneapolis, MN: Institute on Community Integration, University of Minnesota.
- Barnett, E. (2000). **Including the person with dementia in designing and delivering care: I need to be me!** London; Philadelphia: Jessica Kingsley Publishers.
- Center for Health Law and Ethics. **Values history.** Albuquerque, NM: Institute for Public Law, University of New Mexico.
- Cobble Hill Health Center, Inc. (1998). **Speaking from experience: Nursing Assistants share their knowledge of dementia care.** Call (718) 855-6789 X225 to obtain order form.
- Daly, G., Westphal, C. & Felt, J. (2004). **My voice -- my choice: my advance directive package.** Dearborn, MI: Clinical Ethics Center, Oakwood Healthcare System.
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- Aging Services Bureau, Dept. of Public Health & Human Services. (1996). **Memory loss among American Indians: the caregiving experience.** [Video.] Helena, MT.

1 Terra Nova Films. (1995). **Alzheimer's disease: inside looking out.** [Video, 20 minutes]. Chicago, IL.

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Fact Sheets

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- (h) **Depression and Alzheimer's disease**
- (j) **Driving**
- (l) **Feelings (also available in Spanish)**
- (r) **Respect for Autonomy**

C. Care Interactions

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Andresen, G. (1995). **Caring for people with Alzheimer's disease.** Baltimore, MD: Health Professions Press, Inc.

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* Alzheimer's Association fact sheets are frequently updated. Check for current editions on the website at www.alz.org or call 1-800-272-3900.

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Fact Sheets

Alzheimer's Association Fact Sheets*

- (a) **Alzheimer's disease**
- (g) **Communication**
- (i) **Dressing** (also available in Spanish)
- (k) **Eating** (also available in Spanish)
- (o) **Incontinence** (also available in Spanish)
- (p) **Late stage care**
- (q) **Personal care**
- (s) **Safety** (also available in Spanish)
- (t) **Safety at home**
- (u) **Sleep changes in Alzheimer's disease**
- (v) **Sexuality**

Weaverdyck, S. **Caring sheets: thoughts & suggestions for caring**, edited and produced by EMU Huron Woods Alzheimer's Research Program for the Michigan Department of Community Health. Available on the Mental Health and Aging Project webpage: <http://www.lcc.edu/mhap/>

- # 4: **Moving Persons with Dementia? Suggestions for the Physical Environment to Ease the Way:** D. deLaski-Smith
- # 5: **Moving Persons with Dementia? Suggestions for Family and Staff to Ease the Way:** L. Struble & D. deLaski-Smith
- # 6: **Moving Persons with Dementia? Tips Regarding Behaviors to Ease the Way:** L. Struble
- # 7: **The Bedroom: Suggestions for the Physical Environment:** D. deLaski-Smith
- # 8: **The Bathroom: Suggestions for the Physical Environment:** D. deLaski-Smith
- # 9: **Resources: The Physical Environment:** D. deLaski-Smith
- #10: **Communicating with Health Care Providers:** A. Wittle & S. Weaverdyck

* Alzheimer's Association fact sheets are frequently updated. Check for current editions on the website at www.alz.org or call 1-800-272-3900.

- #14: **Helping with Daily Tasks:** S. Weaverdyck
- #17: **Safety after Hip Surgery: Tips for Preventing Complications:** B. Atchison
- #18: **Transferring Persons with Dementia:** D. Dirette
- #19: **Intervention Suggestions for Frontal Lobe Impairment:** S. Weaverdyck
- #22: **Questions about the Environment: An Assessment Checklist:** S. Weaverdyck
- #23: **Questions about Caregiving: An Assessment Checklist:** S. Weaverdyck
- #24: **Questions about the Task & Daily Routines: An Assessment Checklist:** S. Weaverdyck

D. Life Enrichment Support

Books

Ballard, E. & Poer, C. (1993). **Sexuality and the Alzheimer's patient.** Durham, NC: Alzheimer's Family Support Program, Center for Aging, Duke University.

Dowling, J. (1995). **Keeping busy: a handbook of activities for persons with dementia.** Baltimore, MD: Johns Hopkins University Press.

Hellen, C. (1998). **Alzheimer's disease: activity-focused care.** (2nd ed.). St. Louis, MO: Butterworth-Heinemann.

Kubler-Ross, E. & Kessler, D. (2000). **Life lessons: two experiences of death and dying teach us about the mysteries of life and living.** New York, NY: Scribner.

Sheridan, C. (1987). **Failure-free activities for the Alzheimer patient: a guidebook for caregivers.** Forest Knolls, CA: Elder Books.

Zgola, J., OTC. (1997). Programming. In **Key elements of dementia care.** Chicago, IL: Alzheimer's Association National Office, (800) 223- 4405.

Videos

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Video Press. (1996). **Dealing with sexually inappropriate behavior: masturbation and sexually provocative behavior.** [Video.] Baltimore, MD.

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Phone: (800) 328-7450 or <http://www.videopress.org>.

E. Understanding Behaviors

Books

Hoffman, S. & Kaplan, M. (1998). **Behaviors in dementia: best practices for successful management.** Baltimore, MD: Health Professions Press.

Robinson A, Spencer B, White L. (2002). **Understanding difficult behaviors: some practical suggestions for coping with Alzheimer's disease and related illnesses.** Ypsilanti, MI: Alzheimer's Education Program, Eastern Michigan University, 734-487-2335, www.emich.edu/alzheimers.

Silverstein, N., Flaherty, G. & Tobin, T. (2002). **Dementia and wandering behavior: concern for the lost elder.** New York, NY: Springer Publishing Company.

Soreff, S. & Sidle, D. (2004). Understanding and dealing with resident aggression: exploring the extent, causes, and impact of aggressive outbursts and how to handle them. *Nursing Homes Long Term Care Management*. March.

Videos & DVDs

Advanced Healthcare Studies. (2003). **Sundowning: a caregiver's guide.** [Video.] San Marcos, CA. Phone: (800) 444-1384 or <http://www.advhs.com>.

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Eastern Michigan University Huron Woods Alzheimer's Research Program. (2001). **Assisting a person with dementia in bathing.** [Video.] Mental Health and Aging Project, Michigan Partnership for Community Caring.

Fanlight Productions. (1998). **Alzheimer's and dementia care skills for assisted living.** [Videos.] Boston, MA.

Wandering: is it a problem? (14 minutes).

Resisting Care...putting yourself in their shoes (14 minutes).

Agitation...it's a sign (14 minutes).

Terra Nova Films. (1998). **Choice and challenge: caring for aggressive older adults across levels of care.** [Video and manual.] Chicago, IL.

Terra Nova Films. (1993 c). **Dress him while he walks: management in caring for residents with Alzheimer's.** [Video.] Chicago, IL.

Terra Nova Films. (1990 b). **Managing and understanding behavior problems in Alzheimer's.** [Video.] Chicago, IL.

University of North Carolina at Chapel Hill. (2003). **Bathing without a battle: creating a better bathing experience for persons with Alzheimer's disease and related disorders.** [1 hour video / 2 to 3 hour CD.] Chapel Hill, NC.
NOTE: This program is powerful and graphic and is not recommended for nonprofessionals or families.

Video Press. (2002). **Abuse triggers.** [6 videos.] Baltimore, MD:
Incontinence and Other Physical Problems (16 minutes).
The Non-Responsive Needy Resident (16 minutes).
Physical Violence (16 minutes).
Repetitive Behavior (17 minutes).
Resistive Behavior (17 minutes).
Verbal Violence (19 minutes).

Video Press. (2001). **Abuse and the dementia patient.** [Video, 22 minutes.] Baltimore, MD.

Video Press. (1997 a). **Preventing and reducing negative and abusive responses.** [Video.] Baltimore, MD.

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Video Press. (1993 a). **Positive approaches to difficult behaviors.** [Video.] Baltimore, MD.

Fact Sheets

Alzheimer's Association Fact Sheets*

- (d) **Behavioral and psychiatric Alzheimer symptoms**
- (e) **Behaviors**
- (n) **Hallucinations.**

* Alzheimer's Association fact sheets are frequently updated. Check for current editions on the website at www.alz.org or call 1-800-272-3900.

F. Interacting with Families

Books

Bayley, J. (1999). **Elegy for Iris**. New York, NY: St. Martin's Press.

Benedicts, T. Jaffe, J., Segal, J. (2004). **Elder abuse: types, signs, symptoms, causes, and help**. Retrieved August, 14, 2006 from http://www.helpguide.org/mental/elder_abuse_physical_emotional_sexual_neglect.htm.

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Hay, D. (Ed.). (2003). **Agitation in patients with dementia: a practical guide to diagnosis and management**. Washington, DC: American Psychiatric Pub.

Knight, B. (2001). **Blessed are the caregivers: a daily book of comfort and cheer**. Albuquerque, NM: Hartman Publishing, Inc.

Mahoney, E., Volicer, L. & Hurley, A. (2000). **Management of challenging behaviors in dementia**. Baltimore, MD: Health Professions Press.

Mittelman, M., Epstein, C. & Pierzchala A. (2003). **Counseling the Alzheimer caregiver: a resource for health care professionals**. Chicago, IL: American Medical Association Press.

Murphy, B. (1995). **He used to be somebody: a journey into Alzheimer's disease through the eyes of a caregiver**. Boulder, CO: Gibbs Associates.

Videos

Alzheimer's Association National Office. (1990 a). **Caring for the caregiver** [Video, 20 minutes, part of Caregiver Kit]. Chicago, IL. (800) 223-4405.

Terra Nova Films. (2001 b). **String worms at Budd Terrace**. [Video, 71 minutes.] Chicago, IL.

Terra Nova Films. (1999). **He's doing this to spite me: emotional conflicts in dementia care**. [Video, 22 minutes.] Chicago, IL.

Terra Nova Films. (1995 c). **Thousand tomorrows: intimacy, sexuality and Alzheimer's.** [Video.] Chicago, IL.

Terra Nova Films. (1994 a). **Complaints of a dutiful daughter.** [Video, 44 minutes.] Chicago, IL.

Terra Nova Films. (1993). **Alzheimer's disease: a multi-cultural perspective.** [Video.] Chicago, IL.

Video Press. (1991). **Grace.** [Video, 58 minutes.] Baltimore, MD.

Fact Sheets

Alzheimer's Association Fact Sheets*

(f) **Caregiver stress.** Available in Spanish.

(m) **Grief, mourning and guilt.** Available in Spanish.

G. Direct Care Worker Self Care

Books

Kramer, N. & Smith, M. (2003). **Working together: nursing assistants help one another manage stress in the workplace.** Download it at www.sephardichome.org or contact Nanette A. Kramer at nk105@columbia.edu.

Parke-Davis A Division of Warner-Lambert Company. (1994). **Caring for the Caregiver: a guide to living with Alzheimer's disease.**

Ruckdeschel, K. & Van Haitsma, K. (2001). **Building relationships to enhance resident-centered care: a trainer's guide to an emotion-focused intervention.** Contact the Harry Stern Family Center for Innovations in Alzheimer's Care (215) 371-1890, or the Extendicare Foundation.

Videos

Paraprofessional Institute in Philadelphia. (2001). **HeartWork.** [Video.] Available through the National Clearinghouse on the Direct Care Workforce, Bronx, NY.

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* Alzheimer's Association fact sheets are frequently updated. Check for current editions on the website at www.alz.org or call 1-800-272-3900.

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- (a) **Alzheimer's disease**
- (b) **Basics of Alzheimer's**
- (c) **Bathing.** Available in Spanish.
- (d) **Behavioral and psychiatric Alzheimer symptoms**
- (e) **Behaviors**
- (f) **Caregiver stress.** Available in Spanish.
- (g) **Communication**
- (h) **Depression and Alzheimer's disease**
- (i) **Dressing.** Available in Spanish.
- (j) **Driving**
- (k) **Eating.** Available in Spanish.
- (l) **Feelings.** Available in Spanish.
- (m) **Grief, mourning and guilt.** Available in Spanish.
- (n) **Hallucinations.**
- (o) **Incontinence.** Available in Spanish.
- (p) **Late stage care.**
- (q) **Personal care.**
- (r) **Respect for Autonomy**
- (s) **Safety.** Available in Spanish
- (t) **Safety at home.**
- (u) **Sleep changes in Alzheimer's disease**
- (v) **Sexuality.**

Alzheimer's Association. (2005). **Behavior management training for dementia care by the Alzheimer's Association NY chapters.** [Video.] This interactive DVD can be obtained at www.alzwny.org or www.alzcnny.org.

Alzheimer's Association, Desert Southwest Chapter. (2004). **Palliative care for advanced dementia: a self-instructional seven-part teaching program.** [Video.] Phoenix, AZ.

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Andresen, G. (1995). **Caring for people with Alzheimer's disease**. Baltimore, MD: Health Professions Press, Inc.

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Ballard, E. & Poer, C. (1993). **Sexuality and the Alzheimer's patient**. Durham, NC: Alzheimer's Family Support Program, Center for Aging, Duke University.

Barnett, E. (2000). **Including the person with dementia in designing and delivering care: I need to be me!** London; Philadelphia: Jessica Kingsley Publishers.

Barrick, A. (2002). **Bathing without a battle: Personal care of individuals with dementia**. New York: Springer Pub.

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Dippel, R. (1996). **Caring for the Alzheimer patient: a practical guide.** Amherst, NY: Prometheus Books.

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Dowling, J. (1995). **Keeping busy: a handbook of activities for persons with dementia.** Baltimore, MD: Johns Hopkins University Press.

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Wandering: is it a problem? (14 minutes).

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Agitation...it's a sign (14 minutes).

Fazio, S., Seman, D. & Stansell, J. (1999). **Rethinking Alzheimer's care.** Baltimore, MD: Health Professions Press.

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Hoffman, S. & Platt, C. (1991). **Comforting the confused, strategies for managing dementia.** (2nd ed.). New York: Springer Pub. Co.

Hospice of Michigan. (2005). **Caring for a loved one with advanced dementia: a caregiver's manual.** (2nd ed.). Detroit, MI. Hospice of Michigan. 1-888-466-5656 or www.hom.org.

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Kessler, D. (1997). **The needs of the dying: a guide for bringing hope, comfort and love to life's final chapter**. New York, NY: HarperCollins Publisher.
Killick, J, & Cordonner, C. (Eds.). (2000). **Openings: dementia poems and photographs**. London: Hawker Publications. <http://www.careinfo.org/books/>.

Kitwood, T. (1997). **Dementia reconsidered: the person comes first**. Philadelphia, PA: Open University Press.

Knight, B. (2001). **Blessed are the caregivers: a daily book of comfort and cheer**. Albuquerque, NM: Hartman Publishing, Inc.

Kovach, C. (Ed.). (1997). **Late-stage dementia care: a basic guide**. Washington, DC: Taylor & Francis.

Kramer, N. & Smith, M. (2003). **Working together: nursing assistants help one another manage stress in the workplace**. Download it at www.sephardichome.org or contact Nanette A. Kramer at nk105@columbia.edu.

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Midwest Bio-Ethics Center. **Midwest Bio-ethics Center caring conversations workbook.** Kansas City, MO. 816-221-1100. www.midbio.org. (Discusses how people can make known their wishes for end-of-life care.)

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Notes for Trainers and Supervisors of Direct Care Workers

2.1 Overall Notes

- Each worker can and does make a difference in a person's care. You play a powerful role in what kind of difference she or he makes.
- Practice self-examination and reflection, and creatively search for opportunities to more effectively support direct care workers in being the best they can be.
- Set standards of excellence, communicate with them clearly, and reinforce them consistently over time.
- Empower DCWs to be problem solvers and forward thinkers -- breaking the mold and testing new ideas.

2.2 Notes for Trainers

- Use adult learner-centered approaches that:
 - Actively engage participants in discovery, learning and teaching processes.
 - Provide "hands on" training and coaching.
 - Include structured and unstructured activities.
- Help DCWs develop interpersonal, problem solving, and communication skills along with clinical and caregiving skills and knowledge.
- Create an environment that balances support and accountability.

3 Notes for Supervisors

- Promote an environment that encourages DCWs to grow, develop and use their full potential by balancing support and accountability.
- Recognize your own and DCWs' personal limitations and capabilities. Through team work, utilize everyone's strengths and address limitations.
- Promote open communication and problem solving among staff and others.
- Involve DCWs in decision-making around care delivery.
- Encourage DCWs' informal leadership by engaging them in mentoring and training.
- Provide opportunities and encourage DCWs to develop a quality relationship with each individual, which gives work meaning and purpose.
- Give DCWs the information and tools they need to effectively work with people with dementia at all stages, including how to:
 - Learn the individual's history.
 - Gain the individual's trust.
- Celebrate accomplishments.

Key Ideas

Person-Centered Dementia Care assures the highest quality care because:

- **Decision-making power and choice is in the hands of the individual -- or in the hands of those closest to her/him when the individual is unable to make a decision.**
- **A prime task of care is to maintain personhood and recognize each individual's potential for growth and ability to contribute to the lives of others.**
- **The care giver's role is not just to meet the person's physical needs, but to put the individual before the task. This requires that the caregiver:**
 - Know and build a relationship with the person and offer companionship and friendship
 - Respond to the individual's spirit, mind, body, and emotions.
 - Identify and focus on the individual's strengths and abilities, and promote their growth and development.
 - Provide opportunities for the person to give as well as to receive care.
 - Establish familiar routines to promote individualized care.
 - Plan and give care that is uniquely suited to each individual's past experiences as well as their particular experience of dementia, and adjusted continuously to meet changing circumstances.
 - Respect the person's diverse cultural, religious and ethnic norms.
- **Families and DCWs work together to support individuals while maximizing their independence.**
- **Caregivers focus on creating an environment that makes the person feel "at home" and:**
 - Fosters relationships among individuals.
 - Enables interactions and happenings to take place naturally.
 - Promotes variety and spontaneity in daily life.
 - Adjusts to the comfort needs and abilities of the individual.
 - Ensures a sense of community and security.

Acknowledgements

Credit for the development of these dementia competencies for direct care workers goes foremost to Michelle Munson-McCorry. As a home health care agency administrator concerned that her staff be dementia-competent, she initiated the process that led to this guide. Michelle contributed to the development of the description of competencies and provided leadership throughout the process.

Harvey Zuckerberg, Executive Director of the Michigan Home Health Association, and Micki Horst, Coordinator of the Michigan Dementia Coalition, facilitated bringing together individuals with expertise and interest to participate in the initiative. Micki Horst and Lorie Massuch provided staff support and project management assistance throughout the project.

Primary contributors to the development of the competencies were: Kim Curyto, PhD; Chris Hennessey, MA; Micki Horst, MA; Kathryn Ann Kozlinski, LPN, MEd; Lorie Massuch, BA; Michelle-Munson McCorry, RN, CDPI; and Lauren Swanson, MA. Organizations with significant representation were: Complete Compassionate Care, Greater Michigan Chapter of the Alzheimer's Association, Macomb County Department of Senior Citizens Services, Mental Health and Aging Project, Michigan Department of Community Health, Michigan Great Lakes Chapter of the Alzheimer's Association, Michigan Public Health Institute, Michigan Office of Services to the Aging, and Pine Rest Christian Mental Health Services.

Special thanks to Portia Ross-Morehead and Robin Thompson, direct care workers, whose insightful comments contributed to the development process at occasional intervals. Numerous other individuals made important contributions at various stages throughout the process: Jean Barnas, MA; Jennifer Burley, BA; Marci Cameron, MA; Chris Curtin, RN; Cean Eppelheimer; Paula Hoegemeyer, RN; Marcia Mittelman, MA; Maureen Sheahan; Sara Szokowski; Kim Walsh, MS; Dale Adler, MA; Debbie Conarty; Chris Simons, CTRS; Rachel Richards, BA; Shelly Weaverdyck, PhD; Adult Day Programs of the Alzheimer's Association, Greater MI Chapter; Complete Compassionate Care home health workers; Macomb County Adult Day Service Program Staff, Seasons Adult Day Services, and others.

A subgroup of the Dementia Competencies Workgroup developed this Everyday Language version of the Guide. Concepts and competencies remain the same as in the original version. Subgroup members are: Marci Cameron, Kathryn Ann Kozlinski, Lorie Massuch and Maureen Sheahan.

The workgroup would like to recognize various organizations for their support of this project: Alzheimer's Association - Greater Michigan Chapter, Alzheimer's Association - Michigan Great Lakes Chapter, Michigan Dementia Coalition, Macomb County Department of Senior Citizens Service, Michigan Department of Community Health, Michigan Direct Care Workers Initiative Coalition, Michigan Public Health Institute, the Michigan Office of Services to the Aging and PHI.

Development of this guide was supported, in part, by the Alzheimer's Disease Demonstration Grants to States from the Administration on Aging, Department of Health and Human Services, Washington, D.C. 20201 (CFDA #93-051) to the Michigan Department of Community Health. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Point of view or opinions do not, therefore, necessarily represent official Administration on Aging policy.