

Training for Caregivers of Individuals With Dementia

**Developed by Lake Region State College
for the
North Dakota Department of Human Services
Aging Services Division**

January 2006

PREFACE

The “North Dakota Alzheimer’s Disease Demonstration Project: Working Together” is being developed to implement a systems-change approach to save public expenditures by activating disease management efforts and helping families use community-based supports to significantly delay out of home placement of individuals with Alzheimer’s disease and related dementias.

The project focuses on building an alliance between the medical community, the community services network, and the North Dakota Family Caregiver Support Program to increase early dementia identification, treatment options, and caregiver respite.

This manual was developed by Lake Region State College to provide training for caregivers and other service providers as it relates to Alzheimer’s and other dementias. Completion of the training by the family caregiver and their respite care provider(s) will increase their knowledge and skills in caring for an individual with dementia and allow the family caregiver to access additional respite care services.

The project is funded in part by the Administration on Aging and granted through the North Dakota Department of Human Services, Aging Services Division. Dakota Medical Foundation is providing matching funds. Other partners, the Alzheimer’s Association Minnesota – North Dakota, Merit Care Medical Group, and St. Alexius Medical Center, are providing in-kind match.

TABLE OF CONTENTS

Explanation of Disease Stages	1
Recognizing Early Signs of Dementia	3
Basic Concepts and Guidelines for Caregiving	4
Goals of Caregiving.....	4
Behavior	4
ACT - not react.....	6
Prevention and Redirection Techniques.....	7
Agitation/Restlessness.....	7
Sundown Syndrome/Sundowning	7
Aggressiveness.....	8
Wandering.....	8
Hiding and Hoarding/Paranoia and Suspiciousness	9
Catastrophic Reactions	9
Hallucinations.....	9
Delusions	10
Repetitive Actions	10
Inappropriate Activities.....	11
Helping with Nutrition	12
Recreational Activities.....	13
Activity Chart.....	15
Environmental Issues.....	16
Safety Checklist	17
Communication Tips	18
Verbal.....	18
Non-verbal or body language.....	19
Family Dynamics.....	20
Family Caregiver	22
Grief	22
Stress.....	23
Depression.....	24
Information and Referral Sources.....	25
Alzheimer’s Association Minnesota – North Dakota.....	25
Eldercare Locator.....	25
211– Mental Health Association of North Dakota.....	25
North Dakota Family Caregiver Support Program.....	26
North Dakota Senior Info-Line.....	26
North Dakota Family Caregiver Coordinators.....	27
Appendix	28
Fact Sheet: Alzheimer’s Disease and Related Dementias	
Fact Sheet: About Behavioral and Psychiatric Alzheimer’s Symptoms	
Fact Sheet: About Alzheimer’s Association Safe Return	
Pre-Test/Post-Test: Training for Caregivers of Individuals with Dementia	

Explanation of Disease Stages

Cognitive dementia is a loss of intellectual functions such as thinking remembering, and reasoning that is severe enough to interfere with daily activities. Persons with dementia have trouble following directions, finishing sentences, finishing thoughts, and taking care of themselves. Some persons with dementia show signs of personality change, confusion, poor judgment, and behavior changes. Many people with dementia eventually grow worse and become unable to care for themselves.

Alzheimer's is a disease of the brain that causes a steady decline in memory. Alzheimer's is the leading cause of dementia. Scientists are not sure of the exact cause of Alzheimer's disease. Although we do not know its exact cause, we do know that it causes the death and malfunction of nerve cells called neurotransmitters that help to pass messages along the nerve pathways to the brain. No medical test can definitely diagnose the Alzheimer's disease.

Other related dementias include: Huntington's disease, Pick's disease , Parkinson's disease, Creutzfeldt-Jakob disease, multi-infarct or vascular dementia, and Lewy body dementia. More information about Alzheimer's disease and related dementias can be found in the Appendix. It is important to have a reliable diagnosis by a physician to provide proper care for an individual with dementia. An early and accurate diagnosis helps to identify reversible conditions, gives the individual with dementia a greater chance of benefiting from existing treatments, and allows more time to plan for the future.

Individuals progress through the stages of dementia at different rates. Onset is often subtle. However, there will generally be a continuous and progressive decline. As the disease progresses, the individual will become more dependent and require more direct supervision.

The following outlines stages of the progressive symptoms of dementia:

Stage One:

- Realizes something is wrong but cannot change it – they will hide or cover-up the problem
- Loss of recent memory (short term memory)
- Mild confusion, unable to concentrate or short attention span
- Mild communication problems
- Impaired judgment, makes poor decisions
- Personality and behavior changes
- Depression
- Loses interest in people or activities
- Pays less attention to grooming and hygiene
- Delusions

Stage Two:

- Increased memory loss
- Moderate to severe communication problems
- Poor judgment
- Loses impulse control
- Significant confusion – sensory/perceptual changes
- Repetition
- Difficulty in completing activities of daily living such as bowel and bladder control, incontinence
- Difficulty walking
- Sleep disturbances
- Increased behavior problems such as wandering, pacing, sundowning, catastrophic reactions, agitation, and hallucinations

Stage Three:

- Unable to complete activities of daily living, becomes totally dependant
- Very limited, if any, communication
- Does not recognize self or others
- Loses bodily functions – incontinent, minimal mobility
- More prone to infections
- Facial expression no longer change – flat affect
- Seizures



Recognizing Early Signs of Dementia

Early signs are often very subtle and hard to notice initially. The person recognizes something is wrong but will often deny it or try to cover it up due to embarrassment. They may become defensive and resist any help you might offer. Other signs might be:

- Minor forgetfulness
- Inability to learn new information
- Mood swings, crying
- Insomnia
- Changes in appetite
- Lack of energy
- Loss of interest in normal activities
- Simple things become difficult
- Self-confidence declines
- Become more indecisive and insecure

There are more than 70 conditions that can cause dementia; some may be reversible. It is important to see a doctor to determine if one of them is causing the dementia and can be treated. Some of these conditions include:

- Medications
- Infections
- Head injuries
- Nutritional deficiencies
- Sleep deprivation
- Anemia
- Brain tumors
- Hypothyroidism
- Depression
- Drug and alcohol abuse
- Pain
- Stress
- Strokes



Basic Concepts and Guidelines for Caregiving

Goals of Caregiving

The goals of caring for an individual with dementia are listed below:

- Protect the person from physical injury.
- Maintain independence as long as possible.
- Focus on what the person can still do.
- Provide physical and mental activities that the person can do.
- Support the person's dignity and self-esteem at all times.

Some suggestions for dealing with an individual with dementia are listed below:

- Although people with Alzheimer's and other cognitive disorders may exhibit childlike behavior, they are still adults, have the same needs, and should be treated with dignity and respect.
- Communicate in a normal manner. Assume the person can understand you.
- Allow more time for the person to think and act. Be patient.
- Create an environment that is peaceful and quiet, simple and uncluttered.
- Maintain a consistent routine.
- Try different approaches in your caregiving. Be flexible and creative.
- Keep the environment safe.
- Do not argue. Accept their reality.
- Watch and listen to the person to assess the needs.
- Find someone to talk to who understands your situation.

Behavior

It is important to understand the behavior of the person with dementia. Their actions, however inappropriate, are not deliberate or intentional; they are a result of the disease. When a person with dementia exhibits inappropriate behavior, do not try to argue or apply logic. There are other approaches to the situation that will lead to a better outcome. Many times you can influence the behavior by modifying the environment and your approach to the person.

One of the best ways to deal with an individual with dementia is to

- **Prevent** first
- **Gather** information second, then
- **Act** not react, and when possible use
- **Redirection** techniques (Redirection techniques will be discussed in the next section.)

It is better to prevent inappropriate behavior than to just react. The following steps may help caregivers prevent unpleasant moments:

- Be patient, calm, gentle, and loving.
- Take one step at a time.
- Communicate in a calm and loving manner.
- Don't confront the person or try to orient them to reality as it is an ineffective approach. Logic can *increase* fear or agitation in persons with dementia. For example, if the individual with dementia is seeing monsters, some caregivers literally "throw monsters out of the windows." This can be more helpful than arguing "There are no monsters".
- Maintain a calm and secure environment.
- Maintain a routine, especially times for meals, toileting, and bedtime.
- Modify the environment and your approach to meet the needs of the individual.

Stress often causes problem behaviors. Some things that can cause stress are: too much stimulation, noise or unpleasant sounds, glare or too much light, reminders of past experiences or places, too many directions or information. Caregivers can also inadvertently cause stress by speaking in terms they can't understand, speaking too quickly or too loudly, using touch or body language that is misinterpreted as threatening, or reminding the person of someone from the past.

Most behaviors have a cause and a solution. If prevention does not work, treat the behavior as a mystery and gather clues to what is causing it. Use the following techniques to gather these clues:

- Listen for repeated or out of place words.
- Read body language and voice tone.
- Watch what the person does.
- Discuss the person's actions with family members to look for patterns or outbursts.
- Have someone else observe the behavior.
- Determine why the behavior occurs.
- Determine under what circumstances the behavior occurs; are there any antecedents? – What happens before the reaction?

ACT - not react

One way to remember to look for clues to a behavior is the acronym ACT. By remembering to **ACT** not react, you may be able to help yourself and the individual with dementia avoid problem moments. **ACT** stands for the following:

Ask questions such as

- What's the problem?
- What happened just before the inappropriate reaction?
- When does it happen?
- Where does it happen?
- How does it affect the person and others?
- Who might have additional information?

Collect information from others

- Ask them to observe the person's words and actions.

Treat the behavior

- Protect yourself and the person with dementia from immediate danger.
- Trial and error solutions - if a solution doesn't work, try new things.

Remember that the behavior of the individual with dementia is not good or bad, it just 'is'. Learn to live with the behavior if it is not upsetting or unsafe for the person.

Additional information on behavior is located in the Appendix.

Prevention and Redirection Techniques

By redirecting an individual with dementia, you may be able to avoid or delay outbursts and inappropriate behaviors. Conversations and actions of a person with dementia can be redirected with gentle distraction or by suggesting a desired activity. Providing food, drink, or rest can be a redirection. Always offer suggestions for new activities or conversation topics in a reassuring tone. Never focus your redirection on reprimand or by saying “no” or “don’t do that”. The most important thing to remember is that each person is unique. Activities and conversations that successfully redirect one person may not work with someone else.

Agitation/Restlessness

The individual with dementia can become mentally and physically excited. This is usually a sign of underlying problems such as boredom, fatigue, or illness. You can help to settle the agitated person by using the following techniques:

- Offer reassurance, move to a quiet area.
- Maintain a daily routine.
- Maintain a routine of activity and exercise.
- Decrease confusion in the environment such as noise, new people or places.
- Monitor and limit caffeine intake.
- Approach the person slowly and calmly.

Sundown Syndrome/Sundowning

Sundown Syndrome, referred to as sundowning, often occurs in the late afternoon or evening. During this time the individual with dementia may be more sensitive to stress. To keep the individual from experiencing sundowning you may try the following:

- Schedule appointments and more demanding activities in the morning.
- Reduce stimulation:
 - Play quiet music
 - Turn off TV
 - Keep activities low-key
- Adjust lighting levels, use low light or a night light.
- Offer reassurance and companionship.
- Toilet, offer food, and a nap in the early afternoon.
- Maintain a bedtime ritual - having a set routine helps the individual remain calm.

Aggressiveness

Individuals with dementia may become physically or verbally combative. This usually occurs as a result of anger. Most individuals will exhibit some warning signs when they begin to feel agitated. The signs may include:

- Muscle tension – clenched jaw or fist.
- Glaring eyes, rigid posture.
- Pacing, rocking, kicking.
- Speech - loud, rapid, changeable.

To handle an aggressive individual, explain what you are going to do before you do it and repeat it as often as needed. Use good communication skills, and do not respond in anger. Don't stand over or talk down to the person. Use a soothing voice and reassure them it is okay to be angry. Allow the individual to make decisions and choices if they are able. Try your best to maintain a routine or schedule. Keep your movements calm and slow, use touch if you are allowed and a body language that is non-aggressive. Stand at an angle beside the individual with your hands at your side.

If it seems that these tactics are not working and the individual is becoming increasingly aggressive, if possible, leave the area and come back later. If needed, protect yourself. Never corner the individual or turn your back on them and always stay an arm's length away.

Wandering

Wandering is a common behavior among individuals with dementia. Their wandering is often goal-directed. The individual may feel a need for exercise, they may be bored or feel stressed. Dementia itself causes a disturbance in the internal clock of the individual leading to sleep disruptions that can lead to nocturnal wanderings.

To prevent wandering, provide a safe environment. Lock all doors. If possible place alarms on doors. When available, let the individual wander in a safe, enclosed environment. To guide the individual back to a safe place, fall in step with them and gently divert their attention to the direction you want them to go. Let neighbors and police know about the individuals' potential to wander and how they can help. Restraints are not an acceptable method of preventing wandering.

Consider the following when caring for individuals prone to wandering:

- Maintain a regular activity and exercise program.
- Look for triggers – time of day, hunger, response to your behavior.
- Enrollment in the Safe Return Program, a program available through the Alzheimer's Association (additional information can be on page 25 and in the Appendix).

Hiding and Hoarding/Paranoia and Suspiciousness

Hiding and hoarding are signs of basic insecurity. When hiding and hoarding are noticed, remember not to confront the person or use logic to correct the behavior. A good redirection activity is to provide a “rummaging” drawer and to provide activities that keep their hands busy. Never speak to the individual in whispers or act secretly - speak directly to them. With an individual that exhibits hiding and/or hoarding behaviors it is wise to:

- Secure valuables in locked places or out of reach.
- Check wastebaskets before emptying.
- Keep an extra set of keys, glasses, etc.
- Protect the person from embarrassment.

Catastrophic Reactions

Emotional outbursts or overreaction to situations can be common in individuals with dementia. Such outbursts are signals of emotional overload. They are influenced by the caregivers approach to the individual and the environment. During such a reaction, reassure the person, stay calm and give them time to recover. Gently divert the individual to a calm activity or environment and reduce any noise or confusion in the area. Make your approach slow, simple, and calm.

Hallucinations

Individuals with dementia will sometimes see, hear, taste, touch, or smell things that do not exist. Individuals may see the face of a former friend in a curtain or may see insects crawling on their hand. In other cases, they may hear people talking to them and may even talk to the imagined person.

As long as the hallucinations are not upsetting to the person or others around them, no response is needed from the caregiver.

If the hallucinations are upsetting the individual, the caregiver should consult the individual's doctor. Hallucinations could be related to a medical problem or related to the individual's medication. Have the individual's eyesight or hearing checked. Also make sure the individual wears his or her glasses and/or hearing aid on a regular basis.

The caregiver should offer protection or respond in some way that is calming to the individual. Do not try to reason with the person, apply logic, or argue. Remember, the hallucinations are real in their reality. The caregiver should offer reassurance and gently divert attention by using redirection techniques.

Delusions

Unlike hallucinations, delusions are **beliefs** that are illogical or wrong. A delusion is defined as a false idea, sometimes originating in a misinterpretation of a situation.

The same techniques are used to deal with delusions as hallucinations - go along with the individual's reality, offer reassurance, and do not confront the individual regarding their incorrect beliefs.

Repetitive Actions

Repetitive actions or questions are a common behavior of individuals with dementia. Repetitive actions may include hand wringing, clapping, repeating the same question or phrase, singing the same song over and over, wringing a towel, etc.

Repetitive actions may be caused by the illness and its effects on the brain. Some medications can cause side effects that result in repetitive movements or restlessness. If this is suspected, the individual's physician should be contacted.

Individuals with dementia also have problems expressing physical needs such as thirst, needing to go to the toilet, or hunger. This too, may result in increased agitation.

Repetitive questions may be the individual's efforts to regain a feeling of control over an environment that has become increasingly confusing.

Individuals with dementia may become overly dependant upon their caregivers. They may be unable to judge the amount of time their caregiver is away from them and ask repeatedly for their caregiver.

There are many ways to cope with repetitive actions and questions but most importantly, if the action is not harmful or upsetting to the individual or those around them, it may be best to overlook it. The following is a list of suggestions:

- Redirection techniques such as a walk, food or favorite activity.
- Use a calm voice when responding to repeated questions.
- Arrange a medical examination to determine the possible cause, i.e. a side effect of medication, physical illness, etc.
- Do not remind the person that they have already asked the question - instead, divert them to another activity. For the person who is still able to read, try written reminders.
- Use other memory aids such as large, clear clocks and calendars and white board with the daily schedule written on it.
- Try not to discuss plans with the individual ahead of time - discussing just before the event may avoid agitation and repeated questioning.
- Try to keep the routine as consistent as possible as this is reassuring.

- Sometimes certain things in the environment may trigger repeated questions, i.e. seeing a hat or coat may make the individual ask repeatedly to go out. It may help to remove such triggers.
- Repetitive movements may be reduced by giving the individual something else to do with their hands such as a soft ball, paper to tear up, and clothes to fold.
- When an individual becomes stuck on one step of a task, use of touch or pointing may help to cue the individual to move on to the next step.
- Repetitive questioning may be an attention-seeking device - giving your full attention and attempting to respond to their emotional needs may help to break the pattern.
- Take into account the fact that the individual with dementia may have lost the ability to judge time - the caregiver may have only been absent for a few minutes but the individual believes it has been hours. Respond to this by acknowledging the feelings of uncertainty and insecurity.

Inappropriate Activities

Sometimes the individual with dementia will engage in inappropriate public behavior such as removing clothing, exposing self, masturbating, or touching of self and others. Remember the person is confused and disoriented. Do not overreact, scold, argue, or try to reason but do try to remain calm. Remember the client has lost the sense of right and wrong and is not behaving this way on purpose. If the client undresses, provide a robe or dress him/her. Dressing the individual in different clothing such as ones without zippers or buttons; ones that aren't as easily removed can be helpful. If the individual is in a public place, distract him/her and remove them from the scene. Find something else that will keep the individual occupied. Plan ways to distract the individual so you are prepared. Distracting is better than confronting. Remind the individual of appropriate behavior. Provide appropriate touch to show that you care and value the individual.

Helping with Nutrition

Many people with Alzheimer's have problems eating. An individual might lose his or her appetite or the ability to evaluate if food is too hot or too cold. In addition, an individual might forget that he or she has eaten and ask you for another meal.

The individual may be experiencing physical difficulties that are causing the changes in eating habits. Sores in the mouth, poor-fitting dentures, gum disease or dry mouth may make eating difficult.

To ensure the individual with dementia is receiving the proper nutrition you must work to prevent eating and nutrition problems. Consult with the individual's physician and/or dietitian for guidance.

The following tips will help you keep them eating properly:

- Use vitamin supplements only on the recommendation of a physician. Monitor their use.
- Don't serve steaming or extremely hot foods or liquids. Remember, the individual might not be able to tell if the food or beverage is too hot to eat or drink.
- Limit or eliminate highly salted foods or sweets if the individual has a chronic health problem, such as diabetes or hypertension.
- Control potential weight gain. If the individual always seems hungry, serve smaller portions of food at more frequent intervals. Fill the gaps between regular meals with healthy snacks.

Without patience and observation, mealtime can become a painful experience for both caregiver and the individual with dementia. Here are a few more tips to make mealtime more enjoyable:

- Put one food at a time on the plate if too many are confusing.
- Do not use plastic utensils.
- Provide finger foods if the individual can't use utensils or sit up.
- Prepare foods – cut meat, butter bread.
- Remove non-edible items such as napkins.
- Make sure all food taken is swallowed.
- Offer fluids frequently.
- Offer between meal snacks when needed.
- Maintain a quiet and calm environment.
- Supervise and cue as needed.

Recreational Activities

Recreational activities are an important part of a healthy life with dementia. The benefits of recreational activities include:

- improves eating and sleeping patterns
- lessens wandering, restlessness, anxiety
- improved socialization and cooperation
- delays deterioration of skills
- eases behavior management
- source of pleasure and rewards

It is important to find activities that are meaningful and provide success for the person. Meaningful activities create a sense of usefulness and accomplishment, and promote self-esteem. To promote this, match activities to the abilities and interests of the individual. Focus on enjoyment, not achievement. Be sure to observe the individual's behavior during the activity to watch for signs of boredom or tiring. Keep activities adult-like but you may have to use children's materials. Do a variety of activities to hold their interest. Alternate active and passive activities. Examples of activities are listed below.

- card games or board games
- reminiscing and memory stimulation
- music
- crafts and art projects
- outings
- gardening
- pets
- visits from others
- spiritual activities



Activities for the individual with dementia should be structured but flexible. Be sure to allow the right amount of time for the activity. Spending too much time on one activity will quickly tire the person with dementia. Find activities that fit the mood and energy level of the individual throughout the day (*see chart on page 15*). Always make sure there is enough space to do the activity without injury.

Properly monitored physical exercise is also beneficial for the individual with dementia. The benefits of exercise include decreases in restlessness and agitation, better sleep, and a possible decrease in the need for tranquilizer medications. Regular physical exercise will also help maintain the individuals physical abilities, allowing them a larger sense of independence and mobility.



Always check with the individual's doctor before starting any exercise program. Be sure the individual is wearing comfortable clothes and shoes. Watch for signs of fatigue as people with dementia may tire more easily. Offer fluids after each exercise session. The list below gives several examples of low impact exercise:

- walking
- range of motion exercises
- shuffleboard
- balloon toss – back and forth or over net
- parachute
- scarf rhythms
- bowling
- hitting ball with a bat

Activity Chart

1) Waking hours (low key)

- Personal cares
- Reading paper
- Discussing day ahead
- Having cup of coffee

2) Early morning (quiet)

- Clipping coupons
- Folding laundry
- Winding yarn balls
- Craft projects

3) Late morning (more active)

- Group exercises
- Board Games
- Meal prep – set table, pour milk
- Outside walks
- Individual projects

4) Lunchtime/early afternoon

- Eating and sharing
- Resting/napping
- Helping with serving
- Helping with clean up

5) Mid afternoon (active)

- Physical game skills
- Exercising, walking
- Music: singing along, dancing, exercising
- Crafts
- Memory stimulation games
- Cleaning house

6) Late afternoon (quiet)

- Reminiscing
- Helping with meal prep
- Checkers
- Watering plants

7) Dinnertime

- Meal prep, serve, clean up
- Eating and sharing

8) Early evening (quiet)

- Soothing music
- Walking through neighborhood
- Reminiscing
- Evening cares – washing and dressing for bed

9) Other examples of useful activities:

- Winding balls of yarn
- Polishing silverware
- Sorting buttons
- Putting coins into rolls
- Folding laundry
- Shelling nuts
- Cutting out coupons
- Meal preparation
- Watering plants
- Folding and stuffing envelopes, stapling, applying labels
- Dusting furniture, sweep floor
- Organizing closet of drawers
- Washing and drying dishes

Environmental Issues

Environment can affect behavior. The individual with dementia needs an environment that is homey and safe. It is the caregiver's responsibility to ensure the safety of the environment as the individual with dementia has a diminished sense of judgment.

There are three main concerns: safety, mood, and personal/social concerns. Below are points to consider in each of these areas. A checklist that may be used to inspect the environment can be found on page 20. It may be helpful in finding areas that need updating or securing.

- Safety
 - have emergency numbers on hand
 - complete checklist

- Mood
 - color
 - lighting – from several sources
 - sound – reduce noise
 - familiar furniture and objects

- Personal/Social
 - private area that is safe and secure
 - quiet place if the individual needs to calm down
 - furniture arrangements should promote social interaction



Safety Checklist

Kitchen precautions:

- Proper storage of:
- ___ knives, utensils, gadgets; toaster, grill, etc.
 - ___ remove controls for stove, cover burners
 - ___ locks on fridge and cupboards
 - ___ turn hot water heater down
 - ___ cover for garbage disposal

Bathroom precautions:

- Proper storage of:
- ___ shavers, blow dryers, cosmetics, medicines, etc.
 - ___ non-skid mats in tub or shower and on floor
 - ___ safety rails
 - ___ use shower chair
 - ___ monitor water temperature

Fall precautions:

- ___ remove scatter rugs
- ___ keep pathways clear of clutter
- ___ adequate lighting, non-glare
- ___ don't move furniture around
- ___ safety rails in halls and stairways
- ___ gates or locks to keep person out of unsafe areas

Visual aids:

- ___ night lights placed throughout home
- ___ cover door knobs with cloth the same color as the door;
use childproof knobs
- ___ camouflage doors by painting them the same color as
the walls
- ___ use black tape or paint to create a two-foot black
threshold in front of the door

General:

- ___ post emergency numbers by phone
- ___ lock doors and windows
- ___ cover outlets
- ___ working smoke detectors
- ___ hot water heater secured

- Proper storage of:
- ___ chemicals: cleansers, pesticides, paint
 - ___ medications – childproof caps
 - ___ sharps – scissors, glass, knives
 - ___ first aid supplies
 - ___ yard tools

Communication Tips

As the individual progresses through the stages of Alzheimer's disease or related causes of dementia, communication will become increasingly difficult as verbal abilities decrease.

Individuals in the early stages of dementia experience standard conversational responses and social conversation that is well preserved but may exhibit longer pauses, a tendency to wander off topic, or trouble recalling names of people, places or things.

Middle stages of dementia may bring difficulty finding words. The individual may use less complex words and may have difficulty following directions. For most people in the middle stages, reading is still preserved.

As the dementia progresses, the individual may use words inappropriately (very much like a stroke victim), may have trouble rationalizing, reasoning, interpreting data, or making decisions. Because communication has become difficult, the individual may become frustrated or angry, which further decreases their ability to communicate.

Below is a list of techniques to help in communicating with an individual with dementia:

Verbal

- Say the Individual's name and identify yourself.
- Relay your message in the simplest terms.
- Speak slower and allow more time for the response.
- Give a positive aspect to your message.
- Make statements instead of asking questions.
- If you have to ask a question, be specific.
- Give directions one-step at a time.
- Talk to the Individual as an adult, NOT a child.
- DO NOT reason or use logic.
- Assist with finding words.
- Answer questions in a calm, reassuring manner.
- Erase the words "Don't you remember" from your vocabulary.
- Go along with the Individual's reality – go to their time and place.
- Repeat what the individual said.
- It is okay to talk about the past.
- Individualize the conversation.
- Continue to communicate even if there is no response.

Non-verbal or body language

- Make and maintain eye contact.
- Observe the actions of the individual and listen to words.
- Be aware of your own body language.
- Speak in a pleasant tone of voice.
- Use facial expressions – smile.
- Use appropriate touch.
- Use gestures – body movements.
- Observe the individual's body language for signs of understanding, fear, frustration, anger, etc.



Family Dynamics

The early stages of dementia may include a change in cognition and may result in subtle changes in family dynamics. Family members may become aware of memory loss, repetitive questions, depression, or some perceptual changes. Some family members may minimize or deny problems, risky behaviors or dangerous situations exhibited by the ailing family member. Long distance family members may notice or recognize changes in the individual's behavior more readily than those family members close to the individual. This can create family conflicts. The increasing symptoms can cause frustration and anger within the family unit as the individual slowly loses memory, perception, and abilities. Family members may feel sadness or anger about changes in a loved one's personality and behavior. Denial, and the suggestion that these changes are due to the aging process, may delay a formal diagnosis and treatment options.

Family members may become frustrated and hurt as their loved one loses abilities and changes with the stages of dementia. They often feel helpless as the individual declines. They may be confused about how people get the disease and why the individual behaves differently. Family members may also worry that they or other family members will get the illness.

Younger family members especially may become angry and frustrated at the need to repeat activities or questions. They may become frightened of the behaviors that the individual with the disease exhibits. Younger family members may also feel jealous and resentful of the increased amount of time and attention that is given to the individual with dementia. They may feel embarrassed to have friends or visitors to the home.

It is common for younger family members of the individual with dementia to exhibit the following symptoms of stress:

- Withdrawal from the individual with dementia.
- Perform poorly in school.
- Spend more time away from home.
- Complain about vague physical ailments such as stomachache or toothache.
- Spend less time with friends and more time alone.

There are some ways to prevent those stressors or help to deal with them. Explain the disease process and why the individual with dementia acts the way they do. Young people often come up with unique ways of dealing with situations, so ask their opinion. Pick out one thing that upsets the younger person the most and figure out how to change that one thing. For instance, if loss of privacy is the most important, put a lock on the door. Try to find a space where the younger person can be alone or spend time with friends.

Find someone for them to talk to – parent, teacher, relative, church member, doctor, or counselor. Determine if there is a support group just for younger people or start one if

necessary. Suggest the younger person join a group like Scouts, church, or an athletic team to spend time with people the same age and have fun.

Caring for an individual with dementia is both physically and emotionally exhausting. Caring for the individual with dementia can also be costly in terms of time and money. At some point, family members may feel anger and resentment toward the individual and this may lead to a feeling of guilt.

Family members may also feel guilty if they can't help as much as is needed. They may have their own children and jobs and are unable to spend as much time caring for their family member as they would like.

The first stage of care for the individual with dementia must include providing education to the family members as well as assessing function, reviewing needs, and determining treatment options. Involve all family members in the diagnosis and assessment process, family discussions and decisions, meetings with health professionals, and group meetings. Education involves giving information about the disease and its progression, as well as about family care team members and their roles, responsibilities, and functions. It is up to the individual with dementia, caregiver, and family members to assess function and identify treatment options together.

Information regarding support systems for family members should be obtained as early in the process as possible. A support system for family members is as important as the support system for the individual with dementia. Contact the local Alzheimer's Association chapter, local health care facilities, and social service organizations to locate support groups in the immediate area. The emotional and physical reactions to the stress of a family member with dementia are listed in the next section. Although experienced to a greater degree by the primary caregiver, these feelings can be experienced by all members of the family.

Family Caregiver

Taking care of a family member can be a rewarding experience and, at the same time, a difficult one. In order to take care of that family member, you need to first care for yourself. The family caregiver often puts herself/himself last. Doing so may result in problems not only for the caregiver as it may also affect the type of care provided to the individual with dementia. Following are some suggestions that should help you take care of yourself.

Learn how to properly care for your family member. Get training so you know how to perform skills. Correctly performing care tasks will make your job easier and safer.

Practice healthy habits such as eating a balanced diet, limiting intake of caffeine and alcohol, not smoking, regularly exercising, getting adequate sleep, and seeing your doctor when necessary.

Get help when you need it. Don't try to do it all by yourself. Those who might help you are other family members, friends, neighbors, social worker, minister and church members. Arrange for some time away from your family member. Join a support group so you have contact with people experiencing the same things you are. Go out to lunch, to church, a movie, or even a walk.

Do something relaxing. It's important to take a little time and do what you enjoy doing. It will rejuvenate you and allow you to be a better caregiver.

Remember that you probably can't control your situation, but you can control how you react to it. Try to be optimistic and look for the positive. Have pride in yourself and be proud of what you do. It really is your choice to provide care for your family member.

Watch for signs that you are stressed: irritability, loss of energy, weight changes, difficulty making decisions or concentrating, sleeping difficulties, loneliness, change in attitude, or drug/alcohol excess. See your doctor or a counselor to help you pinpoint the stressor and what you can do to ease your stress level.

Grief

It is common for family caregivers to go through the typical stages of grief. Watching a loved one succumb to dementia is an emotional process that can leave the caregiver grieving for "what used to be". The following is a list of the stages of grief. These feelings are normal and should be expected as the abilities of the person with dementia decline.

- Denial – about the illness and its effect on the individual who's been diagnosed.

- Anger – at the individual with the illness or others; angry that treatments and cures do not currently exist and that others do not understand what is going on.
- Bargaining – the family caregiver may try to bargain in a spiritual way or begin believing if they sacrifice in certain areas of their own life it may help the individual with dementia.
- Depression – begins to break the spirit of the family caregiver and affects the ability of the caregiver to hope.
- Acceptance – that the illness has affected the individual and this will not change, the caregiver will accept the changes and understand the individual is no longer acting rationally or as they were before the illness.

Stress

Caring for a family member with dementia can be emotionally, physically, socially, and financially stressful. This stress can cause illness in the family member/caregiver caring for the individual. Some common causes of stress are listed below:

- Burden of care, communication, behaviors.
- Loss of personal freedom and privacy.
- Financial burden.
- Feelings of guilt or denial of negative feelings.
- Lack of acknowledgement of care provided.
- Physical needs required to care for person.
- Experiencing depression and grief over ongoing losses and impending death.
- Change in family roles..

There are many ways of coping with the stress caused by caring for a dependent family member. Some tips for dealing with stress are listed below; however it is important to remember to seek help. Family caregivers can get help from other family members, health care professionals, or support organizations.

- Identify what causes the most stress and minimize exposure to those situations.
- Continue to do things for yourself, watch your diet, exercise and get plenty of rest. Use respite services and take time off for yourself.
- Avoid the “I should” syndrome, realize you are only human and can only do the best you can, give yourself credit and do not feel guilty about what you cannot do.
- Take pride in your accomplishments.
- Practice strategies that help you cope, relaxation techniques, breathing techniques, periodic breaks, exercise, or respite care.
- Seek an understanding doctor who will educate you about your family member’s condition, now and in the future. An understanding doctor will

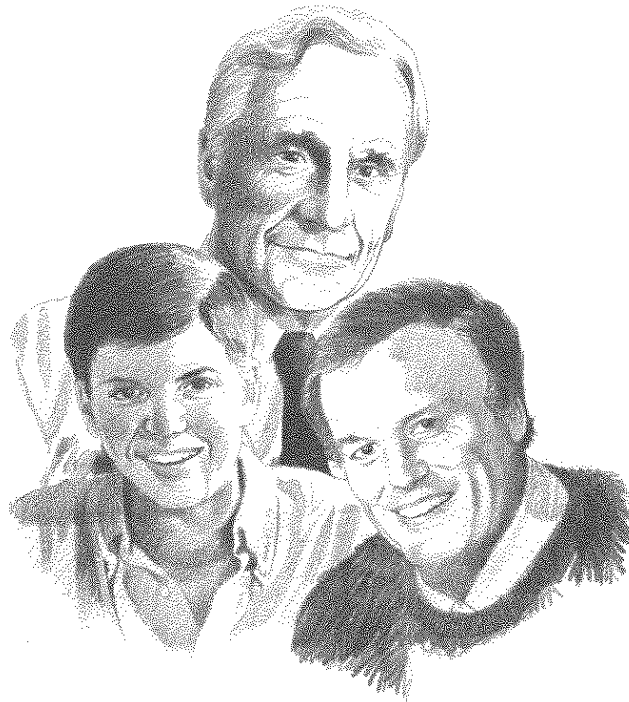
also be concerned with the health of the caregiver and family members and will make referrals appropriately.

- Join a support group.
- Seek spiritual support.
- Seek sound financial and legal help, discuss issues related to power of attorney, living wills and trusts, costs related to future medical care, housing, and other key considerations.

Depression

The stress of caring for a family member with dementia may cause depression in the caregiver. Some symptoms of depression include sadness, feelings of hopelessness, inactivity, withdrawal and decreased interaction with others, poor concentration and attention, and insomnia or excess sleep. If the family caregiver is experiencing any of these symptoms it is important to seek professional help immediately.

Treatments for depression can include antidepressant medication, stress management, and counseling or support groups.



Information and Referral Sources

Alzheimer's Association Minnesota – North Dakota

The Alzheimer's Association is the leader in providing reliable information about Alzheimer's and related dementias. The Association has created supportive programs and services for families, increased resources for dementia research; and influenced changes in public policy.

The Alzheimer's Association Minnesota – North Dakota provides services in North Dakota through offices located in Fargo and Bismarck.

Gretchen Everson, Eastern ND Director
4357 13th Avenue South, Suite 203
Fargo, North Dakota 58103
Phone: 701.277.9757
Cell: 701.799.2879
E-mail: Gretchen.Everson@alz.org

Kristi Pfliger-Keller, Western ND Director
1223 South 12th St, Suite 7
Bismarck, North Dakota 58504
Phone: 701.258.4933
Cell: 701.426.3177
E-mail: Kristi.Pfliger-Keller@alz.org

The Alzheimer's Association Minnesota – North Dakota website can be accessed at www.alzmdak.org. Contact can also be made by calling the toll-free HELPLINE at 1.800.232.0851.

Currently, the Alzheimer's Association Minnesota – North Dakota has a limited amount of funds available to offset costs of enrollment in the **Safe Return Program**. Call the toll-free HELPLINE for more information.

Eldercare Locator

A nationwide directory-assistance service designed to help older individuals and care partners locate local resources can be accessed by dialing 1.800.677.1116.

211 – Mental Health Association of North Dakota

Dialing "211" allows you to access statewide information and crisis assistance. The Mental Health Association of North Dakota operates the service. An on-line resource library is also available at www.mhand.org

North Dakota Family Caregiver Support Program

The North Dakota Family Caregiver Support Program (NDFCSP), funded under the Older Americans Act, provides a system of support services to help informal caregivers of older adults and grandparent/relative caregivers who are caring for children.

Services provided through the NDFCSP include:

- Information – includes public education and assistance in accessing local services.
- Assistance – through a trained Caregiver Coordinator to help the caregiver assess his/her needs, establish an option plan, and arrange for support services.
- Individual or Family Counseling, Organization of Support Groups, and Individual Training – by qualified professionals who will provide advice, guidance and instruction about options and methods of accessing caregiver support and providing care.
- Respite Care – provides temporary relief to caregivers who provide 24-hour care to older adults who need assistance with at least two everyday activities or who have cognitive impairments. Respite is also available to older adults caring for children age 18 or younger so a caregiver can take a break or deal with an emergency situation. Respite care can be provided in the home or at an adult/child day care or other facility.

Caregiver Coordinators are listed on the following page. Contact the Caregiver Coordinator nearest you to access services.

North Dakota Senior Info-Line

The North Dakota Senior Info-Line, operated by the North Dakota Department of Human Services, Aging Services Division, provides free and confidential information to assist the caller in accessing services anywhere in the state.

This information and assistance service can be accessed by calling the nationwide toll-free number, 1.800.451.8693, or e-mailing at the following address:

dhssrinf@state.nd.us

**North Dakota Family Caregiver Support Program
Caregiver Coordinators
January 2006**

<p><u>REGION I</u> Karen Quick, Caregiver Coordinator Northwest Human Service Center 316 2nd Avenue West PO Box 1266 Williston, ND 58802-1266</p> <p>Telephone: 774-4600 Toll Free: 1-800-231-7724</p> <p>Divide, McKenzie, Williams</p>	<p><u>REGION V</u> LeAnne Thomas, Caregiver Coordinator Southeast Human Service Center 2624 9th Avenue SW Fargo, ND 58103-2350</p> <p>Telephone: 298-4500 Toll Free: 1-888-342-4900</p> <p>Cass, Ransom, Richland, Sargent, Steele, Traill</p>
<p><u>REGION II</u> Theresa Flagstad, Caregiver Coordinator North Central Human Service Center 400 22nd Avenue NW Minot, ND 58703</p> <p>Telephone: 857-8500 Toll Free: 1-888-470-6968</p> <p>Bottineau, Burke, McHenry, Mountrail, Pierce, Renville, Ward</p>	<p><u>REGION VI</u> Carrie Thompson-Widmer, Caregiver Coordinator South Central Human Service Center 520 3rd Street NW (PO Box 2055) Jamestown, ND 58402-2055</p> <p>Telephone: 253-6300 Toll Free: 1-800-260-1310</p> <p>Barnes, Dickey, Foster, Griggs, LaMoure, Logan, McIntosh, Stutsman, Wells</p>
<p><u>REGION III</u> Kim Locker-Helten, Caregiver Coordinator Lake Region Human Service Center PO Box 650 200 Highway 2 SW Devils Lake, ND 58301</p> <p>Telephone: 665-2200 Toll Free: 1-888-607-8610</p> <p>Benson, Cavalier, Eddy, Ramsey, Rolette, Towner</p>	<p><u>REGION VII</u> Judy Tschider, Caregiver Coordinator West Central Human Service Center 600 South 2nd Street Suite #5 Bismarck, ND 58504-5731</p> <p>Telephone: 328-8888 Toll Free: 1-888-328-2662</p> <p>Burleigh, Emmons, Grant, Kidder, McLean, Mercer, Morton, Oliver, Sheridan, Sioux</p>
<p><u>REGION IV</u> Raeann Johnson, Caregiver Coordinator Northeast Human Service Center 151 South 4th Street, Suite 401 Grand Forks, ND 58201-4735</p> <p>Telephone: 795-3000 Toll Free: 1-888-256-6742</p> <p>Grand Forks, Nelson, Pembina, Walsh</p>	<p><u>REGION VIII</u> Michelle Sletvold, Caregiver Coordinator Badlands Human Service Center 200 Pulver Hall Dickinson, ND 58601</p> <p>Telephone: 227-7500 Toll Free: 1-888-227-7525</p> <p>Adams, Billings, Bowman, Dunn, Golden Valley, Hettinger, Slope, Stark</p>

Appendix

Alzheimer's Disease and Related Dementias Fact Sheet

<http://www.alz.org/Resources/FactSheets/factrelateddisorder.pdf>

Behavioral and Psychiatric Alzheimer Symptoms

http://www.alz.org/Resources/FactSheets/fs_behavioralandpsychiatric.pdf

Alzheimer's Association Safe Return

<http://www.alz.org/Resources/FactSheets/SRfactsheet.pdf>

Pre-Test/Post-Test Training for Caregivers of Individuals With Dementia

Pre-test	Answer the following True or False questions.	Post-test
	1. Everyone will get Alzheimer's disease.	
	2. People with Alzheimer's forget recent events, but remember events that happened long ago.	
	3. There is no known cure for Alzheimer's disease.	
	4. It is easy taking care of someone with Alzheimer's disease.	
	5. People with Alzheimer's usually like being with a lot of people.	
	6. Being patient and understanding helps people with Alzheimer's disease.	
	7. Behavior change at dusk is called sundowning.	
	8. People who wander should be restrained.	
	9. The best way to manage inappropriate behavior is to use logic to reason with the person.	
	10. At mealtimes, if the individual has problems swallowing offer one food at a time.	
	Enter number of correct responses.	