



Knowledge and Skills Needed for Dementia Care

A Guide for Direct Care Workers

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2006

Mission

To identify the standards to guide direct care workers in their efforts to provide excellent dementia care.

Vision

All direct care workers will have knowledge, skills and empathy to work with individuals with dementia and their families to provide high quality dementia care.

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How to Use This Guide

Providing excellent care assistance for someone with dementia requires special knowledge and skills. In our experience, the rewards of sharing life with someone with dementia increase as our knowledge increases. Some of us have been learning about dementia care for many years. We have discovered that our growing knowledge gives us new ideas and insight, increasing the satisfaction we feel in interacting with someone with dementia. We learn from our own experiences, from the experiences of others, and from research findings. We are never finished learning. We can always learn more.

This guide is meant to help direct care workers¹ identify the knowledge and skills needed for providing ideal dementia care. Our vision for direct care workers is that we will be knowledgeable, skillful, and empathic in working with individuals with dementia and their families.

The knowledge and skills identified in this guide are only part of a broader set of competencies that direct care workers need. The guide identifies the special care assistance skills that are important when working with a person with dementia. It assumes that readers already have the broader set of knowledge and skills. For example, the guide assumes that the reader knows that hydration is a concern for all persons receiving care. When the person has dementia, however, hydration becomes an even greater concern since a person with dementia is more likely to forget to drink fluids. The guide identifies hydration as a special concern for individuals with dementia. Likewise, self-care is clearly an important skill area for all direct care workers, including those who do not work with persons with dementia. It is included in this guide as an area of dementia competency because some direct care workers find dementia care unusually demanding at the same time that it is especially rewarding.

Competency is the ability to perform well. Knowledge provides a basis for competency, but may not be enough by itself. A desire to improve and *practice* help build competency. Competencies may also be thought of as standards or measures of behavior. The competencies for good dementia care are the standards or measures of care giving behavior that best support the person in one's care.

You may notice that some knowledge items or skills appear in more than one place in the guide. We have tried to avoid too much redundancy but have sometimes included an item in more than one place because of its relevance to more than one topic.

One way to use this guide is to look through the competency areas and think about in which areas you have more knowledge and in which ones you have less. If you come across terms or phrases that are not familiar to you, learn about these terms and concepts by reading or viewing the Suggested Resources for that competency area. The Suggested Resources lists books, articles, videos, and DVDs that can help you learn more.

Another way to use the guide is to browse through it and find topics that intrigue you. Again, the Suggested Resources will point you to resources. Or you may wish to find a workshop or class that addresses a specific skill or knowledge area. You can find a Dementia Education and Training Directory for Michigan at www.dementiacoalition.org.

¹ Direct-care workers include certified nursing assistants (CNAs), home health aides, personal care assistants, direct support professionals, and volunteers providing supportive services in individual, acute care, and long-term care settings.

The Suggested Resources section provides resource suggestions for each competency area or topic. The References section lists all resources alphabetically. It includes all of the items listed in Suggested Resources plus additional items.

In our ongoing quest for more knowledge and better understanding, we hope to produce a new and improved guide in the future. You can help us by providing your comments on this guide. What have been your experiences as a direct care worker with persons with dementia? What have you learned that you would like to share with others? We are also interested in your response to this guide. What is most helpful? What is least helpful? What can be done to make it better? Please send us your feedback. A form is provided in Appendix C, or you are welcome to email or mail your thoughts.



Competency Areas and Objectives

A. Knowledge of Dementia Disorders

1. Identify the primary causes of dementia.
2. Differentiate 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 individualize the care you provide to someone with dementia.

B. Person-Centered Care

1. Discuss the key concepts of person-centered care.
2. Describe how the background, culture, and experiences of a person with dementia affect care.
3. Describe how *your* background, culture, experiences, and attitudes affect care.

C. Care Interactions

1. Provide appropriate assistance with basic physical care tasks.
2. Identify and address the unique safety needs of persons with dementia.
3. Consider the person's abilities, needs, and preferences in order to maximize comfort, sense of well-being, and independence.
4. Obtain and apply knowledge of the individual's personal history; personal, religious, and spiritual preferences; and cultural and ethnic background.
5. Identify and validate the feelings, expressed verbally or nonverbally, of the person.
6. Demonstrate effective ways of listening to and communicating with someone who has dementia.
7. Discuss how various aspects of the environment may affect a person with dementia.
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 individuals to maintain their customary activities, social connections, and community involvement.
2. Recognize the importance of persons engaging in activities that give meaning and purpose to them within the context of their cultural identity.
3. Recognize the role of pleasurable activities, including sexuality and intimacy, in a person's life.

E. Understanding Behaviors

1. Understand that behavior is usually a form of communication and often represents an unmet need.
2. Recognize that a person's sense of appropriate behavior may be influenced by cultural background. (For example, cultural background may influence behavior related to gender roles, eye contact, and personal space).
3. Describe effective responses to behaviors that may be perceived as "challenging."

F. Interacting with Families

1. Respond to the family's unique relationships, experiences, cultural identity, and losses.
2. Use a non-judgmental 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 personal feelings, beliefs, or attitudes that may affect your caring relationships.
2. Identify helpful ways to prevent and cope with stress and burnout.
3. Identify the ways you cope with grief and loss.
4. Explain effective ways to talk with employers and co-workers about differences in philosophy or implementation of care practices, with a focus on what is best for the person with dementia.

Philosophy and Values

Life is a journey that revolves around relationships. The development of quality life-enhancing relationships gives meaning and purpose to the interactions between individuals with dementia, families, and Direct Care Workers (DCWs). These competencies are based on a philosophy that values age- and culturally-appropriate, person-centered care. This approach supports continued learning, growth, and development of compassionate relationships in a nourishing environment. The competencies emphasize that DCWs are an integral part of the caregiving team, whose contributions are valued and respected. The competencies focus on assisting DCWs in developing holistic, interpersonal, problem solving, and communication skills with persons, families, and staff in an environment that is supportive, vibrant, and meaningful.

Person-Centered Care

Care that is person-centered is care that focuses on each individual with respect to her or his unique history, abilities, experiences, culture, and personality. People with dementia retain the ability and the right to communicate their likes, dislikes, and preferences. Quality care relies on collaboration between the individual, the person's family, and the DCW.

Growth- and Caring-Centered

Care that is growth- and caring-centered is defined as helping another person to grow and develop. Part of the caring process is acknowledging an individual's needs,² including the opportunity to give care as well as receive it. This caring process may continue through the last stages of life.

Supportive Environment

The physical and social environment plays an integral role in all care settings. The environment should foster socialization, independence, and meaningful activity and offer a sense of community, safety, comfort, privacy, and dignity for everyone. Relationship building is fostered in an environment where interactions take place naturally.

Direct Care Workers

DCWs reach their full potential when the relationships they form are meaningful, standards of excellence are in place, opportunities are available to grow personally and professionally, and their accomplishments are not only acknowledged, but also celebrated. A learner-centered approach to training empowers DCWs to be creative and forward thinking; it allows them to take ownership of their work and to break the mold by testing innovative ideas. Often the best care is provided when decision-making begins with persons with dementia or with those closest to them, which is often the DCW.

See Contribution to the Philosophy and Values Statement in Appendix A.

²Including the need for companionship, autonomy, dignity, individuality, meaningful activity, productivity, physical comfort, emotional security, and spiritual well-being,

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. **Recognize the difference 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. **Explain why it is important to individualize the care you provide to someone with dementia.**

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1. **Identify the primary causes of dementia.**

- 1.1 Explain that there are many causes of dementia and that dementia itself is not a disease, but a group of symptoms that vary.
- 1.2 Recognize the key characteristics (such as progression and behaviors) of diseases and disorders that cause dementia, such as:
 - Alzheimer's disease
 - Lewy body disease
 - Vascular 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 decline in the ability to think that persists long enough and is severe enough to interfere with routine daily activities. Dementia usually begins gradually and persists indefinitely.

Delirium describes a state of confusion that usually begins suddenly and ends fairly quickly. It may include agitation, anxiety, illusions, hallucinations, distractibility, hyperactivity, disorientation, disordered speech, and defective perception.

2. **Recognize the difference between irreversible and reversible dementia.**

- 2.1 Recognize the potential symptoms and causes of reversible dementia.
- 2.2 Understand that there are reversible types of dementia, in which the symptoms can be alleviated with proper treatment.

- 2.3 Understand that treatment may delay decline and improve quality of life for a person with an irreversible dementia.
- 2.4 Explain why it is crucial for a person with dementia to receive an accurate diagnosis.
- 3. Understand the definition and significance of delirium.**
 - 3.1 Understand that delirium is an acute medical condition that can be fatal if not treated.
 - 3.2 Recognize the symptoms and causes of delirium.
- 4. Describe how brain changes affect the way a person functions and behaves.**
 - 4.1 Describe the typical progression of dementia symptoms.
 - 4.2 Recognize that different types of dementia affect different parts of the brain.
 - 4.3 Recognize that different types of dementia have different stages.
 - 4.4 Recognize that different types of dementia have different effects on behaviors.
 - 4.5 Recognize that an individual may have more than one dementia-related diagnosis.
 - 4.6 Recognize that an individual may have more than one area of brain changes.
 - 4.7 Recognize the symptoms that suggest the onset of active dying.
- 5. Discuss why it is important to individualize the care you provide to someone with dementia.**
 - 5.1 Understand that each person's symptoms and progression are unique.
 - 5.2 Understand that each person's symptoms and progress may vary significantly from what is typical.
 - 5.3 Recognize how care may be different depending on the type of dementia the person has.

B. Person-Centered Care

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

1. Discuss the key concepts of person-centered care.
2. Describe how the background, culture, and experiences of a person with dementia affect care.
3. Describe how *your* background, culture, experiences, and attitudes affect care.

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1. Discuss the key concepts of person-centered care.

- 1.1 Identify ways to see the person with dementia as a unique individual.
- 1.2 Explain the importance of relating to the person with dementia as a whole person (physical, emotional, and cognitive; past, present and future).
- 1.3 Explain the importance of focusing on the person's feelings more than on the task.
- 1.4 Recognize the person's ability to make decisions and express choices until the end of life.
- 1.5 Identify ways to enhance the person's ability to make decisions.
- 1.6 Identify how to offer choices in ways that are appropriate to the individual's ability to choose.
- 1.7 Identify ways to keep the decision making power in the hands of the individual or those closest to her or him.
- 1.8 Acknowledge that people with dementia are entitled to 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 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 the background, culture, and experiences of a person with dementia affect care.

- 2.1 Describe how the person with dementia may experience the surrounding world.
- 2.2 Recognize the importance of establishing familiar routines to promote individualized care.
- 2.3 Identify ways to establish familiar routines to promote individualized care.
- 2.4 Describe the importance of being flexible in meeting individual needs.
- 2.5 Discuss things you can do to identify the person's remaining skills and abilities.
- 2.6 Describe ways you can encourage the person to use remaining skills and abilities.
- 2.7 Recognize that every individual has a need for:
 - Attachment to others
 - Inclusion
 - Occupation
 - Individuality
 - Dignity
 - Emotional security
 - Privacy
 - Intimacy and touch
 - Socialization
 - Meaning
 - Physical comfort
 - Meaningful activities
- 2.8 Recognize and encourage each person's ability to:
 - Grow
 - Connect
 - Give
 - Receive
 - Teach
- 2.9 Identify ways to help the person fulfill the need to be a member of a community.

3. Describe how *your* background, culture, experiences, and attitudes affect care.

- 3.1 Acknowledge the importance of working as a team with individuals with dementia, families, and other staff.
- 3.2 Describe the importance of understanding each person's unique story without judgment or prejudice.
- 3.3 Recognize how your own experience and background affect caregiving.

C. Care Interactions

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

1. **Provide appropriate assistance with basic physical care tasks.**
2. **Identify and address the unique safety needs of persons with dementia.**
3. **Consider the person's abilities, needs, and preferences in order to maximize comfort, sense of well-being, and independence.**
4. **Obtain and apply knowledge of the individual's personal history; personal, religious, and spiritual preferences; and cultural and ethnic background.**
5. **Identify and validate the feelings, expressed verbally or nonverbally, of the person.**
6. **Demonstrate effective ways of listening to and communicating with someone who has dementia.**
7. **Discuss how various aspects of the environment may affect a person with dementia.**
8. **Understand why a person with dementia may be more vulnerable to abuse and neglect.**

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1. **Provide appropriate assistance with basic physical care tasks.**
 - 1.1 Understand that appropriate assistance is most likely different for each individual, and may even vary for the same individual depending on the present circumstances.
 - 1.2 Provide assistance with eating in the manner appropriate for the person.
 - 1.3 Promote adequate hydration.
 - 1.3.1 Recognize that individuals with dementia may not feel thirsty.
 - 1.3.2 Recognize that individuals with dementia may not voice or act on feelings of thirst.
 - 1.4 Use techniques that facilitate the person's necessary hygiene while minimizing distress.
 - 1.5 Recognize and respond appropriately to signs or symptoms of pain or discomfort.
 - 1.6 Prevent or minimize pain and discomfort when assisting the individual with physical movement.

2. Identify and address the unique safety needs of persons 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 Use problem solving and creativity to adapt the person's environment to ensure safety.
- 2.4 Recognize changes that can affect safety, such as changes in judgment, sense of time and place, behavior, physical ability, and senses.
- 2.5 Understand the risks of wandering and minimize threats.
- 2.6 Understand the risks of weapons and address appropriately (according to agency policies or as needed to ensure safety).
- 2.7 Recognize the increased need for assistance in emergencies of the person with dementia.
- 2.8 Describe basic emergency assistance steps.

3. Consider the person's abilities, needs, and preferences in order to maximize comfort, sense of well-being, and independence.

- 3.1 Recognize that independence is a goal as long as it enhances the person's self-esteem, pleasure, and confidence.
- 3.2 Understand that some challenges may be stimulating and maximize independence, yet can also overwhelm and tire the person.
- 3.3 Recognize the person's ability to participate in activities.
- 3.4 Simplify activities, break down tasks, or provide assistance to help the individual achieve the highest possible level of independent functioning.
- 3.5 Recognize that the person's abilities fluctuate.
- 3.6 Recognize that different dementias affect abilities and functioning in different ways.
- 3.7 Offer choices as appropriate when providing care.
- 3.8 Discuss how using prompts can help the person function.
- 3.9 Recognize the signs or characteristics that suggest palliative or hospice care may be appropriate and discuss with your supervisor.

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.

4. Obtain and apply knowledge of the individual's personal history; personal, religious, and spiritual preferences; and cultural and ethnic background.

- 4.1 Recognize that gathering information about the person is an ongoing process.
- 4.2 Recognize that you play a key role in the process of gathering information and sharing it with family members and other staff.

5. **Identify and validate the feelings, expressed verbally or nonverbally, of the person.**
 - 5.1 Understand that the person with dementia responds to your emotional state and the emotional state of others within the environment.
 - 5.2 Respond appropriately to the feelings expressed by the person.
 - 5.3 Describe a variety of behaviors a person with dementia may use to express feelings.

6. **Demonstrate effective ways of listening to and communicating with someone who has dementia.**
 - 6.1 Recognize the person's ability to communicate verbally and nonverbally.
 - 6.2 Make sure you have the person's attention before making a request or introducing a task.
 - 6.3 Demonstrate effective listening skills.
 - 6.4 Demonstrate ways to adapt your communication to changing abilities of the person with dementia.
 - 6.5 Communicate in ways that provide physical and emotional comfort to those experiencing loss or actively dying.

7. **Discuss how various aspects of the environment may affect a person with dementia.**
 - 7.1 Recognize that the environment includes social, physical, and organizational components.
 - 7.2 Recognize that the individual's environment can promote or inhibit:
 - Autonomy
 - Personalization
 - Sense of well-being
 - Orientation and way-finding
 - Privacy
 - Safety
 - Social interaction
 - Physical comfort
 - 7.3 Discuss how to identify environmental "triggers" that may create stress for the person.
 - 7.4 Describe how to change the environment to support or improve the person's quality of life.
 - 7.5 Discuss the importance of ongoing changes in the environment 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 evoke feelings and thoughts that undermine your ability to provide compassionate care.
- 8.2 Recognize signs of physical, psychological, sexual, and financial abuse.
- 8.3 Recognize signs of physical or psychological neglect.
- 8.4 Recognize when and how to seek help or clarification.



D. Enriching the Person's Life

As a dementia-competent DCW, you can:

- 1. Support and encourage individuals to maintain their customary activities, social connections and community involvement.**
- 2. Recognize the importance of persons engaging in activities that give meaning and purpose to them within the context of their cultural identity.**
- 3. Recognize the role of pleasurable activities, including sexuality and intimacy, in the person's life.**

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1. Support and encourage individuals to maintain their customary social connections and community involvement.

- 1.1 Assist the person in engaging in individualized, meaningful activities that foster positive interaction, self-esteem, and personal identity.
- 1.2 Recognize the importance of supporting the person's inclusion as a productive member in a community.
- 1.3 Recognize that individuals may need their customary social connections and community involvement for spiritual fulfillment.

2. Recognize the importance of persons engaging in activities that give meaning and purpose to them within the context of their cultural identity.

- 2.1 Understand that activities can be simple and adjusted to the person's ability without being childish.
- 2.2 Encourage individuals to do as much as they can for themselves in order to maintain their dignity and highest level of functioning.
- 2.3 Understand that activities should be tailored to each person in light of the individual's history, experience, cultural background, and identity.
- 2.4 Understand that abilities are fluid and recognize the importance of 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 in light of the disease process.
- 2.7 Understand the importance of the moments of joy.
- 2.8 Understand the importance of individuals reviewing their lives in order to identify remaining goals, tie up any loose ends, make peace, and leave a legacy.

- 2.9 Recognize that the person with dementia can continue to benefit from new experiences.
- 2.10 Recognize that all activities can be adapted to the person's ability.
- 2.11 Understand the importance of respecting the customary routines and daily pleasures of the person.

3. Recognize the role of pleasurable activities, including sexuality and intimacy, in the person's life.

- 3.1 Understand the person's need for intimacy and sexuality.
- 3.2 Allow expression of sexuality that 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 sexuality and intimacy.
- 3.5 Understand that people never lose the need for touch.
- 3.6 Be mindful to protect the dignity of every individual.
- 3.7 Be creative and generous with non-sexual forms of appropriate touch, such as massage, manicures, pedicures, hair combing, etc.
- 3.8 Experiment with all the senses to create pleasure. Examples include music and aromatherapy.
- 3.9 Recognize without judgment the need of the person to be attractive and desirable.
- 3.10 Recognize that individuals 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 individuals 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 behavior is usually a form of communication and often represents an unmet need.**
- 2. Recognize that a person's sense of appropriate behavior may be influenced by cultural background. (For example, cultural background may influence behavior related to gender roles, eye contact, and personal space.)**
- 3. Describe effective responses to behaviors that may be perceived as "challenging."**

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- 1. Understand that behavior is usually a form of communication and often represents an unmet need.**
 - 1.1 Discuss common need-driven behaviors in dementia, such as verbal or physical agitation or aggression.
 - 1.2 Use non-judging, strengths-oriented language when describing behavior.
 - 1.3 Demonstrate awareness that the words and behavior of a person with cognitive impairment, even though seemingly aimed at you, should not be taken personally.
 - 1.4 Respond appropriately to signs of depression.
 - 1.8.1 Understand the increased risk of depression.
 - 1.8.2 Understand the increased risk of depression not being recognized.
 - 1.8.3 Understand the increased risk of depression not being treated.
 - 1.8.4 Explain the benefits of treating depression in a person with dementia.
 - 1.8.5 Recognize the signs of depression in a person with dementia.
- 2. Recognize that a person's sense of appropriate behavior may be influenced by cultural background. (For example, cultural background may influence behavior related to gender roles, eye contact, and personal space.)**

3. Describe effective responses to behaviors that may be perceived as “challenging.”

- 3.1 Recognize that our personal perceptions often determine whether a particular behavior is seen as challenging.
- 3.2 Discuss how to identify the need that underlies the behavior.
 - 3.2.1 Recognize the importance of attending to and understanding the context within which a behavior occurs, including what happens before and after the behavior.
- 3.3 Discuss how to identify the need that underlies the behavior.
 - 3.3.1 Identify underlying needs that may lead to certain behaviors:
 - Physical comfort
 - Emotional well-being
 - Sense of competency
 - Need for socialization
 - Ability to find one’s way
 - Desire to be understood
 - Desire to communicate effectively
 - 3.3.2 Understand how to engage in basic problem solving in order to identify potential causes.
 - 3.3.3 Understand the importance of tracking and reporting behavioral and mental status changes.
 - 3.3.4 Demonstrate how to track and report behavioral and mental status changes.
- 3.4 Respond appropriately to verbal and nonverbal indicators of unmet needs.
- 3.5 Prevent or decrease the incidents of “challenging” behaviors by identifying and meeting the needs of the person.
- 3.6 Adjust your care approach, communication, and attitude to constructively respond.
 - 3.6.1 Use validation and redirection.
 - 3.6.2 Offer simple choices.
 - 3.6.3 Alter the environment.
 - 3.6.4 Alter the task or activity.
- 3.7 Demonstrate the ability to be flexible, creative, and able to try several different approaches to address potential causes.
- 3.9 Identify when, how, and what information to seek from family and other caregivers.
- 3.10 Identify how to evaluate the individual’s response to an intervention and its effectiveness.
- 3.11 Identify the possible effects of chemical (medication) and physical restraint.
- 3.12 Explain the importance of using the least restrictive restraint when necessary.

F. Interacting with Families

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

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

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

- 1.1 Use effective listening skills to learn from the family about the person's individual history, preferences, etc.
- 1.2 Recognize that the family's ethnicity and culture affect how family members understand dementia.
- 1.3 Recognize that the family's ethnicity and culture affect how family members define their roles and responsibilities.
- 1.4 Recognize the other roles and responsibilities family members may have, such as caring for both children and parents that affect their role as caregivers 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 Demonstrate a basic knowledge of family dynamics and their effect on caregiving.
- 1.7 Recognize that you may never know what a family member has experienced with the individual, and avoid judgment and criticism.
- 1.8 Recognize that a person with dementia may be vulnerable to abuse or neglect by family members.
- 1.9 Recognize that individuals living with persons with dementia may be vulnerable to being abused or neglected.
- 1.10 Respond appropriately to signs of depression in family caregivers.
 - 1.10.1 Understand the increased risk of depression for family caregivers.
 - 1.10.2 Explain the benefits of treating depression in family caregivers.
 - 1.10.3 Recognize the signs of depression in family caregivers.

2. Use a non-judgmental 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 express negative emotions and understand how to respond without taking it personally.
- 2.4 Demonstrate understanding of how your own ethnic and cultural values influence your interactions.

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

- 3.1 Recognize each family member's level of understanding and acceptance of the disease process.
- 3.2 Provide information and support as appropriate.
- 3.3 Assist family members in learning more about dementia as appropriate.
- 3.4 Model new skills and approaches for family members as appropriate.
- 3.5 Encourage family members to use new skills and approaches as appropriate.
- 3.6 Discuss the role of families 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 a consistent schedule, consistent activities, and consistent responses to a particular behavior.
- 3.9 Communicate effectively with the family regarding caregiving issues, such as changes in functioning or mood.

G. Direct Care Worker Self-Care

As a DCW who cares for yourself, you will:

- 1. Identify personal feelings, beliefs, or attitudes that may affect your caring relationships.**
- 2. Identify helpful ways to prevent and cope with stress and burnout.**
- 3. Identify the ways you cope with grief and loss.**
- 4. Explain effective ways to talk with employers and co-workers about differences in philosophy or care practices, with a focus on what is best for the person with dementia.**

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

- 1.1 Recognize when you feel uncomfortable with certain characteristics or differences in other people.
- 1.2 Discuss your ethical responsibility, as a care provider, to respect others and be open to learning about differences.
- 1.3 Understand how your own experience and history influence your perception of others.³
- 1.4 Explain how your perception of others may affect how you provide care.
- 1.5 Identify characteristics such as race, culture, ethnicity, sexual orientation, religious beliefs, lifestyle, and weight that make you feel uncomfortable or negative.
- 1.6 Describe ways you cope with situations in which you have strong personal responses.
- 1.7 Recognize when and how to seek help with your feelings.

2. Identify helpful ways to prevent and cope with 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 methods of self-care and the coping strategies that work well for you.
- 2.7 Respond appropriately when you experience stress, burnout, or depression.

³Include in your review any experiences with: Physical abuse, psychological abuse or neglect, sexual abuse, and disrespectful treatment of your property, environment, or self.

2.8 Recognize when and how to seek assistance.

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

3.1 Recognize that over time individuals with dementia and those close to them experience many kinds of physical, emotional, and social losses.

3.2 Understand that it is healthy to experience grief and many other feelings in response to losses.

3.3 Identify personally meaningful ways, such as rituals, ceremonies, special clothing, etc., to respond to losses.

4. Explain effective ways to talk with employers and co-workers about differences in philosophy or care practices, with a focus on what is best for the person with dementia.

3.1 Recognize that your knowledge, experience, and insight can make a valuable contribution to the care team's understanding.

3.2 Recognize that others' knowledge, experience, and insight can make a valuable contribution to the care team's understanding.

Suggested Resources

To assist you in your dementia studies and professional development, some of the resources that work group members have identified as favorites are listed below by competency area. These are only a small number of the many good resources available. The inclusion of any particular resource is not intended as an endorsement. ***Find additional resources in the References section that follows this section.***

We suggest you first check with your local library for any resource you would like to borrow. You may be able to place a special order from a local 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 or the Alzheimer's Association:

Mental Health & Aging Project

Tel: (517) 483-1529

Fax: (517) 483-1852

Email: beham@lcc.edu

Alzheimer's Association

(800) 272-3900

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

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.

* 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.

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.

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

Innes, A. (Ed.). (2003). **Dementia care mapping: applications across cultures.** Baltimore, MD: Health Professions Press.

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

Ramone, V. (1997). **Caregiving across cultures: working with dementing illness and ethnically diverse populations.** Washington, DC: Taylor & Francis.

Volicer, L & Bloom-Charette, L. (1999). **Enhancing the quality of life in advanced dementia.** Philadelphia, PA: Brunner/Mazel.

Zgola, J. (1999). **Care that works: a relationship approach to persons with dementia.** Baltimore, MD: Johns Hopkins University Press.

Videos

Aging Services Bureau, Dept. of Public Health & Human Services. (1996). **Memory loss among American Indians: the caregiving experience.** [Video.] Helena, MT.

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

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

Terra Nova Films. (1992). **Early onset memory loss: a conversation with Letty Tennis.** [Video, 20 minutes.] Chicago, IL.

TMK Productions. (2002). **Facing Alzheimer's: an African-American perspective.** [Video.] Northfield, IL.

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

Fact Sheets

Alzheimer's Association Fact Sheets*

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

C. Care Interactions

Books

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

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

Bell, V., & Troxel, D. (2003). **The Best Friends approach to Alzheimer's care.** Baltimore, MD: Health Professions Press, Inc.

Calkins, M. (2001). **Creating successful dementia care settings.** Baltimore, MD: Health Professions Press.

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.

Feil, N. (2002). **The validation breakthrough: simple techniques for communicating with people with Alzheimer's type dementia.** (2nd ed.). Baltimore, MD: Health Professions Press.

Gwyther, L. (2001). **Caring for people with Alzheimer's disease: a manual for facility staff.** Chicago, IL: Alzheimer's Association. Available from the Alzheimer's Association, (800) 223- 4405, order no. ED554Z.

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

Hudson, R., & Theol, M. (Eds.) (2003). **Dementia nursing: a guide to practice.** Baltimore, MD: Health Professions Press.

Jones, M. (1999). **Gentlecare: changing the experience of Alzheimer's disease in a positive way.** Point Roberts, WA: Hartley & Marks.

Kuhn, D. (2003). **Alzheimer's early stages: first steps for families, friends and caregivers.** (2nd ed.). Alameda, CA: Hunter House Publishers.

* 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.

Lawton, M. P. & Rubinstein, R. L. (Eds.). (2000). **Interventions in dementia care: toward improving quality of life.** New York, NY: Springer Publishing Co.

Mace, N., Coons, D. & Weaverdyck S. (2005). **Teaching dementia care: skill and understanding.** Baltimore, MD: Johns Hopkins University Press.

Mace, N. & Rabins, P. (1999). **The 36-hour day: a family guide to caring for persons with Alzheimer's disease, related dementing illnesses, and memory loss in later life.** (3rd ed.). Baltimore, MD: Johns Hopkins University 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.

White, L. & Spencer, B. (2000). **Moving a relative with memory loss; a family caregiver's guide.** Santa Rosa, CA: Whisp Publications.

Videos

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

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.

Edward Feil Productions. (1991). **Communicating with the Alzheimer's-type population: the validation method.** [Video].

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

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

Terra Nova Films. (1997). **Recognizing and responding to emotion in persons with dementia.** [Video, 22 minutes.] Chicago, IL.

Terra Nova Films. (1990 a). **Assisting the nursing home resident with Alzheimer's disease: a day in the life of Nancy Moore.** [Video, 25 minutes.] Chicago, IL.

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
- #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.

* 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.

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

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

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

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

Video Press. (1996 a). **Dealing with sexually inappropriate behavior: physical touching and disrobing**. [Video.] Baltimore, MD.

Video Press. (1993 b). **Sleep, sex, and wandering**. [Video.] Baltimore, MD. 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. & Siddle, 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>.

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

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.

Video Press. (1993). **Paranoia, suspiciousness and accusations**. [Video.] Baltimore, MD.

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**.

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.

Bryden, C. (2005). **Dancing with dementia: my story of living positively with Dementia**. Philadelphia, PA: Jessica Kingsley Publishers.

Coon, D., Gallagher-Thompson, D. & Thompson, L. (2003). **Innovative interventions to reduce dementia caregiver distress: a clinical guide**. New York, NY: Springer Publishing Co.

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.

* 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.

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.

* 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.

Videos

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

Terra Nova. (1992 a). **Working it out: support groups for nursing home aids**. [Video.] Chicago, IL.

Video Press. (1990). **Caregiver stress in long-term care**. [Video, 20 minutes.] Baltimore, MD.



References

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

Aging Services Bureau, Department of Public Health & Human Services. (1996). **Memory loss among American Indians: the caregiving experience.** [Video.] Helena, MT.

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

- (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.alzcny.org.

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

Alzheimer's Association, Los Angeles Chapter. (1998). **Diagnosis and management of persons with dementia.** [Video.] Los Angeles, CA.

Alzheimer's Association National Office. (1990). **Caregiver kit.** Chicago, IL.

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

Alzheimer's Association, Western New York Chapter. (2001). **Managing nutrition in dementia care: a supportive approach for caregivers.** Depew, NY. To purchase email matthew.lorigo@alz.org or call the Alzheimer's Association at 1-800-273-6737.

Alzheimer Society of Canada. (1998). **Alzheimer's journey.** [Video.] Toronto, Canada.

Amado, A. & McBride, M. (2001). **Training person-centered planning facilitators: A compendium of ideas.** Minneapolis, MN: University of Minnesota, Institute on Community Integration.

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

Aspen Publishers. (1995). **Home care for people with Alzheimer's disease.** [Video.] Gaithersburg, MD.

Aspen Publishers. (2000 to present). **Alzheimer's care quarterly.** Frederick, MD.

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

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

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Beedle, J. (1991). **Carebook: a workbook for caregiver peace of mind.** San Carlos, CA: Lady Bug Press.

Bell, V., & Troxel, D. (2003). **The Best Friends approach to Alzheimer's care.** Baltimore, MD: Health Professions Press, Inc.

Bell, V. & Troxel, D. (2002). **A dignified life: The Best Friends approach to Alzheimer's care, a guide for family caregivers.** Deerfield Beach, FL: Health Communications, Inc.

Bell, V. & Troxel, D. (2001). **The Best Friends staff; building a culture of care in Alzheimer's programs.** Baltimore, MD: Health Professions Press, Inc.

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Brawley, E. (1997). **Designing for Alzheimer's disease: strategies for creating better care environments.** New York, NY: John Wiley & Sons, Inc.

Bridges, B. (1996). **Therapeutic caregiving: a practical guide for caregivers of persons with Alzheimer's and other dementia causing diseases.** Mill Creek, WA: BJB Publishing.

Bryan, J. (2002). **Love is ageless: stories about Alzheimer's disease.** Felton, CA: Lompico Creek Press.

Bryden, C. (2005). **Dancing with dementia: my story of living positively with dementia**. Philadelphia, PA: Jessica Kingsley Publishers.

Calkins, M. (2001). **Creating successful dementia care settings**. Baltimore, MD: Health Professions Press.

Castleman, M., Gallagher-Thompson, D. & Naythons, M. (1999). **There's still a person in there: The complete guide to treating and coping with Alzheimer's**. New York: Putnam.

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.

Coon, D., Gallagher-Thompson, D. & Thompson, L. (2003). **Innovative interventions to reduce dementia caregiver distress: a clinical guide**. New York, NY: Springer Publishing Co.

Coste, J. (2003). **Learning to speak Alzheimer's: a groundbreaking approach for everyone dealing with the disease**. New York, NY: First Mariner Books.

Daly, G., Westphal, C. & Felt, J. (2004). **My voice-my choice: my advance directive package**. Dearborn, MI: Clinical Ethics Center, Oakwood Healthcare System.

Davidson, A. (1997). **Alzheimer's, a love story: one year in my husband's journey**. Secaucus, NJ: Carol Pub. Group.

Davis, R. (1989). **My journey into Alzheimer's disease: a true story**. Wheaton, IL: Tyndale House Publishers.

DeBaggio, T. (2002). **Losing my mind: an intimate look at life with Alzheimer's**. New York, NY: Free Press.

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

District of Columbia Office on Aging. (2000). **Alone but not forgotten: serving people with dementia who live alone**. [Video.] Available only from Duke University Media Services – Medical Center, 919-681-2483.

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

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.

Edward Feil Productions. (1991). **Communicating with the Alzheimer's-type population: the validation method**. [Video.]

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

Fanlight Productions. (1998). **Alzheimer's and dementia care skills for assisted living**. [Video.] 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).

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

Feil, N. (2002). **The validation breakthrough: simple techniques for communicating with people with Alzheimer's type dementia**. (2nd ed.). Baltimore, MD: Health Professions Press.

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

Films for the Humanities and Sciences, (2000). **On our own terms – Moyers on dying in America**. [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.

Gibson, F. (2004). **The past in the present: using reminiscence in health and social care**. Baltimore, MD: Health Professions Press.

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- # 2: **Brain Changes and the Effects on Cognition:** S. Weaverdyck
- # 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
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- #21: **Questions about a Person's Cognition: An Assessment Checklist:** S. Weaverdyck
- #22: **Questions about the Environment: An Assessment Checklist:** S. Weaverdyck
- #23: **Questions about Caregiving: An Assessment Checklist:** S. Weaverdyck
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Contributions to Philosophy and Values Statement

Person-centered ideas:

- Decision-making power 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.
- Individuals need to be given choices.
- The individual comes before the task.
- Families and DCWs work together to support individuals with dementia while maximizing their autonomy.
- Dementia care focuses on the individual and on building relationships.
- Dementia care looks at "doing with" the person, not "doing for."
- Dementia care identifies and focuses on the individual's strengths, not deficits.
- Dementia care establishes familiar routines to promote individualized care.
- Each individual's experience of dementia is unique; therefore, care must be unique.

Growth ideas:

- Within each individual lies the potential for growth and the ability to make a difference.
- Promote the growth and development of strengths and abilities for all.
- When you "care" things grow. "Care" does not mean "treat."
- Provide opportunities to give as well as to receive care.

Caring ideas:

- A prime task of dementia care is to maintain personhood – or to know the person – not just meet the person's physical needs.
- Companionship should be integral part of "care."
- The focus on retaining abilities is important in caring for the individual with dementia.
- Friendship is also a key component in caring for the individual with dementia.
- Care should respect diversity.
- Holistic care responds to the individual's spirit, mind, and body. There should be opportunities to give as well as receive care.
- Care must be continuous and lifelong.

Environment and Culture Ideas:

- The focus is on helping individuals in their homes or home-like settings.
- The emphasis is on making the person feel "at home."
- The environment should foster relationships between individuals and DCWs.
- A community-like setting, not an institutional one, is the goal.
- Culture changes are a journey.

- The environment should be one in which interactions and happenings take place naturally.
- The environment should foster variety and spontaneity in daily life.
- The environment should adjust to the comfort needs and abilities of the individual and ensure a sense of community and security.

For trainers and supervisors of direct care workers:

- Each worker can and does make a difference.
- Practice self-examination and reflection, searching for new creativity and opportunities for doing better.
- Empower DCWs to build relationships.
- Offer a learner-centered approach.
- Emphasize a curriculum that develops interpersonal, problem solving, and communication skills in an environment that carefully balances support and accountability.
- Empower DCWs to be forward thinkers—breaking the mold and testing new ideas.
- Promote growth and development in a supportive environment encouraging DCWs to use their full potential.
- Involve DCWs in decision-making around care delivery.
- Actively engaging in the discovery process is core for training workers.
- Provide opportunities for DCWs to develop quality relationships with the individual, which gives work meaning and purpose.
- Promote open communication with other DCWs and professionals.
- Give DCWs the tools they need to effectively work with people with dementia at all stages.
- Set standards of excellence.
- Use informal leadership.
- Celebrate accomplishments.
- Understand individual capabilities.
- Ensure individuals' rights.
- Recognize personal limitations.
- Provide “hands on” training and coaching.
- Show workers techniques for gaining the individual's trust.
- Give staff tools to learn the individual's history.
- Use structured and unstructured activities.

Reviewers

The workgroup appreciates the valuable comments provided by reviewers and carefully considered all feedback. However, the final document may not reflect the recommendations, opinions, or preferences of individual reviewers.

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Feedback Form

Please continue your answers on additional pages if needed.

1. What did you find most helpful in the guide?
2. What suggestions do you have for improving the guide?
3. How long has it been since you first received the guide?
 - ☐ Less than one month
 - ☐ 1 - 3 months
 - ☐ 3 - 6 months
 - ☐ 6 - 12 months
 - ☐ More than a year
4. Has using the guide led directly or indirectly to any change in how you provide care?
 - ☐ no change (skip to item 6)
 - ☐ some change
 - ☐ a lot of change
5. Please describe what changes you have made as a result, directly or indirectly, of using this guide:
6. Other comments:

Continued...

7. How many years of experience do you have as a direct care worker?

- ☐ Less than one year
- ☐ 1 - 3 years
- ☐ 3 – 5 years
- ☐ More than 5 years

8. How many persons with dementia have you cared for?

- ☐ Fewer than 3
- ☐ 3 – 5
- ☐ 5-10
- ☐ More than 10

9. In what settings have you worked? (Check all that apply.)

- ☐ Assisted living
- ☐ Nursing home
- ☐ Hospital
- ☐ Hospice
- ☐ Home Health Care
- ☐ Home Help Program
- ☐ Other_____

Thank you for your feedback. Please email your forms or comments to lcornelius@mphi.org , fax them to 517.324.7364, or send them to:

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