

Rearranging Lives After Alzheimer's Disease

Providing Effective Supports to Individuals with Alzheimer's Disease and Developmental Disabilities

895.33

THE NORTH DAKOTA STATEWIDE
DEVELOPMENTAL DISABILITIES
STAFF TRAINING PROGRAM

JANUARY, 2002



Rearranging Lives After Alzheimer's Disease Providing Effective Supports to Individuals with Alzheimer's Disease and Developmental Disabilities

**Cathy Haarstad, MS
Mary Mercer, MS
Rita Curl, PhD**

Copyright 2002. We encourage the use of this publication for not-for-profit organizations for educational and research purposes. We request that appropriate acknowledgment be given. Permission is granted for photocopying for personal or internal use. The consent does not extend to other kinds of copying, such as copying for general distribution, for advertising or promotional purposes, for creating new collective works, or for resale. Requests for use of this publication for any other purpose should be submitted to: Minot State University, North Dakota Center for Persons with Disabilities, 500 University Ave. W., Minot, ND 58707.

Suggested citation:

Haarstad, C., Mercer, M., Curl, R. (2002). Rearranging Lives After Alzheimer's Disease. Providing Effective Supports to Individuals with Alzheimer's Disease and Developmental Disabilities. Minot, ND: North Dakota Center for Persons with Disabilities, a University Center of Excellence in Developmental Disabilities Education, Research, and Service at Minot State University.

Funded by:

North Dakota Center for Persons with Disabilities at Minot State University
North Dakota Department of Human Services, Disabilities Services Division
U.S. Department of Health and Human Services, Administration on
Developmental Disabilities, Training Initiative on Aging and Developmental
Disabilities Grant # 90DD0483. Rita M.Curl, Ph.D., Project Director



TABLE OF CONTENTS

	<u>Page</u>
Chapter 1: Assessment	1
Introduction.....	1
Risk Factors	2
Systematic Assessment	2
Chapter 2: Providing Habilitation and Care	9
Understanding the Progression of the Disease.....	10
Changing Plans and Placements.....	11
Understanding Abilities Retained and Lost	11
Adjustments in Environments, Communication, and Care Routines.....	13
Responding to Unexpected or Disruptive Behaviors	14
Recognizing and Responding to Health Care Needs	16
Remain Connected	18
Staff Training	19
Chapter 3: Behavioral Supports	23
Loss of Impulse Control.....	23
Behaviors Associated with Loss of Self Control	25
Trouble Shooting Tips	28
Behaviors Associated with Poor Memory.....	28
Hallucinations and Delusions.....	30
Chapter 4: Personal Care Routines	34
Mealtime.....	35
Using the Toilet and Coping with Incontinence.....	37
Personal Hygiene.....	39
Bathing	39
Dressing	40
Chapter 5: Rearranging the Environment	45
Safety Checklist.....	46
Appendix	
References	49
Feedback Answer Key	50
Assessment Instruments	55

Chapter 1: Assessment

Objectives: After completing this unit, staff members should be able to:

- Explain why and how to complete baseline assessments for individuals with developmental disabilities
- List three ways to compare previous and recent behavior during assessment
- Identify risk factors for Alzheimer's disease in people with developmental disabilities
- List at least five areas of functioning that should be measured when conducting informal and formal assessments for Alzheimer's disease
- Describe situations when the person's team may need to consider alternative placements

Introduction

Alzheimer's disease is a progressive, degenerative disorder of the brain. It eventually results in abnormal brain function and death. The disease was first described in 1907 by a German physician, Dr. Alois Alzheimer.

Alzheimer's disease is a form of dementia that results from disease processes in the brain which cause tangling of the dendritic fibers in the nerve cells. This tangling prevents successful transmission of electrical impulses in the brain and leads to a loss of mental skills and abilities. The changes are most noticeable in the parts of the brain that influence learning, memory, and organized thinking. While the physical changes in the brain are very similar among people affected, the behavioral and psychological symptoms that result are complex and may differ from person to person.

The cause of Alzheimer's disease is a combination of genetic predisposition, environmental factors, and/or infectious disease. It is not a normal part of the aging process. However, the likelihood of demonstrating symptoms increases with age. In the general population, 5 percent of Alzheimer's cases develop before age 50; 2 to 10 percent of all aging persons after age 65; and 25 percent of aging individuals after age 75. Up to 50 percent of elderly individuals over age 85 experience some form of dementia (Anthony & Aboraya, 1992).

Even though half of all dementia cases result from Alzheimer's disease, it must not be assumed that someone has Alzheimer's disease because he or she exhibits some symptoms of the disease. Another leading cause of dementia is multiple small strokes. Dementia can also be caused by many other conditions, some of which are treatable, including: depression, metabolic disturbances, drug intoxication, Parkinson's disease, hypothyroidism, multiple blows to the head (e.g., boxers, uncontrolled seizures), a single head trauma (e.g., car accident), some kinds of tumors, vitamin B 12 deficiency, advanced stages of AIDS, anemia, and alcohol abuse (Anthony & Aboraya, 1992). When there is suspicion about the presence of Alzheimer's disease, medical follow-up must be done to ensure a proper diagnosis. The disease is diagnosed by excluding other potential causes of dementia. However, we can only be sure of the presence of Alzheimer's disease after an autopsy is completed following death.

Risk Factors for Alzheimer’s Disease or Dementia Among People with Developmental Disabilities

Some adults with disabilities are at the same risk for Alzheimer’s disease (or other forms of dementia) as are individuals in the general population. However, the following factors may increase the risk:

- Lack of exercise and poor nutrition
- Lower level of education
- Routine daily activities
- Presence of disease (high blood pressure, cardiovascular disease, epilepsy)
- Down syndrome
- Head injury, especially severe or multiple injuries
- History of Alzheimer’s disease in his or her family

The presence of the risk factors does not necessarily mean that Alzheimer’s disease (or some other form of dementia) will occur. However, the presence of one or more of these risks should alert the care provider to the increased probability for developing this disease.

Alzheimer’s disease may be noticeable at an earlier stage in people with mental retardation. People with higher levels of intellectual functioning are generally more adept at problem solving and making accommodations for declining capacity during the early stages of the disease.

Systematic Assessment

A systematic approach should guide the person’s team in selecting appropriate assessment methods when dementia is suspected due to changes in behavior, communication, or cognitive (i.e., memory, learning, and organized thinking) functioning.

Phase I: Informal Screening and General Disposition

Determine the need for in-house or external consultation. When a consumer first demonstrates changing cognitive patterns, the team decides whether the case is appropriate for the agency to treat alone or with the assistance of other community professionals. The following approaches can help the team with this decision:

- Interview staff members familiar with the consumer.
- Review previous medical history and tests.
- Complete a case study to compare previous and recent behavior.

- Conduct general observations, chart or journal behavior observed in everyday settings. Have general observations completed by a staff member who is familiar with the consumer.
- If the individual is verbal or responsive, a discussion to identify or rule out immediate difficulties (e.g., loss of job, death of friend) may be useful.

Many conditions share the behavioral symptoms of Alzheimer’s disease. This chart summarizes behavioral characteristics of three conditions:

Dementia in Down Syndrome	Mental Illness	Depression
Gait Deterioration	Poor Relationships with Others	Cognitive Behavior Change
Late Onset Seizures	Inflexible/Maladaptive	Neurovegetative Signs
Speech Deterioration	Nonfunctional Behaviors	Behavior Excesses/Deficits
Loss of Bladder Control	Intentional, Repetitive, Nonfunctional Behaviors	Recent Situational Trauma-- Loss, Change, Illness
Loss of Body Weight	Unpredictable/Moody	Crying More Often
Increased Emotionality	Erratic	Sleep Disorders
Deterioration of ADL's	Reactive to Small Changes	Changes in Eating Habits
Loss of Performance at Work	Stress from Programming Increases Disruption	
Change in Sleep Patterns	Aggressive & Angry	
Change in General Orientation	Change in Eating & Sleeping Habits	
Cognitive Deterioration		

Staff are responsible for observing and reporting changes in behavior according to agency policy. A sudden onset of dementia is more likely to be based on a medical problem (i.e., infection, dehydration, nutritional deficits, medication reactions) and should be attended to as quickly as possible. Slow progression of noted behavior changes can be observed over a period of time more safely than sudden changes. The team should refer the consumer for additional assessment(s) if assistance is needed to assess behavioral changes.

Behavioral Methods for Informal Screening. Behavioral screening may be completed with structured observations to identify general problems and to decide the need for further assessments. Of course, having had previous contact with the consumer is necessary in order to identify general changes in performance. A videotape record of each person participating in daily routines at work and home can provide invaluable information for comparison. A baseline video, completed at age thirty, prior to the person exhibiting symptoms of dementia, can be used to help the team identify changes in behavior and abilities over time.

Completing a brief cognitive assessment, or a "mental status" exam may be useful as well. One example is the "Shoobox Task" in which an increased number of objects (1 to 9) are presented and put away. After the objects are put in the shoebox, the person is asked to tell how

many objects were placed in the shoe box immediately after the box is covered and after a brief delay. Observing the person's ability to follow a direction immediately after it is given and after a few minutes delay will also provide some general information about memory ability.

Another approach is to use the Clock Drawing Task or the Mini Mental State Exam. They are quick printed forms which medical people use, but they may have limited usefulness for assessing persons with cognitive disabilities, if the person wouldn't have been able to answer the questions prior to the onset of dementia. (See [Appendix](#)).

Finally, the Instrumental Activities of Daily Living by Powel Lawton helps to identify marked changes in performance of everyday behaviors. (See [Appendix](#)). As with most assessments, it must have been administered previously in order to be useful in documenting change. Baseline assessments for these instruments and the videotape recording are most helpful when completed when the person is in their early thirties.

Phase II: Formal Definition and Quantification of the Problem

During this phase of assessment, the team identifies problem areas and measures the general level of functioning.

Medical Assessments. Ruling out medical problems is the first step in the formal assessment process. Many of the following causes of dementia are treatable:

- Urinary tract infection
- Prostate infection
- Late-onset diabetes
- Anemia
- Thyroid disorder
- Stroke
- Drug intoxication (due to slowed metabolism)
 - Antidepressant
 - Valium
 - Digoxin (heart medication)
 - Depakote (seizure medication)

Functional assessments of causes of problem behavior. If the medical assessments are negative, then the team may decide that a functional assessment is relevant. Functional assessments are used to identify the environmental antecedents triggering the behavior and to identify the consequences that maintain the behavior. Problem behavior may be caused or maintained by the following events:

- Attention from others

- Self-stimulation
- Environmental consequences
- Escape from demands
- Elicited problem behaviors

Data on the target behavior, its antecedents and consequences, and health, medical, and personal variables are used to determine which of the hypotheses may be correct. A behavior intervention specialist or a psychologist may help the team determine what is influencing the consumer's behavior and to identify appropriate program strategies.

Standardized assessments to define the problem. The Ruocco Geriatric Assessment for Persons with Mental Retardation is a practical checklist for gathering and documenting medical and behavioral information that may be pertinent to diagnosis of dementia. It must be used on a routine basis in order for changes in behavior to be noticed. The instrument formally collects the information discussed for informal assessments earlier, and suggests additional detailed observations and assessments. First administrations are recommended by age 40, but current information about dementia and aging persons with developmental disabilities suggests that by age 30 might be best. The general guidelines for administration are:

- Try to be as accurate as possible when answering all questions, do not allow any personal feelings to alter your judgment.
- Try to add comments for each question. This makes things easier for the next person reviewing the individual. Add anything that you think is pertinent.
- When the first assessments are done, have two different staff persons complete the assessment; the work site should do one, and if there is family involvement, they should also do one. Each assessment should be done independently of each other. This aids in estimating the reliability of the tool.
- After the first assessments are done, additional assessments must be done on a regular basis for comparisons. The general rule is that if major changes occur, then quarterly assessments would not be too often. If completed as a baseline without presentation of symptoms, then annually is sufficient. Once symptoms appear, then judge how often assessment should be done.
- Remember, the scores can change, going up and even going down. This can happen if the individual is placed on medication or has reached a plateau. For instance, if the person has been sleeping poorly and as a result is falling asleep at work, is irritable or being non-compliant and a new medicine is added and it works, many of these symptoms can cease, therefore the score might be less than the previous time.

The reason for doing these assessments more than one time, and by more than one person is to aid the staff and the doctor in determining the progression of the disease. It also will

help the doctor rule out any physical causes for the symptoms. In addition, it may be possible to predict how fast the rate of change will happen over time.

A copy of the assessment instrument can be found in the [Appendix](#). Areas of assessment include:

- Personal medical history
- Lab findings, test results
- Family history
- Assessments (mobility, dressing, bathing, personal hygiene, routine memory, wandering, incontinence, orientation, leisure time, routine performance, gait, time, challenging behavior, eating, sleep, personality, vocational, time on task, and memory recall)

The MOSES: Multi-Dimensional Observation Scale for Elderly Subjects is a relatively short 40-item behavior questionnaire that measures five areas of functioning:

- Self-help skills--higher scores suggest the person is less able to look after self
- Disorientation--higher scores suggest greater disorientation and confusion
- Depression--higher scores suggest the person has greater distress and unhappiness
- Irritability--higher scores represent less cooperation and greater abuse toward caregivers
- Social withdrawal--higher scores suggest less interest in people, events, and activities

The MOSES rates the person's performance on a 4-point scale from high ranks of completing tasks successfully and independently to low ranks for requiring total support or inactivity. Higher scores reflect greater dependence and the need for continuous supervision. The form has been standardized for persons with and without Down syndrome with diagnoses of Alzheimer's disease. ([See the appendix](#)).

Phase III: Intervention

After a thorough medical assessment, functional assessment of behavior, and standardized assessments, the team will identify general goals for intervention and determine where and how the consumer can best be served. Early signs and symptoms of Alzheimer's disease do not necessarily warrant changes in programming or residence. Whenever possible, the person should be allowed to "age in place" with dignity and respect. Modifications in activities and supervision may be necessary.

As the disease progresses, staff need to be prepared to adapt treatment practices and environments to the changing needs of the individual. These adaptations should reflect knowledge of the course of Alzheimer's disease and the potential for diminishing abilities among self-care, communication, and orientation skills. A balance should be maintained between compensating for loss of skills and maintaining development.

With the advanced progression of the disease, particularly when there is total loss of self-care skills and mental abilities, some caregivers or service providers may be faced with the difficult decision of whether or not to transfer the individual to a facility that can provide appropriate long-term care. The need to change residence can be reduced by providing increased supports to the individual. However, if the individual's behavior has a marked negative effect upon others in the residence or if the individual's overall deteriorating condition exceeds the level of care which can be provided in the residence, teams may need to consider alternative placements.

Summary

After collecting the data, be sure to continue to gather the same kinds of information across time. The same strategies used in pinpointing and monitoring phases are useful in follow-up. If necessary, sample a wider range of behaviors and environmental factors than those assessed during monitoring.

Dementia appears to be caused by a wide variety of physical and mental conditions. It is important that we thoroughly investigate the possibilities before deciding on a course of intervention. In order to determine successfully what is influencing a consumer's behavior, we must have a wide variety of assessment strategies. The informal, formal, and behavioral approaches described here are only a quick overview of the possibilities. It is a place to begin, and a place from which you will be able to help consumers live as comfortably as possible and to make the best of every day.

Chapter 1 Feedback Exercise

1. Alzheimer's disease _____ (is/is not) a normal part of the aging process.
2. Some forms of _____ (Alzheimer's/dementia) can be treated and reversed/cured.
3. The likelihood of demonstrating symptoms of Alzheimer's disease _____ (increases/decreases) with age.
4. Doctors can only be sure of the presence of Alzheimer's disease by completing an _____.
5. Functional assessments are used to identify the _____ causing the behavior and the _____ that maintain the behavior.
6. _____ (Slow/Sudden) progression of dementia symptoms can be observed over a period of time. _____ (Slow/Sudden) onset is more likely to be a medical problem and should be attended to as quickly as possible.
7. First steps in the formal assessment process include ruling out _____ and _____ causes for the change in behavior.
8. If major changes are noted after conducting standardized assessment, the assessment should be repeated _____ (quarterly/annually).
9. Why is Alzheimer's disease noticeable at an earlier stage in people with mental retardation?
10. What factors place individuals with developmental disabilities at greater risk of Alzheimer's disease?
11. What conditions share some of the behavioral symptoms of Alzheimer's disease?
12. Why does the module recommend videotapes of people receiving services at age 30?
13. What are some other ways to identify decline in cognitive patterns in persons with developmental disabilities?
14. What areas of functioning are measured during an Alzheimer's disease assessment?
15. Why is it recommended to complete the Ruocco Geriatric Assessment more than one time and by more than one person?
16. What are two reasons that would force a team or agency to consider alternative placements for a person with Alzheimer's disease?

Chapter 2: Providing Habilitation and Care

Objectives: After completing this unit, staff members should be able to:

- Explain why it is necessary to provide for a “rearrangement” of care and supports
- Understand the progression of Alzheimer’s disease
- List skills retained and lost as a result of Alzheimer’s disease
- Describe when the team should consider modifying the person’s individualized plan
- List successful communication strategies
- Identify effective behavioral intervention strategies
- List common environmental triggers for disruptive behavior
- State the importance of mild physical activity for persons with Alzheimer’s disease
- Recognize and respond to health care needs

People with developmental disabilities who develop Alzheimer’s disease experience profound changes in the brain on a cellular level. As cells in the brain are damaged, individuals lose their ability to recall, perceive, plan, judge, and eventually to speak and move (Janicki, 1999). Loss of function impacts the ability of people with Alzheimer’s disease to respond to and cope with the demands of daily life. In the face of these changes, personal priorities shift and narrow. Lives cannot go on as they did before. This calls for a corresponding *rearrangement* of the care, supports and relationships that protect and enhance the quality of life for aging persons.

The goal is to continuously adjust the care and supports needed by the individual to match the progression of the disease. In the past, the person may have valued: being independent, productive, and in control. As Alzheimer’s disease progresses, most people come to prefer:

- Safe, familiar surroundings
- Simple, meaningful events
- A sense of comfort and security
- Feeling connected
- Individualized personal/health care

The person’s team should consider changes in the person’s plan as changing behavior or performance indicate that the goals, objectives or supports are no longer relevant. Plans need to be revised to address changing preferences, abilities, or behavioral concerns.

Care providers are faced with several tasks in *rearranging* lives. First, they must understand the cognitive and motor abilities that will be retained and lost by individuals as Alzheimer’s disease progresses. Abilities control functioning and have a direct impact on behavior and relationships. In response to a decline in functional ability, care providers need to:

1. Understand the progression of the disease
2. Consider changes in the placement and habilitation

3. *Rearrange* daily schedules and care routines
4. Make environmental and communication adjustments
5. Manage unexpected or disruptive behaviors
6. Respond to health care needs that accompany each stage of the disease
7. Remain connected over time by creating a new relationship

Understand the Progression of the Disease

Symptoms associated with Alzheimer’s disease progress gradually from a few mild difficulties with conversation or tasks to complete immobility and eventually death. In people with disabilities this progression takes from eight to twelve years (Janicki, 1999). The progressive loss of function is often described in stages. The number of stages described varies depending on the source. What is important to know is not how many stages but rather to:

- Observe carefully for significant changes in typical behavior over time
- Rule out other possible causes for the behavior change (i.e., thyroid problems)
- Understand the inevitable decreases in function that will occur
- Learn effective responses for behaviors demonstrated at each stage

Stage I – Onset	Stage II – Progression	Stage III - Decline
Becomes disoriented	Requires support to do even routine tasks	No memory of recent or past events
Has trouble remembering names, new steps or tasks	No longer joins or participates without cues	Has only a reflex response to touch, voice, demands
Talks less often or uses fewer words, has trouble with word recall	Movement is slow and deliberate, trips easily, difficulty with steps or getting up and down	Unable to process words
Asks for or requires help to do multi-step tasks	Resists direction, even has difficulty with 1 step tasks	Does not speak
Resists change or involvement in activities	Disorientation to time, people & events intensifies	Unresponsive to surroundings
Appears uninterested in events, little emotion or initiative shown	Becomes fearful of noise, mirrors, low light, or water, cannot find rooms	Decrease in appetite, difficulty chewing and swallowing/weight loss
Loses ability to read or understand math	Gets stuck in a movement or step of a task	Limbs become rigid and tremble, becomes immobile
May cling and cry easily, may argue or become suspicious	Unable to understand cause and effect or explanations	Becomes incontinent of bladder & bowel
	May not inhibit behavior	Seizures increase
	Lip smacking, tongue thrusting & inappropriate chewing may occur	Feels pain but becomes unresponsive to sensory stimuli
	Becomes incontinent of bladder & bowel	Develops infection
	Seizures may occur	Death occurs
	May cry continuously or show no emotion	

Changing Plans and Placements

Since the goals, objectives, and supports required by adults with developmental disabilities are coordinated through a written plan, one of the first steps taken in *rearranging* lives is to re-examine and when necessary, to change the plan and/or placement of individuals. As the disease progresses it will be necessary to discard a traditional model that centers around habilitation, for one that focuses on care and comfort. *In Alzheimer's disease, people with developmental disabilities encounter special circumstances that take them outside of the skill building model. Because they are deteriorating and can tell us very little, their changing preferences must guide how we individualize supports* (Tina Campanella, The Council on Quality and Leadership, personal communication, February 18, 2001). Acknowledging changed priorities requires teams to secure a safe living environment, to help the person remain active and connected and empower them to cope with changes in health and functioning. The comforting presence of an exact diagnosis may not be available before a team is required to intervene.

Understanding Abilities Retained and Lost

The following strengths, described in a chapter entitled “Adult Day Services” by L. Force and M. O'Malley, in the 1999 book, *Dementia and Intellectual Abilities*, are typically retained by persons with Alzheimer's disease.

1. **Retention of well-learned or habitual tasks/steps.** The person with Alzheimer's disease remembers steps or tasks that are familiar or repetitive such as spooning up cereal, brushing hair, walking in the backyard, etc. Habitual abilities will eventually break down in the middle to late stages of the disease when the brain cells that control perception, movement, and motor planning atrophy but they will be retained for several years. Daily routines that involve familiar, repetitive tasks and that do not require new learning, give individuals a sense of comfort and provide stability and continuity as perceptual abilities decline.
2. **Retention of remote (distant past) memories.** Persons with Alzheimer's disease remember past events as if they were occurring now. Rather than arguing or attempting to get someone to recognize that an event happened long ago, it is better to use past memories as a point of reference for conversation. For example, if a person talks about going to work at a job that ended ten years ago, rather than argue with them or explaining, it is better to talk about a detail of a job or how much they liked doing it. It is also important to understand that some distant events may now set the person's agenda for the day (going out or coming back at a certain time) as they once did. To obtain participation in a current activity it is best to use actual objects/pictures rather than verbal persuasion to gently focus attention on the here and now.

Short term memories decline and prevent individuals from remembering the answers to questions, or what comes next in a routine or complex task. Individuals with Alzheimer's disease respond to loss of memory in various ways. Some give up and

refuse while others protest or cry. Most people need to be lead through a task step by step. Sometimes success is obtained by bringing a song or activity from the distant past into a routine as part of the prompting sequence (i.e. singing a favorite Christmas carol on the way to the bedroom may encourage the person to come along with you more than a direct request). Most often patience is required and it is necessary to avoid unnecessary or complex steps. Since a person’s alertness and memory may differ from day to day or within the same day, a person’s success can be insured through scaffolding. Scaffolding prompts means providing a varying amount of assistance depending on the person’s functioning at that moment. When using this technique, the amount of support required to participate in a routine is always available to the person, but no more help is provided than is needed.

Example:

Wake- Up Routine
<p><i>Wake Up Time</i></p> <ol style="list-style-type: none"> 1. Usually awake by 8 (check at 7:30). 2. Usually willing to rise if supported to sit up. 3. If unwilling, wait until 9 (put on favorite CD, gently assist to rise.) 4.If unwilling at 9, follow agency procedure.
<p><i>Privacy</i></p> <ol style="list-style-type: none"> 1. Point to robe on hook to door of room. Hold the robe open for him. 2. If he gets stuck and stares at the robe, slip the opening onto one arm & let him finish. 3. If he remains stuck, slip the robe on for him. 4. If he becomes combative, follow agency procedure.
<p><i>Bathroom</i></p> <ol style="list-style-type: none"> 1. On good days, just be sure the toilet seat is up. 2. If he gets stuck, tug at the waistband of his PJ bottoms and he will usually pull down. 3. If he remains stuck, lower his pants for him and he will usually sit down. 4. If he is fearful about sitting, grip both hands from the front and help him to lower.

3. **Ability to see, hear, and move.** Seeing, hearing, and moving are abilities retained well into the later stages of the disease. Activities that stimulate the use of a person’s senses can involve gentle forms of exercise (going for a walk) looking and listening activities (holding a puppy, watching TV) and simple hobbies or crafts. The individual with Alzheimer’s disease may lose the ability to show pleasure in activities before they lose the ability to do the steps so the person may attempt tasks when prompted, but show little interest. As emotional control declines, periods of crying or wandering may interrupt activities. Caregivers should continue to offer a predictable routine, easing demands and individualizing steps. As functioning deteriorates, complex activities such as holding a puppy need to give way to more

gentle visual or motor stimulation such as a listening to a CD or tape or looking at strobe lights.

4. **Ability to persist at repetitive tasks.** The motor planning needed to participate in tasks with repetitive movements such as vacuuming or raking leaves will be retained longer than more coordinated movements such as pouring cereal or sorting silverware. Knowing this makes it possible to adjust the kind of activities planned within a routine, and/or to target steps in tasks that individuals may be encouraged to do as other abilities decline. For example, within a kitchen routine someone may require assistance to clear a table but may be able to hold a dishtowel and dry at least one dish placed on surface. Discriminating among these steps may seem pointless, but in-fact, finding ways for individuals to stay active becomes critical as their health declines, delaying the day when people become totally bedridden and much more difficult to support.
5. **Emotional awareness.** People with Alzheimer's disease retain awareness of the emotional tone in the voices and touches they receive from others, far into the third stage of the disease. Although the ability to participate in functional activities is gradually lost, people remain sensitive to contact from others, allowing caregivers to stay connected through non-verbal communication even when death becomes imminent.

Adjustments in Environments, Communication, and Care Routines

Although individuals with Alzheimer's disease may be aware of emotional tone, they lose the ability to make sense of circumstances or actions and to control their own behavioral and emotional responses to events. People with Alzheimer's disease typically react to the tone of voice, speed and height of the approaching person, and the demand or urgency of their physical contact. If overwhelmed, they may either become combative or withdraw. Although people with Alzheimer's disease cannot change the decline in functioning, the caregiver, by changing and controlling his or her approach and response to behavior can ease the disorientation that is experienced and help the person with Alzheimer's disease remain connected for as long as possible.

Care providers should also expect a decline in **language** (using words to exchange messages), **perception** (filter and integrate sensory input), and **judgment** (attach meaning to sensory input and solve problems) in persons with Alzheimer's disease (Janicki & Dalton, 1999). Behaviors which indicate that the centers of the brain responsible for perception and judgment are deteriorating include changes in **communication** (misuse of spoken words, parrot-like repetition of phrases, inability to name objects), **orientation** (inability to interpret common sounds, or recognize a face or image or location), **planning** (unsure of what to do and when, where and how to do it), and **movement** (difficulty in starting or stopping movements or making sounds).

The decline in language abilities experienced by persons with Alzheimer's disease requires that we adjust our own communication style in order to be understood and accept more

responsibility for the communication process. The following suggestions will help insure success in conveying the meaning of your message:

- Keep the message simple.
- Use one-step directions (i.e., “Pull your sock off.” When that step is done say, “Pull off the other sock.”)
- Ask yes/no questions.
- Allow time for the person to answer.
- Combine demonstration with the verbal message (i.e., pretend to sit down as you say, “Sit down.”)
- Talk about real things (things the person can see and touch).
- Repeat using the same words.
- When offering choices, give limited choices.
For example: Rather than asking, “What do you want for a snack?;” show the person an apple and an orange and say, “Do you want an apple?” Pause briefly and ask, “Do you want an orange?”

Changes in sensory-motor abilities leads individuals to act impulsively without considering social expectations or their own well-being. They may sit passively without participation or become very confused about what is said or what is happening or has happened. Sometimes people with Alzheimer’s disease whine or cling to others and become very fearful of various aspects of their surroundings. The combined impact of these sensory-motor problems requires several environmental adjustments. Changes in language, perception, judgment and memory require *rearrangements* to make the living environment safer, and to make components of that environment easier to predict and recognize. An environmental safety checklist useful for planning is included in [Chapter 5](#).

Behavioral changes also require specific adjustments to the individual’s self-care routines. Caregivers should begin by simplifying tasks and using object/picture cues to enhance memory. As the disease progresses, it will be necessary to eliminate objects which may confuse or frighten an individual such as mirrors (due to a distorted perception of the image) and to provide increased support by doing some and eventually all task steps for the individual. A list of ways to modify personal care routines and the physical environment can be found in [Chapter 4](#).

Responding to Unexpected or Disruptive Behaviors

Families and service providers should expect and adjust to changes in the personality and behavior of individuals with Alzheimer’s disease. Behavioral change occurs both as a result

of cellular damage which leads to confused or impulsive behavior as well as the individual's attempt to cope with demands. Staff and families should anticipate limited interest in most activities, fluctuations in mood, and diminished capacity for self-determination and learning. People with Alzheimer's disease will experience difficulty with orientation (understanding who is with them, what will happen next, what time of day it may be, etc.), self-control and emotions, conversation, and routine.

Sometimes caregivers make vigorous and persistent attempts to encourage people with Alzheimer's disease to participate in planned activities in a misguided attempt to help them retain skills. Since a brain that has Alzheimer's disease gradually loses its ability to process many types of demands, these well intentioned attempts often result in further confusion and stress that may then negatively impact health. For this reason, confrontational techniques are considered to be ineffective and contra-indicated. Care providers will need to learn alternative approaches. The following behaviors described by Hamdy, et al are typical of adults with Alzheimer's disease who also have developmental disabilities.

Unexpected or disruptive behavior
Inability to complete tasks without step-by-step instruction
Individual coping styles (some withdraw, others cry, others become giddy).
Tendency to wander or pace
The need for a predictable, calm, secure environment.

When responding to typical behaviors seen in Alzheimer's disease, staff should keep in mind:

- Individuals do not have control over their behavior
- They cannot remember appropriate responses
- They cannot learn new ways of responding

Staff are challenged to respond to behavioral changes in a respectful manner and to learn new effective intervention techniques, recognizing that behavior will continue to decline (Urlings, et al., 1998). These techniques include:

- Minimize demands to reduce confusion and stress
- Simplify tasks and prompts
- Create opportunities for success
- Give people a sense of predictability, security and control
- Treat the person with dignity
- Take greater responsibility for communication

Milbradt, Carlson & Riley (1999) suggest the following sequence when responding to repeated or disruptive behaviors:

- Remain calm
- Respond to feelings
- Remove or eliminate sources of agitation
- Offer reassurance
- Attempt to orient the person to reality using a familiar object or activity
- Remove yourself if necessary (after making sure the person is safe), and return later

Caregivers should be watchful for behavior that occurs in reaction to environmental triggers such as changes in light or noise levels (cited in Robinson, Spencer & White, 1989). The person's disruptive behavior ultimately ends when their ability to perceive and move deteriorates to the point where specific combative or wandering behaviors are no longer physically possible. Generalized crying may continue until late in the third stage of the disease. Some behaviors associated with Alzheimer's disease require special responses. These include delusions, sundowning (increased symptoms in late afternoon), and fear of items such as mirrors or water. Suggestions for managing these behaviors are included in [Chapter 3](#).

Recognizing and Responding to Health Care Needs

Individuals with Alzheimer's disease encounter unique health challenges as their brains and bodies decline. Interest in activities may wane and confusion often increases. It is in the best interest of the consumer to remain active and participate for as long as possible (Hamdy, 1994). Mild physical activity can help individuals with Alzheimer's disease to sleep better, retain mobility and appetite, serve as a topic for conversation, counteract confusion in the wake/sleep cycle, and sustain interest in life. Activity may also prevent depression, constipation, and delay progression to a bed-ridden state. Some health challenges faced by persons with Alzheimer's disease are similar to those of the aging population. Unique challenges include:

1. **Providing adequate hydration and nutrition.** As functioning deteriorates, people with Alzheimer's disease may forget *how* to eat or the appetite centers in the brain may no longer function optimally, eliminating motivation for eating. Individuals may *forget to drink* water and lose the ability to ask for a drink. At this stage people usually lose a great deal of weight and any nutritional stores that help brain function and metabolism are rapidly depleted. This leaves individuals vulnerable to infection and disease since a strong immune response is dependent on good nutrition. It takes people with Alzheimer's disease much longer to recover from routine colds and flues and behavior can seem to deteriorate to a third stage level while the person is ill. [Chapter 4](#) details ideas for helping individuals get enough to eat and drink.
2. **Prevent falls/retain mobility.** People with Alzheimer's disease experience a decline in motor planning as the disease progresses. They also have greater difficulty with depth perception and in scanning their surroundings as they move. Eventually walking and getting up and down or in and out of beds or chairs may become difficult. Individuals with Alzheimer's disease may then refuse to get out of bed or

to take the short walks they used to enjoy. Changes in motor skills often lead to falls or rapid deterioration in mobility. Care providers need to carefully assess motor functioning to determine ability and motivation for movement. Provision of a walker, early on may give an individual the confidence they need to attempt continued movements. Caregivers require training on physical guidance strategies and to be shown how to respond to a sudden loss of balance. Letting the person set their own schedule and pace to the extent possible and modifying the physical environment to prevent tripping and perceptual hazards are also helpful.

3. **Prevent choking.** As motor planning deteriorates further, individuals with Alzheimer's disease will lose the ability to chew and may experience choking. People may be unable to remember or coordinate the movements needed to feed themselves or to chew. Careful observation is needed to prevent injury and caregivers require training in feeding techniques and use of the Heimlich maneuver. Consultation with a nutritionist or dietician who is familiar with the impact of changes in food texture will be required. Switching to a liquid diet may worsen problems with bowel control and continence so it is best to retain some food texture for as long as possible.
4. **Maintain good hygiene.** As the functional skills of people with Alzheimer's disease deteriorate, they lose the ability to bathe, brush their teeth, wash hands, etc. Caregivers will need to gradually provide more assistance for these essential tasks. However, as motor planning deteriorates, the ability of staff to lead the individual through the process of hygiene will also become compromised. This can create several problems. It will be necessary to examine daily routines and decide which tasks are non-essential. For example, a person who is not sweating from physical exertion may not need to shower daily and could find a sponge bath less overwhelming. Hand washing may continue to be critical to prevent exposure to germs and bacteria.
5. **Manage incontinence or constipation.** As functioning declines, some individuals who have never had problems with incontinence or constipation will experience these difficulties. Care providers and nursing staff may need to gain experience in supporting individuals who face these challenges. This can impact aspects of care such as laundry, exercise, hygiene, diet, and staff and consumer moral. It is important not to underestimate the embarrassment or discomfort that may result for a person who was previously independent in this area. Personal ability to cope with any pain or discomfort associated with bowel constipation will be diminished. A gradual slowing of physical activity may lead to constipation in a person who relied on this activity to stay regular. Similarly, eating less bulk can cause problems as well. Incontinence is often related to forgetting lifelong habits or difficulty in finding the bathroom or remembering steps in the task of using a toilet. Careful, frequent communication between the nursing and care providers is critical.
6. **Other health challenges.** Other health challenges faced by people with Alzheimer's disease may include, developing and managing seizures, and communicating about

changes in vision, hearing, or about health symptoms (i.e., shoes that rub following weight loss). Many, but not all, individuals experience difficulty with the sleep/wake cycle and depression. As functioning declines they will become unable/unwilling to participate in routine health care visits.

People with Alzheimer's disease require end stage care, which has traditionally been beyond the capability of service providers to give in typical settings such as group living arrangements or apartments (Udell, 1999). Teams should consider eventual transitions and plan time for the individual to adjust. Some agencies make the commitment to allow people with Alzheimer's disease to age in place, but the decision to provide end-stage care should be considered carefully before proceeding to offer it. Home health and hospice care services may provide the supports necessary to allow the person to remain in their current setting.

Remain Connected

It is not enough to simply change the focus of a plan and simplify personal environments. As brain cells atrophy, individuals are no longer able to maintain their relationships with others or to relate to the world in the way they once did. The person changes, moment-by-moment. This results in a gradual alteration in personality that requires caregivers and families to adjust or *rearrange* the way in which they relate to the individual (Urlings et al., 1998).

Caregivers require time to grieve the very real loss of the person they knew and to form and adjust to a new relationship. Staff may not like the new personality very well at first. People who used to be very independent now repeat questions just seconds after an answer is given. They get lost easily and remember the past but not a familiar name. They are suspicious of staff and their attempts to help them. They may cling or cry easily. They are unable to learn new skills and can no longer reward efforts by showing progress. For this reason, some caregivers are unable to make the adjustment and may need to transfer or change programs.

The confusion or anxiety that people with Alzheimer's disease experience as the disease progresses is significant. If caregivers focus on the person they used to know, rather than the person who has become slower and more easily confused, that individual will experience a profound sense of isolation. Remaining connected involves learning new ways of relating and meeting unique needs for health/comfort at each stage of the disease. Caregivers are required to systematically adjust the care and supports they provide to match the progression of the disease, remaining connected with individuals as they decline and supporting one another in saying good-bye. Caregivers experience hope by helping the person hang on to what they can, remain as comfortable as possible, and by focusing on what they can do and who they are today rather than what once was. Some tips for assisting with rearranging relationships include:

- Use picture/objects to help recall significant people in his/her life as long as possible.
- Take greater responsibility for communication by interpreting behavior and messages.

- Enter the person's reality and give him or her a way to feel secure.
- Create a therapeutic environment,
- Learn how to approach and comfort the individual at each stage of the disease.

By forming a new relationship with the individual, a familiar person can accompany an individual with Alzheimer's disease on the journey to death so that he or she is not alone.

Staff Training

Agencies must prepare to adequately support increasing numbers of persons with Alzheimer's disease as the population of persons with developmental disabilities ages. Systematic efforts to train staff and develop needed resources and programs are required. Training should include:

- Knowledge of the disease and its progression
- Awareness of the abilities that are lost/retained
- Ability to modify environments and routines
- Realistic expectations for behavior and control
- Ability to respond to disruptive behaviors
- Approach and interaction skills useful at each stage
- Opportunities to practice skills and obtain mentoring
- Ability to modify and scaffold prompts
- Ability to observe and report behavior change
- Ability to plan and individualize activities
- Effective use of strategies to communicate and connect
- Ability to provide/adjust health care within typical routines
- Awareness of the limitations of the habilitative model
- Adjustment to personality changes and decline
- Support for end of life circumstances and transitions

Information can be shared using videos, fact sheets, role play, modules, performance based tests, and on-the-job feedback. Staff can learn to generalize training by listing how to approach and interact with a person at each stage of the disease and update the list as needed. Staff may role-play how people with Alzheimer's disease typically respond so that needed interaction skills and knowledge can be applied within realistic situations (Urlings, et al., 1998). Finally staff may benefit from training to understand death and dying which is available through the agency or a community based program.

Summary

Alzheimer's disease results in a progressive loss of functional ability that leads to death. Although there is currently no cure for the disease, there is hope for new treatments and a possible cure. People with Alzheimer's disease require support to *rearrange* plans, individualize care routines and environments, and change relationships as needed to assure safety and enhance quality of life.

Chapter 2 Feedback Exercise

1. Alzheimer's disease will ultimately result in _____.
2. The progression from onset to death takes from _____ to _____ years in adults with developmental disabilities.
3. Some of the many behavioral symptoms which can occur as a result of Alzheimer's disease are listed below. Beside each symptom, indicate at what stage of the disease the behavior change is typically seen **first:** (1=Onset, 2=Progression, 3=Decline)
 - a. _____ Disorientation
 - b. _____ Trouble remembering names, new steps or tasks
 - c. _____ Slow and deliberate movement, trips easily, difficulty with steps
 - d. _____ Unable to speak
 - e. _____ Seizures may occur
 - f. _____ Appears uninterested in events, little emotion or initiative shown
 - g. _____ Only reflex responses to touch, voice, demands
 - h. _____ Fearful of noise, mirrors, low light, or water
 - i. _____ Gets stuck in a movement or step of a task
 - j. _____ Clinging, crying, argumentative, suspicious
 - k. _____ Requires support to do even routine tasks
 - l. _____ Talks less, uses fewer words, has trouble with word recall
 - m. _____ Loss of short term memory
4. Explain why it is necessary to provide for a "rearrangement" of care and supports when a person with developmental disabilities develops Alzheimer's disease symptoms.
5. As Alzheimer's disease progresses _____ is no longer the goal. Instead, teams focus on creating a _____ _____; helping the person remain _____ and _____; and assisting them to cope with changes in _____ and _____.
6. List 5 types of skills that are retained during the early stages of Alzheimer's disease.
7. Since a person's alertness and memory may differ from day to day or within the same day, prompts should be _____.
8. _____ (Short/Long) term memory declines and prevents individuals from remembering the answers to questions, or what comes next in a new routine or complex task.
9. How can music be used to foster cooperation in persons with Alzheimer's disease?
10. What are some examples of activities which may stimulate a person's senses?

11. Why is it important to help people stay active as long as possible?
12. When responding to typical behaviors seen in Alzheimer's disease, staff should keep in mind:
 Individuals _____(do/don't) have control over the behavior.
 They _____(can/cannot) remember appropriate responses.
 They _____(can/cannot) learn new ways of responding.
13. Effective behavioral techniques include:
 _____demands.
 _____tasks and prompts.
 Give people a sense of _____, security & control.
 Treat people with _____.
14. List four common environmental triggers for disruptive behavior in persons with Alzheimer's disease.
15. List health challenges for persons with Alzheimer's disease.
16. What precautions can be taken to prevent falls?
17. Switching to a liquid diet to prevent choking may worsen problems with _____ _____.
18. Caregivers may require time to _____ the very real loss of the person they knew and to form and adjust to a new relationship.
19. People with Alzheimer's disease remain sensitive _____ _____ and _____ from others, even when death is imminent.
20. People with Alzheimer's disease may _____ to drink, and lose the ability to _____.
21. People with Alzheimer's remember past events as if they were occurring _____.
22. Instead of attempting to get someone to recognize an event happened long ago, it is better to _____.
23. To be successful when communicating with people with Alzheimer's disease:
- Keep messages _____.
 - Use _____ directions.
 - Ask _____ questions.
 - Combine _____ with verbal messages.
 - Talk about _____ things.
 - Repeat using _____ _____ _____.

Chapter 3: Behavioral Supports

Objectives: After completing this unit, staff members should be able to:

- List steps to take to reduce or prevent occurrence of inappropriate behaviors.
- Describe appropriate responses to inappropriate behaviors.

Loss of Impulse Control

As Alzheimer's disease progresses, people gradually lose the ability to remember which behaviors are acceptable and which are not. Individuals may begin to act without thinking things through. Also, the person's awareness of time may also be lost while their awareness of pain and pleasure remain. For that reason, when needs are not met immediately, the person may swear, cry, or attempt to demand or take what they want. They may call out others names or even hit out at others. Behavior can be quite intentional, without awareness of its impact on the person's relationships with others.

As many of these behaviors are impossible for the person to control, scolding, punishing or verbal reprimands are usually ineffective and make the situation worse. The person is not likely to remember the consequences of a behavior and know to avoid yelling or hitting in the future to avoid a consequence. What is effective, is to understand the function of the behavior:

- To obtain immediate attention or affection.
- To fill a basic need such as hunger or thirst.
- To communicate a specific desire (use the toilet).
- To avoid something that is frightening, confusing or overwhelming.

It is usually effective to ignore the negative behavior and to address the underlying function. Ignoring the behavior does not mean pretending it did not occur or not responding, but rather, to respond without giving the problem behavior undue negative attention. Strategies for addressing the underlying include:

- Offering frequent reassurance and remaining close by so the person does not act out to obtain attention or avoid an overwhelming environmental demand
- Suggesting an appropriate way of getting the need met and then meeting the need as quickly as possible

It is important to understand that inappropriate behaviors may continue to occur and that the person may not "learn" from the intervention due to the disease process. Although not all outbursts can be prevented, intervention can minimize the negative attention and feelings and decrease the number and frequency of future crisis. Examples of steps that may reduce difficult behaviors that could be taken include:

Take these steps *before* inappropriate behaviors occur to reduce the chance for an outburst:

- Meet the person's immediate physical needs (hunger, thirst, pain, etc.).
- Avoid circumstances that the person views are dangerous or frightening even if those thoughts are not rational.
- Break large tasks into small ones to avoid frustration. Speak in short, simple sentences using a soothing tone of voice. Pause and give the person additional time to process and think about what you say. Be willing to repeat the words if necessary.
- Stand nearby when providing care to provide a sense of security.
- Avoid positions which leave you vulnerable to an unexpected grab or lunge, if a person has a history of being combative. A shoulder-to-shoulder stance is safer than bending over to tie someone's shoes (purchase elastic laces instead).
- Be alert to signs of frustration. End activities before inappropriate behaviors occur.
- Avoid activities that involve several groups in one room, making it difficult to hear and confusing to follow the conversation or activity. Keep everything calm and quiet.

Take these steps *after* inappropriate behaviors occur to reduce the length of an outburst and discover a better solution to the problem.

- Be flexible and come back to an activity later. Keep things in priority.
- Remain calm, even in the face of offensive behaviors. Don't raise your voice or act surprised or angry. The person may remember your angry looks and tone more than the underlying events that provoked it.
- Reframe the situation. Instead of saying to yourself or others: "That was uncalled for, I don't have to take that from anyone", it may be more helpful to think, "Mary is becoming combative, this situation is too much for both of us".
- Distract the person by presenting an equally attractive alternative.
- Smile and praise accomplishments, even though they may only be single steps within an activity.
- Avoid drawing attention to the person. Try to divert the attention of others from the person with the inappropriate behavior.

Behaviors Associated with Loss of Self Control

People are neurologically programmed for a fight or flight response. When a person with a developmental disability develops dementia, the brain's ability to control this response deteriorates and a variety of behaviors take place that evidenced diminished self-control.

Wandering

People with Alzheimer's disease not only pace restlessly, but actually wander away from rooms or homes. Approximately 75% of people with Alzheimer's disease wander sometime during the course of the disease. Wandering may take place in the day or night, may interfere with the privacy of others and poses a risk of injury.

During the early stages of the disease a person may continue to come and go with safety. However, as the disease progresses it is common for people with Alzheimer's disease to begin to wander. The person with dementia may wander around the home or leave the house and wander around the neighborhood. As skills disintegrate, the ability to cross streets safely or to remember when and how to get back may be compromised. This can become life threatening. Attempt to find a clue as to why they are wandering (too hot inside, trying to go somewhere, escape) and offer a reasonable alternative such as a fenced backyard or a daily walk whenever the person is restless. Other factors which may contribute to wandering include:

- The person has always walked or paced to reduce stress.
- The person has a habit established of always leaving the house after a meal.
- The person may be searching for something that was put away, especially if the environment recently changed.
- The person may be searching for a loved one or caregiver who was out of sight.
- The person may be trying to find the bathroom, and wander out the front door.
- The person is feeling pent-up or restless and needs to escape.
- The person may be unable to separate dreams from reality, may not know what time it is, or may need to use the bathroom.
- The person may be experiencing a medication reaction. Let the doctor know.
- The person may have gone to bed too early and may not need as much sleep as opportunity allows.

Plan in advance for potential wandering. Follow agency procedures prior to any restrictions of movement. Team involvement is critical. If restrictions have been secured through due process, a small hook at the top of the door may prevent an individual from slipping out while a caregiver is in the bathroom. Provide a walking route through a series of

rooms or within a fenced yard. Reduce sound and noise (turn down/off the TV or radio) to prevent the person from leaving to look for quiet. Make sure they have identification on them and keep up-to-date photographs of them, in case they get lost. If the person is lost, then alert neighbors, friends and local police immediately. It is worth warning the police in advance of the person's condition and the possibility that they may get lost. Check the usual stops that they visit to eliminate those from the search.

When the person is found, avoid confrontation and showing anger - speak calmly, with acceptance and love. Approach the person from the front and begin to walk with them to provide direction and prevent disorientation. Slowly guide the person back toward home without turning him or her around directly. Talk to the person to distract him or her from the wandering behavior. Reassure the person as to time and place in a normal tone.

Sundowning

Human beings are most vulnerable physically during the late afternoon and early evening. The greatest number of deaths occur at that time in the general population in spite of the widely held belief that most people die in their sleep. Little children often have a "cranky" period at this time. The cause for this trend is unknown and most people may be unaware of any specific problems at this time of day. However, people who have Alzheimer's disease may be impacted in a dramatic and visible way. Symptoms include:

- Increased symptoms of paranoia, suspicion, and agitation.
- Increased wandering.
- Increased hallucinations and delusions.

Causes for this mysterious condition may be related to fatigue and its impact on the immune system and brain, the difficulty of seeing and perceiving in the fading light or other causes which are unknown. Strategies to support individuals through this difficult time period include:

- Try offering a *short* nap earlier in the day. Make sure this does not impact the person's ability to sleep through the night. A 30 minute nap should be sufficient.
- Plan a comforting and reassuring activity to take place at that time of the day.
- Turn on lights to keep the amount of lights constant until bedtime.
- Limit the number of visitors and reduce noise levels that the person must respond to at that time of day for those people who are sensitive to noise or confusion.
- Avoid any changes in surroundings that seem to contribute to problems in coping at that time.

- Provide additional reassurance and support. Don't expect the person to "get over it". Instead, look at this as an opportunity to provide an increased sense of security. Also, expect behavior to vary greatly from day to day.
- Be sure the individual's needs for nourishment and liquids are met.

Depression and Anxiety

The person with dementia may experience depression and be withdrawn and unhappy. Dementia is a disabling disease, and it is understandable for a person with dementia to be depressed at times. Become familiar with the symptoms of depression and report them early and often. Recognize that the depression is not only a reaction to the limitations of the disease but a real change in brain chemistry that the person cannot control or will away. Also, don't expect the person to recover from depression immediately even with treatment.

Depression and anxiety can affect daily routines and interest in food, resulting in declining health. It is essential to provide more support for the person during these periods. The physician may be able to help or offer a referral to a counselor, psychologist or psychiatrist. Depression associated with Alzheimer's disease may differ biochemically from other forms of depression and may be more difficult to treat. Careful follow-up and feedback for the physician is critical.

Violence and Aggression

There are many reasons why a person with dementia may feel angry or frustrated. They may not like being helped with things they used to do on their own, or the growing inability to do things. As the disease progresses, the ability to remember which actions are appropriate and which are not deteriorates, the person may act more and more on impulse. The person also loses their sense of time and may be unable to handle delays. They may need to be told how to wait (reminded that they could do a specific waiting task). At the same time, the experiences of pain, pleasure, and discomfort remain. When needs are not met, the person may become angry and begin to yell, curse, or hit others.

If the person feels angry, aggressive or violent, keep calm and try not to show fear or alarm. Give them more space and try to draw their attention to a calming activity. Many times these behaviors are expressed as demands for attention or affection. Giving attention in the form of a pat or hug before agitation escalates may be most helpful.

This is one of the most difficult things to cope with for a caregiver, and if violence occurs often, the team will need to consult with the physician about help in managing the behavior when less restrictive options are not effective. Talk to your supervisor or coworkers for support.

Behavior or Circumstances	Trouble Shooting Tips Effective Responses
The person won't get out of bed in the morning.	Be flexible and allow the person to wake up on their own. Allow the person to get up when ready. Show them something they will be motivated to get. Move the bedtime hour back to an earlier time.
The individual can't sleep or is awake at night.	Introduce a walk or a ride in the car just before bedtime. Try a light snack before bedtime. Try adding or eliminating a night light. Check the room temperature. Keep it cool. Discourage day time naps. Speak softly. Allow wandering but check for safety. Check with the team and the doctor about sleep aids.
The person's attempts to communicate don't make sense.	Keep a sense of humor - laugh with, not at people. Don't take it personally if names/important dates are forgotten. Don't fill in the blanks or suggest words for the person. Learn the new words that replace old language. Don't interrupt if the person loses track and rambles. Be aware of your mood and its impact on behavior. Avoid pronouns (he, she, it), use names for clarity. Keep sentences short and directions clear.
The person has delusions or hallucinates.	Provide extra light. Make sure the person can see and hear as well as possible. Go for a walk as a distraction. Avoid contradicting or arguing with the person. Check with the doctor to see what medications may help. Offer reassurance.
The person is frightened of the environment.	Cover mirrors. Mark the floor near doorways to show where the exit is. Fill the tub with water after the person is inside. Listen and provide reassurance or distraction. Don't insist that the person move too quickly. Listen to statements he or she makes about the environment. Remove objects that frighten the individual when possible.

Behaviors Associated with Poor Memory

Repeated Questioning

Dementia can make a person forget what they have said or done from one moment to the next, leading to repetitive questioning and actions. This may cause irritation. Repetitive questioning is similar to a behavior sometimes used by people with cognitive disabilities called perseveration. Some people repeat statements or questions whenever they think about a particular topic. These people often have difficulty letting go of certain topics (fixation). They usually know the answer to the question but repeat the statement to reduce anxiety or because they don't know what else to say to start or keep a conversation going.

However, when a person gets Alzheimer's disease he or she may begin to repeat questions because they can't remember the answer. Giving the answer over and over does not provide reassurance because the person forgets the answer, much the same way people do when they ask what time it is and then forget a few minutes later and have to ask again.

Rather than answering the question again and again, it may be helpful after the first time to say that everything is fine and try to make the person more secure. It might help to write the answer down or to use a picture or symbol to represent the answer (a photo of what is for lunch). It may help to coach the person to use another phrase that is less irritating.

It is also important to recognize that the person may forget how to ask questions and may repeat the same question over and over because they can't remember how to express what it is they wish to know. You can try to discern what the unmet need might be (the person asks, "Time for lunch?") and voice it correctly for the person ("Were you wondering how long until lunch?"). Or you can distract the person by changing the subject or giving some appropriate form of physical affection. These techniques will be helpful only part of the time and a good deal of patience and humor may be needed to cope.

Clinging

The person with dementia may become extra dependent and begin to follow others everywhere. This can be frustrating, difficult to handle, and rob people of their privacy. The person may act this way as a result of feeling insecure and fear that when others leave them, they will not return. It also can occur as the individual forgets how to start activities to occupy their time. It is important to recognize that supporting a person with Alzheimer's may require higher levels of person-to-person contact than they may have accepted or sought previously.

Whenever a caregiver leaves a person with dementia, it is important to tell them they will come back. If necessary, write this information down for the person or give them something safe to hold that they can associate with their return (i.e., the person could be given a wristwatch to wear while a caregiver goes to the bathroom). Another method is to provide the person with something to occupy their attention while the caregiver steps away. If this is not possible, caregivers may need to ask another support person to sit with the individual. It is also important to relay critical information about the day during a change of shift. This exchange should be conducted privately with respect to the person's dignity or the information can be recorded or logged.

Losing Personal Items

An inevitable part of dementia is forgetting where objects were placed. This behavior is caused by insecurity, combined with a sense of loss of control and of memory. In some cases the person may accuse others of taking the missing objects. It is vital to respond to the accusations without confrontation or anger. The first step is to agree with the person that the item is lost and help find it. It is pointless getting into an argument over the loss, which will only upset everyone involved.

When items are missing, the person has often hidden them to prevent them from disappearing again. They then forget about the hiding place. Luckily people tend to use the same hiding places over and over. Always search for the missing item in these favorite locations first. Keep copies or spares of important items, such as keys, eye wear and documents. Use checklists and make sure items are stored out of sight or within sight (depending on the preferences of the individual) at key moments in the daily routine. Limit amounts of valuables and money left about. This reduces the chance of a real theft. Always check waste baskets before emptying them to prevent accidental loss of items.

Hallucinations and Delusions

It is common for the person with dementia to experience hallucinations or delusions. If the person is experiencing a hallucination, they might perceive (see, hear, or sense) things that are not real; for instance, figures at the foot of the bed, or voices in the room. Although what is seen or heard is not real to an observer, it is all too real to the person experiencing the phenomenon, and arguing with or denying that the hallucination is real is counter-productive, producing unnecessary agitation and resistance.

A delusion is a false belief that is held despite evidence to the contrary. For example, the person may believe that the caregiver stole their watch even though it is tucked inside the top drawer of the dresser, or the person plans for a relative to visit even though that person has been dead for many years. To the person, this delusion is real, and they may avoid or report the caregiver or make elaborate plans for the upcoming visit. Do not argue about the validity of what they believe, as any attempt to do so may result in increased anxiety or aggression. Imagine how you would feel if everyone began to insist in a serious or straightforward manner that your eyes were a different color than you know them to be or that you had lost all your hair and needed to wear a wig when you knew your hair was still there. You can then imagine the intensity or responses to delusions.

Both hallucinations and delusions can be difficult to deal with, but the following suggestions may be helpful:

- Distract the person by gently drawing their attention to something real in the room.
- Arrange an appointment with the optician or audiologist, since hallucinations can be associated with poor vision or hearing.
- Keep rooms well-lit and quiet to ensure that the person is not misinterpreting what is going on around them.
- Report either hallucinations or delusions to the doctor and review possible options, since medications may sometimes contribute to the problem.
- Try to give the person a sense of security, since hallucinations can be related to the need to feel safe.

- Use validation techniques. Tell and show the person that you are listening. Agree with the feelings expressed, “Your watch is important, you want it to be safe; you are excited to plan for a visit.” Indicate by questions and comments that you hear what the person is saying, not if it is correct or incorrect. (For example: if the person says their mother or husband (other deceased person) is coming to visit, rather than correcting them, visit with them about pleasant memories of the person).
- Look for a link to past behavior (the family always celebrated the birthday of the dead relative about this time of the year).

Chapter 3 Feedback Exercise

1. List four functions of behavior:
2. Steps to take before an inappropriate behavior occurs include:
 - a. Be sure that immediate _____ needs are met.
 - b. _____ circumstances the person views as dangerous or frightening.
 - c. _____ large tasks into small steps. Speak in _____ tone. Give time to _____ information. _____ words if necessary.
 - d. _____ activities before frustration occurs.
 - e. Keep everything _____ and quiet. No _____ group activities.
3. How can staff protect themselves if a person has a history of combative behavior?
4. To reduce the length of an outburst, staff should: keep voice and facial expression _____; _____ the person by presenting an equally attractive alternative; and _____ drawing attention to the person.
5. What are some reasons for wandering?
6. How should the caregiver respond after finding the person who has been wandering?
7. The _____ and _____ _____ should be involved before restrictions of movement are put in place.
8. _____ refers to increased symptoms of Alzheimer's disease that occurs in the late afternoon and early evening.
9. When an individual can't sleep, the caregiver might: Introduce a _____ or car ride before bedtime; Try a _____ before bed; Eliminate day time _____; keep the room temperature _____ or _____; add or eliminate a _____.
10. If the person's attempts to communicate don't make sense, the staff should: Laugh _____ the person; Don't take it _____ if names are forgotten; _____ fill in the blanks, suggest words, or interrupt; Keep communication messages _____ and _____.
11. If a person is experiencing delusions, provide _____; make sure the person can _____ and _____ well; go for a walk as a _____; avoid _____; check with the physician about _____, offer _____.
12. Changes to the environment which help reduce fearful responses include: cover _____; mark the floor near _____ to show where the exit is; fill the tub with water _____ the person is in the tub; listen and provide _____; allow the person to move _____; _____ objects that frighten the person.
13. How should the caregiver respond when a person asks repetitive questions?

14. Describe how you would use a validation technique when a person is experiencing a delusion or hallucination.

15. To minimize the impact of sundowning on people with Alzheimer's disease:
 - a. Offer a _____ nap _____ in the day
 - b. Plan a comforting and reassuring activity for _____ or _____
_____.
 - c. Turn on _____ until bedtime.
 - d. Limit the number of _____ and reduce _____ at that time of day if the person is sensitive to noise or confusion.
 - e. Avoid any _____ to the environment
 - f. Provide additional _____ and _____.
 - g. Be sure that the individual's needs for _____ and _____ are met.

16. A person with Alzheimer's disease may require _____ levels of person to person contact than they sought previously.
17. Approximately _____% of people with Alzheimer's disease will wander sometime during the course of the disease.
18. Depression associated with Alzheimer's disease may _____ from other forms of depression.
19. How should a caregiver respond to clinging behavior?

Chapter 4: Personal Care

Objectives: After completing this unit, staff members should be able to:

- Describe how personal care routines can be structured to support people as perception and orientation decline during the progression of Alzheimer's disease.
- Explain how to preserve the person's dignity and nutritional needs as their mealtime independence declines.
- List strategies to prevent toileting accidents.
- Recognize why people with Alzheimer's disease may resist bathing.
- List strategies to help persons with Alzheimer's disease to be as clean as possible yet still maintain a sense of control.

People with Alzheimer's disease benefit from routines that are individualized, familiar, meaningful, secure and structured. Activities should be selected based on the kind of activities the individual remembers and enjoys most now. An effective program of day activities:

- Helps people remain active
- Promotes good nutrition
- Offers stimulation in recreation/leisure activities
- Creates opportunities and support for socialization
- Provides adequate supervision and monitoring
- Offers safe environments

Several aspects of personal care routines can be *rearranged* to support the person as perception and orientation decline. General guidelines include:

- Structure activities to use the skills the person retains and accommodate skills the person has lost.
- Provide assistance when individuals forget how to do a task they used to do without help.
- Reduce or eliminate exposure to mirrors, water, or movement during personal care routines.
- Simplify tasks and directions.
- Eliminate unnecessary steps and give more help as functioning deteriorates.
- Prioritize what has to get done and let the rest go.

When planning a personal care routine for an individual, consider the following factors:

- What can/will the person do in a task/routine?
- What does the person seek out/avoid?
- How does the person approach, start, and continue tasks?
- What steps may be left out or simplified?
- When, where, and with whom does the person perform best?
- What can we build into the task that will be comforting?
- How can we structure the task, interaction, setting to reduce stimuli that bother the person?

Remember, as the person's condition changes, our approach to personal care routines will need to be adjusted.

Mealtime

Take care to make sure that meals remain a relaxing and enjoyable experience. Remember that mealtime is not just a time to take in nourishment but a time to enjoy the time spent with one another. Eating together creates an atmosphere of belonging and comfort that is reassuring and should continue as long as possible. Visit with rather than question the person to avoid pressuring them to recall information. Inability to answer questions about the day's event can be very frustrating.

While it is important that people maintain their independence for as long as possible, their health must not suffer. As the person's capacity diminishes, they may begin injuring themselves with burns or cuts when cooking. It may be hard for some individuals to give up this role if they are used to looking after themselves and/or their family or partner, so try and make cooking an enjoyable shared activity.

Expect the person will need to concentrate a little more on eating. People with dementia often forget if they have eaten or how to use utensils. You may have to remind the person *how* to eat. Contact an occupational therapist for further information about devices that help with eating.

People with dementia need good nutrition to help their brains fight the disease and to function optimally. Ask the dietician about sources of Vitamin E and foods that contain natural antioxidants, such as blueberries. Avoid any fad or unproven treatments/diets.

Remember that the meal must also be digested. It is natural for the person with Alzheimer's to slip into a very sedentary lifestyle, and end up spending much of the day seated in a chair or slipping into short naps. A 30 minute walk, twice a day when possible will provide the gentle stimulation that may reduce gastric distress and the need for laxatives.

As the disease progresses, physical problems may arise such as not being able to chew properly or swallow. If the person has difficulty swallowing, you may need to consult a speech therapist or occupational therapist to learn a technique to stimulate swallowing. A dietician may recommend changes in food texture. In the later stages of dementia the person may need to be fed or you may have to mash or puree food.

Plan, Prepare, and Serve Meals

Involve the person in preparing parts of meals for as long as possible. Use lists, picture recipes and pictures on cupboards to help people recall steps and locate items by themselves. Pick tasks that have a single repetitive movement (e.g., peeling potatoes) that is easy to remember.

If forks become difficult, use spoons or finger foods. Feed the person only when they can no longer meet their own needs but do not wait for the person's health to deteriorate before making the decision. Offer food items one at a time if presenting a whole meal becomes confusing. Cut food in the kitchen before serving to avoid embarrassment.

Use a plastic or washable stain resistant tablecloth or place mat. Choose materials that do not look institutional. Make sure dentures are in place for meals. A meal shirt offers more dignity than either a bib or stained clothing.

Go out to eat during non-peak hours, if possible, during the early stages. Although we would ordinarily not order a meal for someone else, doing so might simplify the process for the person and enable them to enjoy eating out for a longer period of time. It may also be necessary to remove extra glasses and condiments from the table and advise the waiter or waitress in a discrete manner of things to avoid so that the individual is not confused.

Recognize that as the disease progresses, the person may lose their ability to sense hot and cold safely. Make sure foods are warm through but not hot. Do not serve dishes that should be hot or warm, at a cold temperature. If you must feed the individual, wipe any spilled food immediately and do not over fill the spoon. Never attempt to feed the person when they are lying down. They may choke. Support the person in getting up and going out to the kitchen or dining for as long as possible. Involve the person in doing what they can, holding a cup or a spoon, for as long as possible. Pause between spoonfuls so the person can swallow and enjoy the taste of the food.

Appetite and Portion Control

Appetite will vary from not hungry to extreme hunger. Some people may become ravenous or forget that they have already eaten. If the person wants numerous helpings, serve one or two and remove the remaining food from sight. It is more typical for people to lose interest in eating or have little/no appetite as the disease progresses. A few people vary from one extreme to the other.

- Serve favorite foods often, especially if the person has little appetite.

- Honor preferences for having foods cooked a certain way.
- Add extra ingredients if the person eats too little (crackers to soups).
- Try five small meals rather than three large ones.
- Try health shakes or supplements as the nutritionist or doctor advises.
- Keep finger foods available in the refrigerator if the person will not eat meals.
- Avoid confrontation. If the person is upset or sleepy, wait until later.
- Keep a simple record of how much the person eats/drinks to share with the doctor/dietician.
- Serve foods that don't need much chewing: soups, ground meat, applesauce.
- Maximize texture, if foods need to be ground up or pureed to prevent choking. Blend and serve foods separately and add condiments (add catsup on top of blended meat patty). Don't lump foods together in the blender (blend peas separate from meatloaf).

Using the Toilet and Coping with Incontinence

There are three goals when it comes to using the toilet if a person has Alzheimer's disease. Try to make the experience:

- Comfortable
- Safe
- Healthy

Individuals may remain independent during early stages and gradually require help as the disease progresses. People may need:

- Reminders to use the toilet
- Reminders or help to shut the door
- Reminders to remove clothing and help to remember how
- Support to sit on the toilet
- Reminders or help to flush
- Reminders or help to wipe or clean properly

The person with dementia may lose the ability to recognize when to go to the toilet, where the toilet is, or what to do when on the toilet. Confusion is often the cause of incontinence, but it can also occur in response to changes in medication or for other health reasons. Therefore, always let the doctor know that incontinence has occurred if it represents a

change for the person. Be sensitive in referring to this problem in the presence of the person (who may be aware and feel a sense of shame that they cannot express) and others.

There are some steps you can take to reduce the risks of toileting accidents. Limit large drinks late at night and create a schedule for going to the toilet. Frequent toilet trips reduce the risk of accidents happening. During the night consider waking the person at a set time and suggesting they go to the toilet if that practice will not make it difficult for the person to return to sleep. Remember that a person with dementia can be easily confused and might need to be taken to the toilet, especially if it is not near the bedroom. A commode by the bedside may be helpful in an emergency.

Around the house, try a special colorful picture to mark the bathroom door and leave it open to make it easy to find. A glow in the dark strip or hair scrunchy on the doorknob can also be an easy way to help the person recognize a specific room. Finally, make sure that clothing can be easily removed, as this makes going to the toilet easier. Skin can be damaged if left exposed to urine, so if you cannot shower the person immediately after an accident, consider using baby wipes to clean the affected skin. Carry spare clothing when you go out.

Incontinence means more work for others, which can be both upsetting and distasteful. These feelings are understandable and it is important to recognize and talk about the problem and feelings. It is human to resent the circumstances when people make more work for us. It is equally important that we do not scold or punish the individual no matter how tempting that may be. They cannot help the loss of control. Seek extra support if frustrated. Doctors, nurses, home health specialists, and hospice volunteers all have come across these problems before and will be able to offer practical suggestions and support.

Support is best provided using the following steps:

1) **Simplify the process as much as possible:**

- Make it easy to find the bathroom by using a picture or colored door.
- Use a night light to show the way.
- Wear loose fitting, easy to remove clothing.

2) **Recognize behaviors that may indicate that the individual needs to use the toilet:**

- Identify the behaviors.
- Write down the details to share with others.
- Observe the individual and respond *quickly!*

3) **Prevent constipation and accidents:**

- Go for daily walks.
- Make sure there is fiber in the diet.
- Consult the physician before giving laxatives or stool softeners.
- Drink plenty of liquids (eight glasses of water a day).
- Make sure impaction isn't due to swallowing inedible objects or drug side effects.

- Follow a regular schedule of using the bathroom.
- Limit large drinks late at night.
- Use absorbent pads rather than briefs or diapers for as long as possible.
- Report bowel incontinence to the physician as it is difficult to reverse.
- Use protective bed padding when necessary.

Personal Hygiene

It is more pleasant to spend time with a person who is well groomed and clean. Many individuals with disabilities have been very independent in their personal hygiene routines. For some, accepting offers to help with personal hygiene will be embarrassing which can lead to resistance. A firm approach may work with some people. Other people may quickly give up and need reminders and encouragement to do what they can. When a person starts to forget daily grooming habits, don't immediately perform these tasks for the person, instead remind them of what comes next. Don't make these reminders a power struggle "he could do it if he really wanted to" or "I'm *not* doing it for her". You may need to help people get started and then back off as they continue. These simple tips may help:

- Suggest an easy to care for hairstyle. Try using the kitchen sink to wash hair. Keep going to the beauty parlor or barbershop for as long as tolerated. Complement the individual about their looks.
- Begin by supervising shaving. Use an electric razor if tolerated. Shave all the parts the person normally would shave (under arms, legs, face, etc.).
- Try applying a light touch of make up (if the help is tolerated), if a woman stops using it.
- Cover the mirror to prevent a fearful response, if the person is frightened of their own reflection because they don't remember who that person is.
- Encourage the person to trim their nails. When you need to take over, do it at a time when the person is relaxed and occupied (watching TV).
- Check periodically to make sure shoes still fit, if the person gains or loses weight. Visit the podiatrist if needed.
- Provide special training when needed on how to brush and care for someone else's teeth and dentures.

Bathing

People with Alzheimer's disease often develop intense phobias (fears) about water. A phobia is more than a feeling of caution or a simple fear. Phobias are deep, irrational states that may be brought on as brain cells in the emotional centers of the brain lose functioning. Because phobias are irrational, the person cannot respond to arguments or discussions of why/when they

should bathe or how. Memory may also play a role if the person can't remember how the water got in the tub or who is reflected in the water. They may also become fearful of climbing in and out of the tub because of these and other memory related problems, the issue of bathing must be approached with great sensitivity and care. The goal is to provide support in a way that allows the person to retain a sense of control and be as clean as possible.

Someone with dementia may also forget to bathe because they don't remember when they did it last or no longer recognize the need. In this situation it may be helpful to associate washing with an activity, such as going to a restaurant, visiting friends (during the early stages of the disease) or something always done right before/after a certain activity such as a meal, TV program or walk (during the middle stages).

A person may also resist bathing because they don't remember how to go about it. Simplify the task to make steps easier to remember and allow the person to do as much as possible unaided. If the person appears embarrassed, keep portions of their body covered. If the person refuses to be washed, try again later when their mood may have changed. Rather than forcing the person to wash, try to make it enjoyable and relaxing. Use praise and encouragement when the person is freshly bathed. Play favorite music while the person is in the tub or shower. A shower, or stand-up wash may be easier than a bath. However, if the person is not used to a shower, take baths instead. Other tips include:

- Help rather than do for as long as possible.
- Use the same consistent steps/method across time/helpers.
- Do not insist on every day bathing when every third day will do if the person dislikes or actively resists bathing.
- Limit water depth and stay with the individual, if he or she seems fearful of bathing. The individual may feel safer if he or she is sitting in the tub or in a tub chair before the water is turned on
- Consider having the person keep a towel wrap on in the tub for privacy. Draw the shower curtain.
- Don't rush. A bath that takes all morning is fine. Give time to play and relax. If nothing else gets done, wash the most important parts.
- Provide physical support, with grab bars, mats, shower or tub chairs.

Dressing

A person with dementia often forgets how to dress and may not recognize the need to change clothes. Although it is tempting to just slip on a robe and stay in pajamas (and even practical if the person just won't dress), continuing to dress as long as possible is preferred. Dressing is a simple way of keeping the person active and helping them retain their sense of

independence and self-esteem. Individuals may remain motivated to dress if they can wake/get up at the time they wish instead of being forced into a routine that someone else has decided “is good for them”.

Allow plenty of time for dressing, make sure the atmosphere is calm and warm. If the person is struggling, lay out clothes in the order they should put them on, or verbally suggest which item to put on next. Explain how or help the person put on the clothing. Try to ensure that the person with dementia is comfortable with the clothes selected, involving them in the selection process.

1. Simplify clothing by making it easy to put on, wear and remove:

- Use large front fastenings.
- Use zippers and velcro tabs.
- Buy pants with elastic waistbands.
- Try wrap around skirts or reversible fabric.
- Wear loose-fitting garments.
- Get front or over-the-head openings.
- Wear velcro shoes or slip on styles.
- Eliminate unnecessary items (bra, etc.) or use an easy to put on style.
- Use tube socks rather than tight elastic.
- Use soft cotton rather than satin underwear.

2. Keep clothing up to date, clean, color-coordinated and neat:

- Buy cotton or washable/no iron fabrics.
- Suggest styles or types that will make good gifts so families and others will know the person’s real needs.
- Place clothes on racks within the person’s reach.
- Make sure room/closet lighting is adequate enough to see colors.
- Keep all alike items together in drawers or closets.
- Use the same kind of hangers for each kind of clothes.
- Put out of season or out of fashion clothing away and out of sight.
- Put scarves, belts, ties, sashes or other accessories with pants and shirts.
- If a person can’t remember how to use an accessory, adapt or eliminate it.

3. Make dressing a safer activity by taking a few simple precautions:

- Dress while seated to reduce the danger of falls.
- Remain close to give support.
- Offer limited choices: “Do you want to wear the red or the green sweater”.
- Check to make sure all fastenings are closed.
- Avoid lowering your head or bending over within reach, if the individual is combative.
- Squat instead of bend to reach the person’s feet or foot rests on a wheel chair.

4. Plan for continued use of accessories and adaptive devices:

- Have more than one pair of glasses available. Keep a copy of the prescription.
- Check to make sure that dentures are removed and kept moist.
- Use neck cords to hold glasses only if the cords do not present a safety problem.
- Put glasses and hearing aids in a case at night.
- Be sure to help clean glasses periodically throughout the day.
- Check hearing aides and batteries daily.
- Keep wallets and purses in an easy to find, out of sight place.
- Use evening and morning checklists to account for everything.

Chapter 4 Feedback Exercise

1. Characteristics of effective day programs for persons with Alzheimer's disease include:
 - a. Helps people remain _____.
 - b. Promotes good _____.
 - c. Offers _____ in recreation/leisure activities.
 - d. Creates opportunities and support for _____.
 - e. Provides adequate _____.
 - f. Offers _____ environment.
2. Guidelines for structuring personal care routines include:
 - a. _____ skills the person retains and _____ skills the person has lost
 - b. _____ when the person forgets how to do a task.
 - c. Reduce or eliminate exposure to _____, _____, and _____.
 - d. Simplify _____ and _____.
 - e. _____ what has to be done.
3. What can be done to encourage people to eat if they lose their appetite?
4. Digestion can be aided by: _____ twice a day; use the maximum _____ the person will tolerate; ensure that the person drinks enough _____.
5. During mealtime it is better to _____ rather than question the person.
6. While it is important that people maintain their independence for as long as possible, their _____ must not suffer.
7. What are some mealtime strategies that can help preserve the person's dignity while providing extra support that they need as the disease progresses?
8. What are three possible explanations for incontinence (toileting accidents) in person's with Alzheimer's disease?
9. Strategies to prevent accidents include:
 - _____ large drinks at night.
 - Create a _____ for going to the bathroom.
 - Make it easy to find the _____.
 - Recognize _____ that may indicate the person has to go to the bathroom.
 - Make sure that clothing _____.
 - _____ by the bedside.
10. As the disease progresses, the individual may need more and more support with toileting. What sort of reminders may be required?

11. Why is bathing resisted by many people with Alzheimer's disease?

12. Practical tips to provide support for bathing include:

- Associate washing with an _____ .
- _____ the task, provide assistance when needed.
- Play _____ during the bath or shower.
- _____ instead of bath.
- Use _____ sequence of steps.
- Reduce the _____.
- Fill the tub _____.
- _____ the water depth.
- _____ if they want.
- Use the shower curtain or towel for _____.
- Don't _____, take time to play and relax.
- Provide _____, i.e., grab bars, mats, shower or tub chairs.

13. What are some strategies to simplify dressing for persons with Alzheimer's disease?

- Offer _____ choices. (Do you want this shirt or that shirt?)
- Use large front _____.
- Use zippers and _____.
- Buy pants with _____ waistbands.
- Wear _____ clothing.
- Get _____ or _____ openings.
- Wear _____ shoes or slip-on style shoes.
- _____ unnecessary items (bras, slips, scarves).
- Allow plenty of _____.
- Make sure the atmosphere is _____.
- Lay out clothes _____.
- _____ or help to put the clothes on.

14. What are some tips to make dressing safer?

15. People with Alzheimer's disease often _____ interest in eating and have _____ appetite.

Chapter 5: Rearranging the Environment

Objectives: After completing this unit, staff members should be able to:

- Identify environmental features that support the person's ability to age in place.

People with developmental disabilities often prefer to age in their own home or living arrangement. It is very difficult for many people with Alzheimer's disease to cope with certain environmental features as their perceptual skills deteriorate. The following components to the physical environment are most helpful to people with Alzheimer's disease. These strategies help to remove, minimize, or accommodate environmental features which may be perceptually confusing, frightening, or difficult to remember.

- 1) Floors and walls are different colors, making them easier to distinguish.
- 2) Lines or tripping hazards that may be perceptually confusing are covered or removed.
- 3) Exits or bathrooms are clearly marked and easy to access. Doors have levers instead of knobs or close automatically. A bathroom may be marked with a pretty calendar picture, or a cloth hair scrunchie that is placed on the knob.
- 4) Secure areas are accessible inside the home or outdoors where people can walk when restless without feeling trapped.
- 5) Furniture is homelike, has distinct edges and firm so that the person does not have trouble getting up from the surface.
- 6) Common gathering spaces do not have televisions or radios that are left on and contribute to perceptual confusion.
- 7) Unnecessary noise sources such as alarms or radios are minimized.
- 8) Activity areas are perceptually distinct from one another (different colored carpets, tiles or large area rugs).
- 9) The exterior of the building appear inviting and accessible.
- 10) Calendars, clocks, and seasonal decor provide orientation to time and place.
- 11) Individuals have space they can withdraw into and control such as a bedroom or private sitting area.
- 12) Mirrors or shiny reflective surfaces (front of the microwave) may need to be covered or muted.

- 13) Objects that serve as effective cues to signal upcoming activities are set out without being moved by well-intentioned persons.
- 14) Furniture and decorations are kept in the same place so that features seem familiar. Individuals are supported in sitting in favorite locations.
- 15) Strong, constant lighting sources are available. Lights are turned on and left on in the late afternoon until individuals leave or go to bed so that a twilight effect is avoided.
- 16) Individuals are offered water periodically throughout the day.
- 17) Information in the form of pictures and key words are used to show who will be coming to support the person during a later time in the day.
- 18) Individuals have access to pictures of their family and friends to help them remember.
- 19) Individuals receive appropriate and comforting touch in the form of hugs, back rubs, hair combing, etc., as needed to help them feel connected and secure.

Safety Checklist

- 1) A first aid kit is available and well supplied
- 2) Secure places are designated for lost items (glasses, hearing aids, dentures, keys, wallet etc.)
- 3) Duplicates are available if possible.
- 4) A stove that may be turned off by valve or electric outlet is secured at night.
- 5) Protective covers are available or knobs may be removed from burners on a stove.
- 6) Matches and lighters are secured. Electrical equipment unplugged.
- 7) Water temperature is set to non-scald. Hot water faucets are color coded to minimize confusion. Knobs are replaced by easier-to-use- levers.
- 8) Smoke detectors are wired with a battery back-up in working orders.
- 9) Weapons and sharp objects are removed when needed.
- 10) Medicines and hazardous chemicals are locked up.
- 11) Rooms are well lit without tripping hazards such as small rugs or collectibles. Any rugs or mats present are secured to the floor.
- 12) Stairs have gates if needed.
- 13) Coverings for mirrors are available when needed.

14) Cords are moved out of the path of traffic. Sharp edges are padded.

15) Floors have a mat rather than a high gloss finish.

16) Windows may be locked as needed.

17) Clutter is removed from homes and vehicles.

Chapter 5 Feedback Exercise

Describe how to structure the environment to allow the person with developmental disabilities to “age-in-place” as they experience the decline in perception that characterizes Alzheimer’s disease.

1. Floors:
2. Noise:
3. Furniture:
4. Kitchen:
5. Doors/Exits:
6. Walls and decorations:
7. Bedrooms:
8. Lighting:
9. Bathrooms:
10. Staff supports:

References

Anthony, J. C., & Aboraya, A. (1992). The epidemiology of selected mental disorders in later life. In J. E. Birren, R. B. Sloane, & G. D. Cohen (Eds.), *Handbook of mental health and aging* (pp. 28-73). San Diego, CA: Academic Press.

Bee, H. L. (1996). *The journey of adulthood* (3rd ed.). Upper Saddle River, NJ: Prentice-Hall, Inc.

Dalton, A. J., Fedor, B. L., Patti, P. J. (1999). *Multi-dimensional observation scale for elderly subjects: Adapted for persons with Down Syndrome*.

Force, L., & O'Malley, M. (1999). Adult day services. In M. Janicki and A. Dalton, (Eds.), *Dementia and intellectual abilities*, (pp. 294-315) New York, Taylor & Francis.

Hamdy, R., Turnbull, J., Clark, W., Lancaster, M. (1994) *Alzheimer's Disease: A Handbook for Caregivers*, St. Louis: Mosby.

Hawkins, R. P. (1979). The functions of assessment: Implications for selection and development of devices for assessing repertoires in clinical, educational, and other settings. *Journal of Applied Behavior Analysis*, 12, 501-516.

Janicki, M., Dalton, A.,(1999). Aging and dementia. In M. Janicki and A. Dalton, (Eds.) *Dementia and intellectual abilities*, (pp. 6 and 448) New York: Taylor & Francis.

Martin, G., & Pear, J. (1999). *Behavior modification: What it is and how to do it* (6th ed.). Upper Saddle River, NJ: Prentice-Hall, Inc.

Milbradt, J., Carlson, M.A., Riley, A. (1999). *Alzheimer's disease and developmental disabilities, an alzheimer's training program*, Edina, MN: Alzheimer's Association, Minnesota - Dakotas Chapter.

Robinson, A., Spencer, B., & White, L. (1989). *Understanding difficult behaviors*. Ypsilanti, MI: Geriatric Education Center of Michigan, Eastern Michigan University.

Ruocco, L. E. (1996). *Ruocco geriatric assessment for persons with mental retardation*. Lruocco191@aol.com; 314-569-2492.

Udell, L. (1999). Supports in small group home settings. In M. Janicki, & A. Dalton, (Eds.) *Dementia and intellectual abilities*, (pp. 294-325) New York: Taylor & Francis.

Urlings, H., Schroyenstein, L., & Maaskant, M. (1998). *Face to face, respectful coping with dementia in older people with intellectual disability*, European Network on Intellectual Disability and Aging, The Netherlands.

Warner-Lambert (1994). *Caring for the Caregiver*, Warner-Lambert Company.

Winninger, J. (Producer & Director), & Harper, D. C. (1991). *Topics on aging: Mental illness and mental retardation in the elderly*. Bloomington, IN: Indiana University.

Feedback Answers

Chapter 1 Feedback Answers

1. is not
2. dementia
3. increases
4. autopsy
5. antecedents; consequences
6. Slow; sudden
7. medical; behavioral
8. quarterly
9. People with higher levels of intellectual functioning are generally more adept at problem solving and making accommodations for declining capacity during the early stages of the disease.
10. Lack of exercise and poor nutrition
Lower level of education
Routine daily activities
Presence of disease (high blood pressure, cardiovascular disease, epilepsy)
Down syndrome
Head injury, especially severe or multiple injuries
History of Alzheimer's disease in his or her family
11. Mental Illness
Depression
Several medical conditions (i.e., stroke, drug intoxication, anemia, thyroid disorder, anemia).
(See pages 1 and 4 in the module)
12. Videotapes can be used to collect baseline information to identify changes in behavior and abilities over time.
13. Interviews with people familiar with the consumer
Review medical history and tests
Informal and formal assessments conducted at regular intervals.
14. Mobility, dressing, bathing, personal hygiene, routine memory, wandering, incontinence, orientation, leisure time, routine performance, gait, time, challenging behavior, eating, sleep, personality, vocational, time on task, and memory recall, orientation, depression, irritability, social withdrawal.
15. To aid the physician in determining the progression of the disease .
To help the doctor rule out any physical causes for the symptoms.
It may be possible to predict how fast the rate of change will happen over time.
Aids in reliability of the assessment. Gives more objective complete picture of the person's functioning.
16. If the person's behavior has marked negative effect upon others in the residence.
If the person's overall deterioration exceeds the level of care provided in the current situation.

Chapter 2 Feedback Answers

1. death
2. eight to twelve

3.
 - a. 1
 - b. 1
 - c. 2
 - d. 3
 - e. 2
 - f. 1
 - g. 3
 - h. 2
 - i. 2
 - j. 1
 - k. 2
 - l. 1
 - m. 1
4. Individuals lose their ability to recall, perceive, plan, judge, and eventually to speak and move. This calls for a corresponding *rearrangement* of the care, supports and relationships that protect and enhance the quality of life for aging persons. The goal is to continuously adjust the care and supports needed by the individual to match the progression of the disease.
5. Habilitation; safe environment; active and connected; health and functioning.
6.
 - a. well learned or habitual tasks/steps
 - b. memory of past events
 - c. vision, hearing, movement
 - d. ability to persist at repetitive tasks
 - e. awareness of emotional tone in voices and touches
7. Scaffolded
8. Short
9. Bringing a favorite song from the person's past into a task or routine, often helps the person to be more willing to participate.
10. Many answers are correct. Some examples are: going for a walk, holding a puppy, listening to music, baking, dancing.
11. Mild physical activity can help individuals with Alzheimer's disease to sleep better, retain mobility and appetite, serve as a topic for conversation, counteract confusion in the wake/sleep cycle, and sustain interest in life. Activity may also prevent depression, constipation, and delay progression to a bed-ridden state.
12. Don't; cannot; cannot
13. Minimize; simplify; predictability; dignity
14. Water, mirrors, changes in light or noise levels
15. Provide adequate hydration and nutrition; prevent falls/retain mobility; prevent choking; maintain good hygiene; incontinence or constipation; seizures, difficulty with sleep/wake cycle and depression.
16. provide a walker early in the diagnosis, modify the physical environment (no throw rugs, etc.); let the person set the pace; training for caregivers in physical guidance techniques.
17. Bowel control
18. Grieve
19. nonverbal communication; contact
20. forget; ask

21. now
22. use past memories as a point of reference for conversation.
23. simple; one-step; yes/no; demonstration; real; the same words

Chapter 3 Feedback Answers

1.
 - a. To obtain immediate attention or affection
 - b. To fill a basic need such as hunger or thirst
 - c. To communicate a specific desire
 - d. To avoid something that is frightening, confusing, or overwhelming.
2.
 - a. Physical
 - b. Avoid
 - c. Break; soothing or calm; process; repeat
 - d. End
 - e. Calm; large
3. Use a shoulder-to-shoulder stance.
4. calm, distract; avoid
5. Too hot inside; trying to go somewhere; escape; searching for something, a loved one or caregiver who was out of sight; trying to find the bathroom; unable to separate dreams from reality; a reaction to a medication; may have gone to bed too early.
6. Avoid confrontation and showing anger - speak calmly, with acceptance and love. Approach the person from the front and begin to walk with them to provide direction and prevent disorientation. Slowly guide the person back toward home without turning him or her around directly. Talk to the person to distract him or her from the wandering behavior. Reassure the person as to time and place in a normal tone.
7. Team and appropriate agency committees.
8. Sundowning
9. Walk; snack; naps; cool; nightlight
10. With; personally; DON'T; simple and clear.
11. Extra light; see; hear; distraction; contradicting/arguing with the person; medications; reassurance.
12. Mirrors; doorways; **after**; distraction or reassurance; slowly; remove.
13. After the first time, reassure the person. It may be helpful to write the answer down or give the person a picture or a symbol with the answer to the question.
14. Tell the person that you are listening. Indicate by questions and comments that you hear what the person is saying, not if it is correct or incorrect.
15.
 - a. short; earlier
 - b. late afternoon; early evening
 - c. lights
 - d. visitors; noise
 - e. changes
 - f. reassurance and support
 - g. food; liquids
16. higher
17. 75%
18. differ

19. Tell the person you will return; leave an article for them to hold while you are gone; give the person something to occupy their attention while you are gone; ask another support person to stay with them while you are gone.

Chapter 4 Feedback Answers:

1.
 - a. active
 - b. nutrition
 - c. stimulation
 - d. socialization
 - e. supervision
 - f. safe
2.
 - a. Use; accommodate
 - b. Provide assistance
 - c. Mirrors, water, and quick movements
 - d. Tasks; directions
 - e. Prioritize
3. Serve favorite foods often; cook foods the way they like them; try five small meals; health shakes or supplements; finger foods for snacks; provide condiments even if food is pureed; add extra ingredients.
4. 30 minute walk; texture; water
5. visit
6. health
7.
 - a. Cut the food in the kitchen.
 - b. Use meal shirt rather than a bib.
 - c. Offer foods one at a time if needed to avoid confusion.
 - d. Go out to eat during non-peak hours when there won't be as much noise or confusion
 - e. Order the meal for the person in a restaurant if that simplifies it for the person and makes it possible for them to continue going out to eat.
 - f. Remove extra dishes and condiments from the table.
 - g. Make sure the person's dentures are in.
 - h. If you have to feed the person, wipe spilled food immediately & don't overfill the spoon.
 - i. Involve the person in doing what they can for as long as they can.
 - j. Use finger foods or spoons if the forks become unmanageable.
8. Confusion about when to go, where to go, or what to do on the toilet; medication change; and other health reasons.
9. Limit; schedule; bathroom; behaviors; easy to remove; commode.
10. Reminders to: use the toilet; shut the door; remove clothing; sit on the toilet; flush, wipe or clean properly.
11. Phobia (intense, irrational fear) of water; can't remember when they last bathed; can't remember how to bathe; fear of getting into the tub; fear of person reflected in the water.
12. Activity or event; simplify; favorite music; shower; consistent; frequency; after the person gets in; limit; stay with the person; privacy; rush; physical support.
13. Limited; fasteners; Velcro; elastic; loose; front or over-the-head; Velcro; eliminate; time; calm; in order they should put them on; explain how.

14. Have the person dress while seated; remain close to give support; do not put yourself in a vulnerable position while assisting if the person is combative; squat instead of bending to reach the persons feet.
15. lose; little/no

Chapter 5 Feedback Answers

1. Floors: Matt rather than gloss finish; different color than walls; no lines in floor pattern; no rugs, cords, or clutter that would create tripping hazards; different colored carpets or rugs distinguish activity areas.
2. Noise: televisions or radios are not left on in common areas; unnecessary noise sources are minimized.
3. Furniture: firm so person can get out easily; kept in the same place so that features seem familiar.
4. Kitchen: protective covers are available for the burners or knobs are removed; knives, sharp objects, matches and lighters secured. Electrical equipment unplugged.
5. Doors/Exits: clearly marked; levers instead of knobs; lead to secure areas inside or out where people can walk safely.
6. Walls and decorations: Calendars, clocks, and seasonal decor provide orientation cues; mirrors or shiny reflective surfaces are covered or muted; objects that serve as cues remain in place; people have access to pictures of family and friends.
7. Bedrooms: Individuals have private space; secure places found for easily lost items.
8. Lighting: Strong constant lighting sources available; lights are turned on and left on in the late afternoon.
9. Bathrooms: Water set to nonscald; hot water is color coded; levers instead of knobs; medicines and hazardous chemicals locked.
10. Staff supports: Water is offered periodically during the day; comforting touch provided.

Assessment Instruments