



Alzheimer's Caregiver Manual

*For families and caregivers of persons
with memory loss from Alzheimer's
disease and other dementias*

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INTRODUCTION

This manual is an effort to put together helpful information, in a concise and easy-to-read format, for families and caregivers of persons with memory loss from Alzheimer's disease and other dementias. It is hoped that the information in this booklet will be of some assistance.

In addition to the formal sources of information listed in the bibliography, information in the manual comes from many years of professional experience at the House of Welcome (HOW), North Shore Senior Center's specialized adult day services for persons with memory loss, as well as personal experience with my own mother, who died from Alzheimer's disease. Knowing and working with these families and individuals is a privilege. They are our best teachers.

Julie Lamberti, LCSW, Director
House of Welcome Adult Day Services
1988-2014

The information and advice presented in this manual apply to persons with memory loss from Alzheimer's disease and other dementias and these dementias are found in both men and women. For ease of writing, the terms Alzheimer's disease, memory loss and dementia are often used interchangeably and the he/she and his/her pronouns are alternated by chapters.



MEMORY AND AGING

“How do I know if it’s Alzheimer’s disease? Can memory loss just be part of getting older? When do I know it’s a problem?”

Memory and Aging These are good questions because there are common, normal changes in our memories as we age. And, there are many factors that affect memory in people of all ages. There are also indications when there is a serious problem that needs attention.

Many of us have anxiety about our own memories. You should know that most people over the age of 65 do not suffer from severe memory loss or cognitive impairment. If you don’t develop a disease that damages the brain, like Alzheimer’s, most brain functions remain intact throughout life. The aging brain does lose cells and changes in some ways, but it also continues to have a good capacity to compensate, recover, and rewire itself—not as well as a baby’s brain, but it can still do a pretty good job. Think about it, though. A teenager has more brain cells than an older person, but would you want a teenager as a Supreme Court Justice?

Factors Affecting Memory There are many factors that affect memory in people of all ages—stress, inattention and distraction, anxiety, depression, loss and grief, inactivity, lack of organization in daily life, fatigue,

physical illness, some medications, vision and hearing problems, alcohol, and poor nutrition. Memory may be more affected in older people, because they may have more of these factors operating at any one time.

Reasons People Forget There are also many reasons you may forget something, whether you are young or old. You didn’t pay attention to it. You didn’t really hear it, understand it or care enough to remember it. You got distracted by something else or you didn’t need to remember it. You may also forget it if the memory is too similar to other memories, or you don’t know much about something and have little with which to associate it, or you don’t have enough cues to retrieve it.

Common, Normal Changes in Memory as We Age Most of us have noticed changes in our memories as we have aged. There are changes that are common and normal and nothing to worry about. Although very short-term memory seems to remain much the same (remembering a phone number to dial just after looking it up), short-term memory (recent events) seems to diminish. We just seem to have a harder time adding information to our memory and recalling recent events.

As we age, it’s harder to pay attention to more than one thing at a time. We are more easily distracted. It takes greater effort to learn something

new. We can learn new things, but it takes longer. It becomes increasingly more difficult to access familiar names and vocabulary words on demand, that is, retrieval is slower, especially for names.

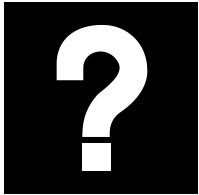
It is believed that some memories fade over time, for example, foreign language vocabulary words we learned in high school. And, memories change over time. They are overlaid with other experiences. They change as you remember and retell them. That's one of the reasons two people at the same event recall it differently later. However, there's no change in vocabulary, judgment, comprehension and general information, which add up to wisdom.

Keeping Our Brains Fit There's a lot of research into why and how good cognitive functioning is maintained into old age. Some studies have indicated that one's level of education is a predictor. It's thought that education increases the number and strength of connections between brain cells. This may help older people maintain their mental functioning and may also delay the symptoms of Alzheimer's disease when it is present, because there are more connections to compensate for

those that the disease process damages.

There's research focusing on nutrition, certain medications and other factors such as lifestyle, attitude and outlook, and their effects on memory. Other research on maintaining and protecting cognitive functioning relates to keeping mentally active, which may have a protective effect. Common sense tells us it sure can't hurt to keep active and involved and stay engaged in activities new and old. Clearly, it's important to maintain good health—especially cardiovascular health—through proper nutrition, exercise, and avoiding smoking and excess alcohol.

For persons who are not experiencing a disease process, there are a number of tips, strategies and techniques for improving memory. They include concentrating on what you want to remember, making lists, forming associations, getting organized, developing habits and routines, writing things down, rehearsing, using rhyme and rhythm, and using acronyms. There are also a number of memory enhancing courses offered in the community



IS IT ALZHEIMER'S DISEASE?

Is it Alzheimer's? Although most people experience changes in memory as they age, these changes should not interfere with the ability to function independently. When you start to see changes or behaviors that are a threat to safety or interfere with a person's ability to be independent, these are indications that the process is not normal and you need to intervene and take action.

For example, your husband gets lost for four hours driving home from the grocery store he has frequented for twenty years. Or your father, who took meticulous care of the family finances for the past forty years, is now repeatedly bouncing checks and not paying bills on time. You may find moldy food in the refrigerator or no food at all in spite of your mother's reassurance that she is eating regular, nutritious meals. Burnt pots may be found in the cupboard.

Families, or the person himself, sometimes note subtle changes and get the feeling that something isn't quite right. Often a person in the early stage of Alzheimer's disease will become more withdrawn at social gatherings or give up interests and hobbies for no apparent reason. Sometimes a crisis, for example, a hospitalization, brings to light a developing problem. After the death of a spouse, who has been compensating or covering up for his

wife, an ongoing problem may become more obvious to unaware family members.

What is Alzheimer's Disease?

First and foremost, Alzheimer's disease is not part of normal aging. Serious and chronic memory problems are not normal at any age. Alzheimer's disease is one type of dementia. Dementia is a group of symptoms that characterize a number of diseases or conditions. It is a decline or impairment of memory and other intellectual functions that is serious enough to interfere with a person's independence and ability to perform normal activities of daily living. What's important to remember is that there is a disease process that is damaging the brain and this is what causes the cognitive changes you see. What used to be called "senility" we now know is Alzheimer's disease or other dementia and not a natural consequence of aging.

Symptoms In addition to memory loss, symptoms of the illness include loss of language functions; inability to think abstractly, use good judgment and make good decisions; disorientation to time, person and place; mood and personality changes; and changes in behavior.

Causes/Types of Dementia The more the medical/scientific community learns about dementia, the more complex a picture emerges.

There are many reasons for dementia, the most common being Alzheimer's disease (AD). Other causes of dementia include Mild Cognitive Impairment (MCI), Vascular Dementia, Dementia with Lewy Bodies, Parkinson's Disease, Frontotemporal Dementia, Creutzfeldt-Jacob Disease (CJD), Normal Pressure Hydrocephalus, Huntington's Disease, Wernicke-Korsakoff Syndrome, and brain injury.

Evaluation A small percentage of people with symptoms of dementia have a treatable condition, such as depression, malnutrition, thyroid disease, acute or chronic infection. Sometimes medications can cause memory problems and confusion. For these reasons, a thorough evaluation by an internist, neurologist or psychiatrist is always recommended. With a good evaluation—medical history, mental status evaluation, physical and neurological exams, lab tests and sometimes psychiatric or other evaluations—other reasons for the cognitive problems are ruled out and probable Alzheimer's disease is the diagnosis by exclusion. Studies have shown that these diagnoses are 80 to 90% accurate, although a diagnosis of Alzheimer's disease can only be confirmed by an autopsy of the brain.

Frequency of Dementia Currently, Alzheimer's disease affects more than 5 million Americans and this number is rising. Of people age 65 and older, about 10% have Alzheimer's disease. The incidence increases with age with an estimate of about 45% of those age 85 and older.

Stages Alzheimer's disease is

often broken down into 3 stages lasting from 2 to 20 or 25 years. The average life span after diagnosis is 8 years.

The **early stage/mild dementia** lasts from 2 to 4 years and leads to diagnosis. The most common early symptom is short-term memory loss. Also present is mild confusion and disorientation, mild communication difficulties (words and names), impaired judgment and inability to make sound decisions, and some personality and behavioral changes (depression, withdrawal, hypersensitivity, suspiciousness). For example, the person forgets to pay bills and has problems handling money, has difficulty cooking, loses things, gets lost driving familiar places, takes longer to do chores.

The **middle stage/moderate dementia** is the longest, lasting from 2 to 10 years after diagnosis. All the symptoms of the first stage become progressively worse and there begin to be some difficulties completing activities of daily living (dressing, bathing, eating, etc.) There may also be increased behavioral changes. For example, the person repeats questions and stories, has difficulty expressing self verbally, has problems with reading comprehension, confusion about people and relationships, may gain weight, has visual-perceptual problems, refuses to bathe, wears the same clothes all the time.

The **late stage/advanced dementia** is 1 to 3 years. During this stage, the person becomes totally dependent and often requires nursing home care. For example, the person

sleeps a great deal, has severely limited verbal expression or may be mute, has difficulty swallowing, loses weight, has limited mobility.

Keep in mind that these “stages” are in some ways artificial and should be viewed as guidelines. Each person is unique in his or her progression through the illness.

History In 1906, Dr. Alois Alzheimer, a German physician, presented his findings of a brain autopsy of a 56-year-old woman who had died with dementia. He described the neuritic plaques and neurofibrillary tangles (degenerating brain cells) that are still the diagnostic signs looked for during brain autopsy to confirm Alzheimer's disease. In 1910, the disease was named for Dr. Alzheimer. For some time, it was thought to be found in younger people only and called pre-senile dementia. The signs of dementia or "senility" in older people were thought to be normal, from some unknown cause, or "hardening of the arteries." It wasn't until the late 1960's that British physicians determined that what we called "senility" in older people was primarily due to Alzheimer's disease.

Theories There are many theories about causes of Alzheimer's disease, but no one knows for sure. There seems to be genetic involvement in some forms of the disease and there does seem to be some genetic predisposition for the illness. However, current thinking is that Alzheimer's disease is

very complex and there may be many different types caused by a variety of influences.

Treatment In terms of medical treatment, drug research studies continue. Drugs approved by the FDA to treat Alzheimer's disease are available. None cure the disease or entirely stop the progression. They may help some persons for a period of time. However, treatment is individualized and options should be discussed with the person's physician.

The other "treatment" is psychosocial/behavioral/environmental—in other words, all the things caregivers can do to support quality of life and optimal functioning for the person with memory loss. This is the essence and heart of dementia care.

Although there is a general decline and progression through all of the stages and symptoms of Alzheimer's disease, each person is unique in how he or she presents with this illness. No one can tell you exactly what the future will be for your family member, although you can be told what to expect. And, in spite of the cognitive changes and losses, your family member will still be capable of relationships and meaningful activities. Through all of this, it is important to remember that “the person comes first” (to quote from Tom Kitwood's philosophy of person-centered care), the need for ongoing quality of life, and that there are people and programs to help you and your family through the process.



EARLY MEMORY LOSS

As information about Alzheimer's disease has become increasingly available, more and more individuals are seeking evaluation and being diagnosed early in the disease process. Early diagnosis presents many challenges and opportunities for the person, as well as family and friends.

It's difficult to exactly define early memory loss, and, as in other stages of the disease process, no two persons are exactly alike. In general, though, persons with early memory loss may be very much aware of their diagnosis and the cognitive changes they are experiencing. They may be able and even eager to talk about their situation and be involved in future planning. They may be involved in making and preparing for changes necessary as the disease progresses. They may be able to continue to function with some degree of independence for a period of time. Their independence and control over their lives should be encouraged and respected unless it presents safety concerns for themselves or others. This is where it can get tricky, as issues about driving, managing money, or being alone begin to emerge.

Educational/support groups for persons with early memory loss and their families and friends are a great source of information as well as coping techniques. They can help with learning about current medical and research information, legal and financial planning, changing roles and responsibilities in social and family relationships, daily living skills, problem solving and community resources. Group activity programs specially designed for persons with early memory loss address these issues in addition to providing socialization and stimulation.

In the early stage, as in all stages of memory loss, learning about the illness, finding support, and planning for the future, while continuing to be active and involved and maintaining a quality of life are important.

All of the information in this manual applies and can be adapted to persons with early stage memory loss.

(It is important here to distinguish between early memory loss and early-onset or young-onset memory loss, which refer to the age of onset, generally under 65 years old, not the stage of dementia.)



PERSON-CENTERED CARE

Person-centered care, a philosophy and approach to caring for someone with memory loss from Alzheimer's disease or another memory disorder, is reflected in all of the advice and information in this manual.

Good caregiving requires a good foundation involving our understanding of the other person, our attitudes, our feelings, our philosophy and approach to care. If these aren't right, nothing will work quite as well.

Person-Centered Care The philosophy and approach of person-centered care was developed by Dr. Thomas Kitwood, a social psychologist with the Bradford Dementia Group at the University of Bradford in Bradford, England, and is presented in his book, *Dementia Reconsidered: The person comes first*. Person-centered care came into vogue a few years ago, although there's actually nothing terribly new about it for those of us involved in good dementia care for many years. However, there is something special about the way he articulates and conceptualizes it. His writing is unique. Kitwood was an Anglican priest before he became a social psychologist and that really comes through. There's a passion and spirituality in his writing that is inspirational. So, this information may not be new to you, but hopefully it will validate and energize you. And, perhaps you will discover a few new insights.

Actually, person-centered care has been practiced in many settings by many individuals for a long time—families, friends and professional caregivers with good instincts and good hearts who have learned, through experience, training and education, what works well in understanding, being with and caring for persons with dementia. It has also been conceptualized by many—Virginia Bell and David Troxel's *Best Friends Approach to Alzheimer's Care*, Carly Hellen's *Activity-Focused Care*, Jitka Zgola's *Relationship Approach to Care*, in addition to Tom Kitwood.

What is Person-Centered Care?

The premise of person-centered is really quite simple. Persons with dementia are persons like you and me with all the same needs, wants and desires. Those of us who care about and for them need to keep this first and foremost in our minds, and it is up to us to adapt to changes in them to provide the best quality of life we can and to see that those needs, wants and desires are satisfied as fully as possible.

Kitwood implores us to see a person with dementia as a person first. That is, we should see a *PERSON* with dementia, not a person with *DEMENTIA*.

Person-centered care maintains and upholds the value, dignity and respect of the person, recognizes and honors the individual, despite the level

of cognitive impairment.

Person-centered care sees so-called “problem” behaviors as attempts at communication—letting us know what is needed or what is wrong. We caregivers should see these situations as opportunities for communication with the person.

Person-centered care believes all behavior has meaning—all action is meaningful.

Person-centered care attempts to provide for the needs of the person.

What do Persons with Dementia Need? What do persons with dementia need according to Kitwood?

They need *comfort*—support, warmth, tenderness in times of anxiety and need.

They need *attachment*—to be in relationships with others, to be bonded with others, perhaps even more than the rest of us.

They need *inclusion*—to be part of things, to be part of the group, to feel like they belong.

They need *occupation*—to use their abilities, to work, to play, to help, to be involved in activities.

They need to have a sense of *identity*—we need to hold their memories, life histories and their pasts for them and to respond to them in the present as unique, valued persons.

Persons with dementia have limited ability to get their needs met. It is up to us to help them.

Kitwood’s Twelve Types of Interactions In his book, Kitwood lists 12 types of interactions that comprise good dementia care.

Recognition—being acknowledged

as a person. This includes being greeted cheerfully, making good eye contact, using a person’s name, listening. At HOW, when our participants arrive, they are greeted with a warm, “Hello, Bill, how are you? We’re so happy to see you.” It makes a difference. Recognition doesn’t have to be verbal—good eye contact and smiling are ways of connecting. A variation on recognition are memory/life story books. In providing recognition, caregivers need to see each person with dementia as a person first—a unique individual. There’s a saying, “If you’ve met one person with dementia, you’ve met one person with dementia.” In my work at HOW, I’ve met hundreds of people with dementia and no two are the same. They are individuals just like you and me—they are you and me—with unique histories and personalities, and good caregivers need to be able to see and appreciate this.

Negotiation—allowing persons with dementia as much control as possible and appropriate; consulting them about their wants and needs; giving them some power and control. At HOW, we invite participants to join in on activities, but never force them. We ask for their input into the daily schedule of activities. Give choices that can be managed, for example, “Would you like apple juice or water?” You must always take into account the level of ability and not overwhelm the person with decisions, but as much as possible, give choices. In negotiation, caregivers need to forget about their ideas of what needs to be accomplished and how, and ask, consult and listen to the

persons with whom they are working.

Collaboration—“working together” with the person. Rather than doing things to and for a person, join together to get it done. For example, when a person can no longer dress independently, lay clothes out and give cues for dressing, or have your spouse help with dinner by chopping carrots for the salad or setting the table. At HOW, we do everything together. It takes longer, and as a family caregiver you can’t always do this, but do it as much as you can. We all need to feel like we are still competent and capable. With collaboration, good caregivers allow as much control as possible and refrain from imposing their will. One of our participants once told us, “I love coming here. It gives me a place to come and something to do. We all need something to do.”

Play—which Kitwood defines as activity that “has no goal that lies outside the activity itself.” In other words, have some fun. We probably do this best at HOW when the children visit for our intergenerational programs. It’s easy to play when children are around. Play games. Tell jokes. In play, caregivers need to be able to be open to the fun of the moment.

Timalation—is a British word for sensory stimulation activities, for example, aromatherapy or massage. These activities can provide contact, stimulation, reassurance and pleasure in a direct manner without a lot of expectations or demands on the person. These activities work well in the later stages, but are appropriate at any stage. You can do hand or foot

massage. For these types of activities, caregivers need to be comfortable with touch and sensuality.

Celebration—of holidays, special occasions or of spontaneous joy. This can become difficult and forgotten if you are feeling overburdened and burnt out. Don’t give up your celebrations. Modify and adapt them so they are manageable, but continue them. In celebration, caregivers need to be able to put work aside and be open to joy and grateful for the moment and the life they have.

Relaxation—the need for time out, recharging our batteries. People with dementia may need more of this, because of the increased difficulty handling stimulation. Often people with dementia need another near them or touching them to relax. It’s important to remember this need for time out and to plan for it. Caregivers themselves also need to be able to slow down, let go, and take a break.

Validation—acknowledging a person’s reality and feelings, trying to understand his or her experience and responding back in a supportive way. It’s empathy to the highest degree. When someone is upset and asking for his or her mother and looks scared, acknowledge it. “You seem scared. Mothers are great at making us feel safe. Tell me about your mother. Was she good at making you feel safe? I’m sorry she can’t be here with you now, but I’m here and you are safe with me.” With validation, caregivers need to be able to connect and be open to the experience and feelings of the other without their own presumptions.

Holding—Kitwood’s metaphor for “providing a safe psychological space,” allowing the person to safely feel and express emotions, including fear and anger. When someone is upset, ask him or her what’s wrong. Acknowledge feelings and frustrations, don’t deny or dismiss them. When someone is fearful or angry about the changes in his or her memory and mental functioning, validate this fear or anger, and offer reassurance. With holding, caregivers need to be able to tolerate the feelings and emotions being expressed, while offering reassurance.

Facilitation—Kitwood says is “enabling the person to do what otherwise he or she would not be able to do, by providing those parts of the action—and only those—that are missing.” In other words, don’t do what they can do for themselves. Only intervene as necessary, but do provide the structure, support and assistance needed so they can do things themselves. With facilitation, the caregiver needs to be responsive to the direction and action of the person with dementia. It’s a delicate balance of being sensitive to what the person needs without going too far.

Creation—creative expression, spontaneous singing or dancing. Creative arts therapies are very effective in dementia care. They are failure-free. With creation, the caregiver accepts and acknowledges creative gestures and actions of the person with dementia.

Giving—the person with dementia expressing concern, affection, and reaching out to others. Caregivers need

to be able to accept what the person with dementia gives and allow opportunities to do so. The caregivers are the receivers.

I think we can all agree that person-centered care is a good thing. It’s a good thing for persons with dementia. Heck, it’s a good thing for all of us!

Good dementia care is simple, it’s basic, and it’s about what’s really important in life. But it’s not always so easy to do.

At the risk of stating the obvious, it’s all about the quality of our interpersonal interactions. The details of how we relate to persons with dementia are exceedingly important.

Good dementia care is demanding on the caregiver. Kitwood talks of British society and culture as not naturally inclined toward good dementia care. I think this also holds true in our culture. Although these are broad generalizations about our dominant culture, we tend to be thinkers, problem-solvers, highly valuing people for their intellectual capacities and accomplishments, and status is related to wealth and material possessions. We rush around; we’re overstimulated; we’re distracted; we’re disconnected.

Quite to the contrary, persons with dementia need our time, our attention, our love, our compassion, and our presence. Other cultures view dementia differently. Some Native American communities call persons with Alzheimer’s disease “time travelers,” and they are treated with special reverence.

Qualities of Good Caregivers What does it take to be a good caregiver? Who are good caregivers? What are their qualities?

Good caregivers must have the ability to be present for the person receiving care. They must be emotionally and psychologically available. For persons with dementia, the here and now is where it's at. We need to be there with them. We don't have to "do" so much as "be." We must be willing to give of ourselves—our time, attention, caring and compassion.

We need to know and understand persons with dementia by understanding their personality styles and coping skills. We must know their life histories, likes and dislikes, and special memories. We need to know about their physical health and limitations. We need to understand their cognitive limitations—what do they have

difficulty with and what are their strengths.

In summary, person-centered care is about being a good, caring human being in relationship with another person. It's basic, it's simple, it's about being present and available emotionally. It's about knowing people as individuals, who they are, their history, their personalities, their strengths, wishes and needs. It's about accepting people for who they are and where they are at, providing support and validation, working together with them, providing autonomy and control as appropriate, celebrating and having fun, and accepting what they can give back.

As Kitwood said, good dementia care ***"may become an exemplary model of interpersonal life, an epitome of how to be human."***



COMMUNICATING EFFECTIVELY

Alzheimer's disease and other dementias affect a person's ability to communicate. It's important to understand the changes and adapt our manner of interacting with the person.

Early Memory Loss Early in the illness, vocabulary shrinks, the person will have trouble finding words or use wrong but similar words. She may become quiet or withdrawn or make comments that may seem irrelevant.

Moderate Dementia Later on, there is further vocabulary loss and difficulty naming things. The person may not be able to fully understand what is read or spoken and may be aware of her own language mistakes but unable to correct them.

Advanced Dementia In the advanced stage, vocabulary is very limited. There is extreme difficulty in speaking and the person cannot self-correct. She may appear mute. She probably cannot understand the written word, and it is unclear how much she understands of what is spoken.

A word of caution—at any stage, even though it may appear as though someone is unaware or unable to understand, you must never assume this and never speak as if the person is not there. You should still include her in conversations, speak to her as an adult and as if she is able to understand, and never say anything in front of her you would not want her to hear. I am

reminded of a story about a woman who seemed unaware. A neighbor spoke about the woman to her husband in front of her as if she was not there, and the woman began to cry. Clearly, she understood.

Techniques There are techniques that can enhance communication with the person with memory loss.

Approach the person from the front making eye contact. Address the person by name, identify yourself and your relationship and explain why you are there. For example, “Hi, Mom. It’s your daughter, Julie. I’m here to visit with you today.”

Express your message in simple, straightforward terms telling the person what you want her to do, not what you don't want her to do. For example, not “Mary, don't sit there.” Instead say, “Mary, sit here.”

Give the person choices and a sense of control as much as possible and appropriate, but don't give choices when the person can't make them or there really is no choice. For example, “Sylvia, would you like apple juice or water?” Or, “Sylvia, here’s some juice for you to drink.”

Avoid inappropriate questions and never ask a person if they remember something. That is, don't ask questions that the person may not be able to answer, putting her on the spot. Provide her with cues and information

in your questions or comments. For example, "Ida, you raised five children. I'll bet that kept you very busy."

If your mother asks about breakfast that was just eaten half an hour earlier, never respond, "Don't you remember that you just had breakfast?" Reminding her that she did, in fact, have breakfast will only make her feel badly. You might offer a snack or say, "We'll be having lunch soon."

Divide tasks into simple, step-by-step directions. For example, "Unbutton your coat...Take off your coat...Hang up your coat." Use your judgment in breaking down the steps based on the needs of the person.

Use nonverbal communication, cues and all senses. Touch is important and helpful. Point to things and demonstrate.

Match your tone of voice, facial expression and demeanor with what you are saying, and remember always to speak to the person as an adult, being aware of your tone of voice. Conflicting verbal and nonverbal messages are confusing, and persons with dementia are often very sensitive to nonverbal messages.

Speak more slowly than normal and give the person time to process information. Repeat a question or request again using the exact same words. If this doesn't work, try different words or a different approach.

Avoid rational explanations and don't argue or correct the person. Accept the person's reality and try to understand what she is trying to communicate. For example, you are asked, "When is my mother coming?"

Don't say, "Now, you know your mother has been dead for 15 years." Say, "Your mother was a wonderful person, wasn't she?" Or, "Tell me about your mother." Or, "Your ride will be here at 3:00," if she is waiting for someone to pick her up. This is called "**validation therapy**" rather than "reality orientation" and it works better. Correcting the person only makes her feel badly. You may bring her around to reality gently, but do not be confrontational about it.

Keep your sense of humor. Don't be afraid to laugh. Once, I was helping a woman in the bathroom and we were struggling to get her slacks down because they were a bit tight. Both of us were uncomfortable and tense. Finally, I said, "Boy, Sally, these are some tight pants!" (What woman can't relate to her pants being too tight?!) We laughed together at the situation and both of us relaxed.

Encourage reminiscence. The person with memory loss remembers the distant past better. It was a time when she was functioning well, so she feels good talking about it.

Identify and acknowledge the person's feelings if she is angry, sad or frustrated. Offer acceptance and reassurance, comfort and empathy. I believe that a person with memory loss knows that something is wrong even if she denies it. If someone is upset, ask what's bothering her or try to articulate it for her. If she seems anxious but can't speak the words, say, "You seem anxious about something. I'm here with you to be sure everything is ok."

Hallucinations and Delusions
Sometimes the person with memory

loss will have hallucinations (seeing, hearing, feeling or smelling things that are not there) or delusions (thinking things that are not real). If it is not upsetting to her, go along with it. You can also use distraction or redirect the person when this happens. Don't confront her or try to rationalize. After a long afternoon of football on TV, one of our participants asked her husband upon retiring to bed, "What are we going to do about all those football players downstairs in the family room?" Her husband replied that they would see themselves out and his wife turned over and went to sleep.

If hallucinations and delusions cause the person to be frightened or agitated, you may want to speak to her doctor about medication.

Late Stage Communication

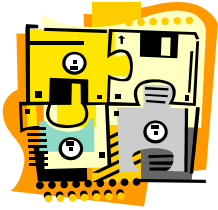
Communication in the late stage is still important. Talk to the person as you normally would. Share information about family. Touch is very important. Be aware of sounds, facial and body movements as her way of communicating with you.

A lot of this is common sense and

common courtesy. These are general guidelines. Use your intuition, creativity and your relationship with and knowledge of the person you are caring for. Try different approaches. What works for someone else may or may not work for you. Try and try again, because what doesn't work today may work tomorrow.

Above all, remember that persons with memory loss are still persons to be treated with love, dignity and respect. Put yourself in their shoes and imagine what it must be like. It's really unimaginable, but think about what it must be like to be living in a world that is becoming ever more strange and confusing, and to be losing the roles and responsibilities and relationships you once thrived on. To try to understand, show respect, allow as much independence as possible, and give love are just a few small ways we can all make this illness a little more bearable.

With all of this, we learn from each other and from the persons we care for.



BEHAVIORAL CHANGES

The person with Alzheimer's disease or other dementia will experience behavioral changes. It is important to remember that these changes are the result of the person's effort to compensate for or adapt to the changes in his mental functioning. It's difficult to predict the course of behavioral changes for individuals because each person is so different, but there are common trends and themes. Completely unmanageable or violent behavior is the exception. Often, behavior identified as "troublesome" is the result of the environment or the manner in which the person is being treated, and can be avoided.

All behavior is an attempt to communicate. Persons with dementia are doing the very best they can and probably working a lot harder at it than the rest of us. We need to try to understand their behavior.

Social skills usually remain intact for some time. The person will "rise to the occasion" and tend to function at his best when in public or with "strangers." Isn't this true for all of us? At HOW, we meet with participants before they enroll in the program. Frequently, the family member will speak to us after the visit and report that their loved one functioned much better than usual. Because of this, others often don't understand or believe the caregiver when he describes what

he is going through in terms of the challenges of caregiving. Sometimes the best solution to this problem is to have the doubting person spend a good chunk of time caregiving.

General Principles There are some general principles to keep in mind when dealing with changes in functioning and behavior.

Alzheimer's disease can cause changes in behavior that are not purposeful on the part of the person. When someone refuses to bathe, it's not because he doesn't want to or has become "slovenly." It's probably because he is frightened of the experience, anxious because he's not sure how to do it anymore, or embarrassed to accept help with such an intimate area of personal care.

You may need to let go of your concerns about some of these changes in behavior. When someone is seeing people who are not there and having a friendly conversation, he is not upset, but you may be. Another person may remove his dentures at the dinner table. He is not upset, but you may be. You need to ask yourself if it's worth getting upset or if it's something to get used to.

The caregiving environment has a significant impact on a person's functioning and behavior. This is a very important concept. Good caregiving techniques can make a world of difference. Learn as much as you can

about them. This booklet is a good start and you already know a great deal yourself, but there are many good sources of information. There are books to read, literature from the Alzheimer's Association, educational seminars. Support groups are a great source of sharing of coping skills.

It's important to make the environment trusting and secure, allowing as much freedom and independence as possible. Use the person's remaining strengths and abilities. When a person feels comfortable and secure, when he feels like he is able to do things for himself and others, when he feels accepted and understood, he will feel good and will function at his best. Isn't this how any of us would react? The point is that people with Alzheimer's are people and we need to keep this in mind at all times. We must remember that person and relate to that person.

Look for the meaning behind the behavior. Try to understand why the person is doing what he is doing. With this information, you will be able to intervene more effectively.

One morning, a participant was at our front door refusing to come in. One of our staff went out to assist his wife, who thought her husband might be afraid that someone in our group was going to hurt him. This gentleman had been experiencing paranoid delusions as part of his illness. Our staff member asked him if he was afraid. He responded that he was and she reassured him that he would be safe inside and no one was going to hurt him. With that, he relaxed and joined

the group.

Techniques Good communication techniques are imperative. These have been discussed at length previously. Maintain a calm, patient, loving manner. Get the person's attention before speaking to him. Maintain good eye contact. Speak simply, but keep your tone of voice as though you are speaking to an adult, not a child. Avoid too many questions or directions at one time. Provide simplified and modified step-by-step instructions when assisting with tasks or giving directions. Speak more slowly than normal and give the person time to process the information and respond.

Try to anticipate behavior instead of reacting to it. For example, when you go out to a restaurant to eat, remove the clutter from the table—salt, pepper, sugar, condiments, etc. This may prevent the person from pouring salt into his coffee.

Keep things simple, structured and routine. It's important to have a predictable schedule. Even if the person doesn't remember what he did a few hours ago, there seems to be a familiarity and comfort with a regular schedule and routine. At the same time, you need to be flexible. If something just isn't working, you need to have plan "B."

Try not to criticize or correct. This just makes the person feel badly. Go along with what he says, even if it isn't right. If your husband thinks he still works, let him think that. We had a gentleman who came to HOW whom we "paid." He thought he was working for us—would not attend under any other

circumstances—and it made him feel good.

If someone is doing something that needs to be changed or stopped, don't say, "Don't do that." Say, "Do this." For example, if you want the person to sit in a different spot at the table, say, "Bill, would you please sit here," instead of, "Bill, you know that's not your usual place."

Avoid logical explanations when the person is no longer able to understand them. Don't argue or confront. Present things in a manner that will be comfortable and reassuring for the person. For example, if your wife insists that the children still live at home, don't correct her. Engage her in reminiscence about your family life. If your husband resists attending a day program, don't discuss it at length. On the day he attends the program, tell him you are going to bring him to visit his friends. If your father anxiously asks where his mother is (who is long deceased), tell him she's not here now and talk to him about her, what she was like, and what she meant to him. Tell him that you know that she was a comfort to him and that you'll try to provide similar comfort.

Don't tell the person about plans ahead of time. It only makes him anxious and he's likely to be up at 2:00 a.m. getting ready for that doctor's appointment you told him he had.

Use diversion. When a behavior becomes troublesome, distract or divert the person to another activity. One of our participants gets anxious around leaving time and repeatedly asks to go home. We reassure him that his ride will

be here at 3:00 and then ask him to help us serve juice.

Use reassurance and praise. It makes the person feel good and don't we all function better when we feel good about ourselves. But don't overdo it. People are sensitive to being patronized.

Proper rest and nutrition, regular physical activity and exercise are important. They relieve stress and reduce restlessness.

Keep the physical environment simple, consistent and safe. Remove clutter and have clear pathways and safe places to pace or wander. Avoid too much noise or too many things going on at once. Overstimulation can cause anxiety, confusion and agitation.

Keep the person active and involved in life. He needs to feel useful, productive, to have roles and relationships. Adult day programs can help meet these needs.

Afternoons and evenings are sometimes more difficult, so plan restful, calming activities and routines. Keeping the person active earlier in the day also helps.

Addressing Particular Behaviors
Following are some tips on addressing particular behaviors.

Catastrophic reactions occur when a person becomes extremely upset. Look at the environment for what might have triggered it. Were there too many questions or too much stimulation or was the person unable to perform the requested behavior? Diffuse the reaction by removing the stimulation or the person from the situation. Use diversion or change the subject. If

appropriate, use touch.

When a person is experiencing **confusion** or **disorientation** to person, time or place, use reassurance. When a person is **agitated**, restless, pacing, moaning or crying, he may be bored, sick, tired or frightened. Try to calm and reassure. Regular activity and exercise can be preventive, as can a structured daily routine. Minimize confusion or overstimulation in the environment and eliminate caffeine.

Sundowning is restlessness, anxiety, and agitation in the afternoon and evening. It may be due to fatigue or lower light. Do more demanding activities early in the day. Again, regular activity and exercise can be preventive. Quiet, calming activities like soft music or massage may help.

Pacing or walking about may represent the need to be active. The person may also be looking for something or someone or may be bored. Have a safe area for the person to walk or pace. Guide the person back with diversion. Try to determine the meaning behind the behavior—just ask! An identification bracelet is an absolute necessity for safety. Also keep a recent photo on hand and notify neighbors and police of the risk of wandering. You may need to install a door alarm. Again, keeping the person active can help.

Supervision becomes necessary when the person is at risk of wandering off unattended. It is difficult to know when this will first occur. Therefore, no one should be left unsupervised who would be at risk if he left the house alone. Another rule of thumb is that no one should be left alone who cannot

recognize danger and/or take appropriate action or seek appropriate help. Ask yourself, “Would my husband recognize an emergency situation and would he be able to react appropriately, for example, evacuate, get help or call 911?”

Paranoid behavior can reflect feelings and reactions as the person loses cognitive functions and control over his life. He may misplace things or misinterpret the environment. He may be covering up for his losses. Do not argue, confront or use rational explanations. Do not talk behind his back as this only feeds paranoia, and include him in conversations, tasks and planning as appropriate. For example, if he is concerned you are stealing his money, have him “help” you with paying the bills. Put valuables in a safe place and have extra keys, glasses, etc. Check the wastebasket for lost items. Maintaining the person’s dignity and respect will help him feel more competent and secure and may prevent some of these problems.

Hallucinations are seeing, hearing, smelling and feeling things that are not real. Try to understand what they might mean to the person. Do not rationalize, correct, confront or argue. If the hallucinations are not upsetting to the person, you need not do anything. If the person is upset, offer protection and reassurance. Be sure there is no medical cause, such as medications or illness. If you think there might be a medical problem and the person continues to be disturbed, you should talk with his physician.

Delusions are believing things

that are not real. Again, try to understand the meaning behind them. Accept his reality and use reassurance. Reason and logic probably won't work.

Remember, there are solutions to these difficult situations. Sometimes it takes awhile to figure them out. A lot of trial and error and intuition are involved. Trust your instincts and use your knowledge of the person. Remember that what doesn't work today may work tomorrow or in the next few minutes, for that matter. Don't be afraid to try and fail. You will have many opportunities to try again.

Keep your sense of humor. Sometimes people have difficulty seeing the humor in their situation or feel it is disrespectful, but it is so important to be able to laugh therapeutically. I am a true believer in laughter sometimes being the best

medicine. You are laughing with the person and at the situation. It can release tension and diffuse an uncomfortable situation.

Remember that phases change and pass. This is especially important when you are going through a difficult time. As the illness progresses, behavior will change.

A word of caution—behavioral changes can be caused or complicated by conditions other than the dementing illness, such as medications, problems with vision or hearing, a cold or the flu, infection (for example, a urinary tract infection), pain or physical discomfort that the person cannot communicate to you, depression or fatigue, dehydration or constipation. Any sudden or dramatic change in behavior should be evaluated for one of these problems.



MANAGING ACTIVITIES OF DAILY LIVING

Assisting with activities of daily living, including personal care, can be one of the most difficult aspects of caregiving. It seems childlike and embarrassing to need assistance with these activities, and it's difficult for both caregiver and care receiver. It takes away a person's independence in private and intimate areas of care. There can be resentments and discomfort on both sides.

As roles change, it is important to remember that they are role changes, not role reversals. The person you are caring for is still your spouse or parent, not your child. With these role changes, there are new things to learn. Men may need to learn to help with makeup. Women may need to learn to help with shaving.

As with other behaviors, there will be changes from day to day. One day your family member may be able to dress without assistance, and the next day, she may need some help. It's important to remember to monitor and assist as needed, but not to take over. The person feels better when she is as independent and involved as possible. Of course, all this requires a good deal of patience and time. Sometimes you won't be able to do it because you have to be somewhere or you're just too tired!

General Principles General principles in personal care are consistent with other areas of caregiving.

Maintain the person's independence and self-esteem to the greatest degree possible. Remember good communication techniques. Recognize the person's limitations, but more important, recognize her abilities and encourage her to do what she can for herself. Early on, reminders and cues will suffice. Later, more assistance will be necessary. You will need to adjust as the person changes over the course of the illness.

Make things easy for the person. For example, instead of several utensils on the table, put only the fork by her plate.

Provide for personal and physical safety. Get a medical ID bracelet for your family member and keep a recent photo on hand. Proper clothing and non-skid shoes are important. Glasses and hearing aids, when needed, are important. Keep cleaning supplies, medications and anything harmful or toxic locked up or clearly out of reach. Remove scatter rugs, furniture that tips or can be tripped over (coffee tables), and loose cords. Lower the thermostat on your hot water heater to avoid burns.

Look at the environment. Altering the environment can alter behavior.

Think of it as a prosthetic approach, providing aides for the person's losses. Camouflage to reduce access and accent to increase access. For example, paint the door and frame the same color as the wall if you want to discourage access. If you want the person to notice a door or doorway, paint the trim a contrasting color.

Use labels, pictures and signs to orient or give the person instructions. Put a sign on the bathroom door. Have an easy-to-read calendar and clock. Have good lighting. Night-lights can help the person find the bathroom at night. Keeping overhead lights on at night can be disorienting. The person may think it's time to get up and get dressed if she awakens during the night and all the lights are on.

Keep the environment simple and consistent. Remove clutter and distractions. Remove mirrors when the person becomes confused or frightened by her reflection. Reduce noise. It can be overstimulating. Keep to a routine as much as possible. This can be comforting and the person will become familiar with a routine. Of course, you need to be flexible when things are not going as expected.

In all areas of personal care, remember that sometimes it's easier to do things for your family member than to help her do it for herself, but it's vitally important for her to maintain skills for as long as possible. Just do the best you can.

Eating Structure food and the eating experience to mimic the person's

prior habits, making it as normal and familiar as possible. Allow the person to do as much for herself as possible.

Use plates with no pattern on them—the person may try to eat "flowers" off the plate. A solid line around the edge is good, however, because it defines the plate area. Placemats or tablecloths should be plain. The plate should contrast in color with the table or table covering underneath so it can be easily seen.

Give the person one utensil at a time. Remove clutter from the table to avoid problems like salt being poured into coffee. Too many different foods on a plate can be confusing. Present one food at a time. If there are several foods on the plate, ignore the order eaten. Eating dessert first is just fine!

Use "real" silverware. Plastic may be bitten off or break. Paper cups may be squeezed and liquid spilled, so "real" glasses and mugs are preferred. Fill them only 3/4 full.

Offer a balanced diet and nutritious snacks. Sandwiches that stick together (tuna salad, melted cheese) are easier to manage. Sometimes it helps to cut them in four sections.

Do not force the person to eat and allow plenty of time. Cues may be needed to get the person started or keep her going. For example, put a fork in her hand and say, "Eat your dinner." Or, hand her a section of sandwich saying, "Eat your sandwich." You may need to repeat these reminders throughout the meal.

Serve finger food when it becomes too difficult to use utensils. This is less demeaning than feeding

someone and you can provide a nutritious diet with finger foods. Actually, you can make a sandwich out of just about any meal. For example, meat loaf, peas and mashed potatoes can easily be put between two slices of bread. Use chicken nuggets, French fries, cut-up fruits and vegetables, and other bite-size finger foods. This also can allow the person to wander while eating.

Watch for swallowing difficulties, which are common, especially as the disease progresses. You may need to remind the person to swallow. Semi-soft foods and thicker liquids are easier to swallow. Mixed consistencies are difficult (crunchy cereal and milk). Offer fluids between meals. Dehydration can be a problem, as she may not realize she is thirsty.

Forget about moderate weight gain, which is common in the middle stage. She forgets she's eaten. There is also a theory that the part of the brain that tells the person she is full doesn't work. Many people with memory loss seem to crave sweets. However, weight loss is common later in the illness, so you shouldn't worry unless there is a health problem or the person is extremely overweight. Buy clothing with elastic waists!

Mouth Care Check dentures to be sure they are comfortable and fit well. Remove and clean them daily. Give step-by-step instructions for brushing teeth. One family member told me that his wife had no idea what to do with her toothbrush until he just touched it to her lips, and then she was able to complete the task on her own. Regular

dental exams are important.

Bathing Follow old habits and schedules. Do not discuss whether or not a bath is needed, simply proceed as if it is taken for granted—a "matter of fact" approach. Take one step at a time and simplify things. Use the person's help and talk her through it. For example, "Put your foot in the tub. Put your other foot in the tub. Sit down. Here is the soap. Wash your arm..." If the person is really agitated, stop and try later. If possible, bathe at a time when both of you are not tired. If appropriate, showering together can work.

Remember how frightening and embarrassing this experience can be. Consider alternatives—hiring someone or sponge baths. Daily bathing or showering is not usually a necessity. Agencies or individuals can be hired for a fee to come in regularly for bathing. This often works well because the worker has the appearance of a nurse.

Never leave your family member unattended in the bath or shower. Bubble baths and oils can be slippery and cause infections. Bath stools and grab bars help with safely moving in and out of tub or shower. One woman found that singing with the person helped her through her bath. Another woman found that putting food coloring in the bath water helped.

Dressing Simplify, structure and supervise. Decrease choices of clothing. Remove clothing that is not appropriate, for example, winter clothing during the summer. Coordinate clothes in the closet or have all mix-and-match outfits. When the person cannot choose, lay

clothes out in the order to be put on. Later, step-by-step cues and assistance will be necessary. Buy jackets and coats a size or two larger. They will be much easier to put on and take off. Eliminate accessories such as belts, ties, scarves—keep it simple. Replace buttons, buckles and zippers with Velcro or elastic. Tube socks can't be put on wrong. Jogging outfits and slip-on shoes are easy to manage. There are stylish knit ladies' outfits with elastic waists that are washable and easy to put on. If your family member loves a certain outfit, buy several alike so she can wear it daily.

You should keep in mind old habits when thinking about clothing, but don't assume the person can't change. We had a participant who had worn many layers of undergarments for years. They became too difficult for her to manage in the bathroom, so we suggested to her family that they reduce her undergarments to underpants only. This way, she could continue to function independently in the bathroom. Although they were skeptical, they tried. They removed everything from her drawers except underpants without saying anything to her and she got dressed with underpants only. Although she did comment for the first few days that something was "missing," she adjusted without a problem and was able to be independent in the bathroom.

Grooming Hair, nails, foot care and makeup are important to the person and those around her. Grooming contributes to self-esteem and to how others treat the person. Getting

manicures or hair done regularly can be a treat and an activity for the person. They are also activities that others may be able to help you with. It can be a focus for a visit by a family member or volunteer. Simple, attractive hairstyles can make daily grooming easier. Of course, you need to balance good grooming with being flexible. Don't make it too hard on yourself or your family member.

Foot care can be done by a podiatrist. Under certain circumstances, Medicare may cover this service.

Toileting Although it's difficult to predict when problems with toileting will begin, they are inevitable. Initially, the person may start having occasional accidents. When this happens, there are steps you can take that help. Be sure the person knows and remembers where the toilet is. Mark it with the word, "toilet." Be sure clothing is easy to manage.

Sometimes the person may wait too long to get to the bathroom and then has trouble getting clothing undone. Notice her usual schedule and remind her according to that schedule. If this doesn't work, try a schedule of upon rising in the morning, every two hours during the day, after meals and before bedtime. At some point, asking the person if she needs to go doesn't work and you should just take her. She may say no but really need to go. Look for other cues, for example, restlessness. One HOW participant used to say she needed to go home when she needed to use the bathroom.

As time goes on, more than reminders will be necessary. Cues may

also be needed or step-by-step assistance and instructions in the bathroom. A HOW staff member discovered that one participant only needed his belt buckle undone and he could then complete toileting independently.

Eventually, the person may lose complete control and become incontinent. Then you will need to use adult incontinence products. There are many varieties at your local pharmacy. There are also catalogues from mail order companies or information on the Internet that have pictures and describe a variety of supplies. Some will send you samples to try out.

Remember to keep in mind that problems with incontinence can be related to medical problems, for example, a urinary tract infection, some medications, even dehydration. Be sure to consider this, particularly when incontinence problems begin suddenly.

There are other tips that help with toileting. Use a toilet seat that contrasts in color with the background so the person sees it easily. This is a visual cue. Removing or covering the mirror in the bathroom may help if the person thinks someone is in there with her when she sees her own image. For safety, remove the lock from inside the door or have a key readily available. Limit fluids a few hours before bedtime. However, do not limit fluids to prevent accidents. This can cause dehydration.

Install grab bars and an elevated toilet seat if necessary.

As much as you can, respect the need for privacy. At HOW, when we are not sure if someone needs help, we "peek" through the door.

Sleeping Sleep problems are very difficult, because caregiving on little sleep is at least twice as hard! Too much daytime sleeping or not enough activity and exercise can cause sleep problems. So can caffeine, illness, pain, hunger, side effects of medication, agitation from upsetting daytime events, disturbing dreams and depression. All of these causes should be considered when sleep problems occur.

To avoid sleep problems, try to prevent too much daytime napping. Keep the person active. Have a regular exercise and/or walking program. Eliminate caffeine and alcohol. Do not talk about the next day's plans or lay out clothing. Avoid upsetting activities in the evening. Have a bedtime routine. Try soft music or a massage. Be sure the person is comfortable in bed and not hungry or cold. Sometimes disrupted sleep patterns are due to the dementia itself and nothing seems to work. Consider letting the person be up at night and provide a safe place to wander or hire a nighttime aide.

Usually these problems pass and the person sleeps more as the dementia progresses.



STAYING ACTIVE AND INVOLVED

When a person develops Alzheimer's disease or other dementia, often one of the first signs is withdrawal from regular activities. Family members will comment that the person stopped doing certain household tasks, such as yard work, cooking or cleaning. The person stopped going to bridge or golf or lost interest in longstanding hobbies, like reading, crocheting or watching sports on TV.

As cognitive functions become impaired, it becomes more and more difficult for the person to independently initiate and complete activities of all kinds. So, he withdraws from them, frequently with excuses to cover up the real reason. This can lead to feelings of uselessness, boredom and depression.

It is important to keep the person active and involved in life. For all of us, much of our day is filled with routine activity. We often complain about it, but think about having day after day with nothing to do. There are many ways to keep the person active. It's not always easy and often requires a great deal of energy and patience, but all you can do is the best you can and following are some ideas.

General Principles Your family member needs to be involved in purposeful, meaningful and pleasurable activities that provide a feeling of

usefulness, support self-esteem, provide pleasure, and provide the sense of continuing to have roles and being part of life, family and community.

Alzheimer's disease doesn't mean an end to enjoying life. Each person has special qualities and abilities. Make use of them. One of our participants doesn't go in much for music, games and other recreational activities. However, he's the first to help with setting the table for lunch and cleaning up afterwards. He thinks of our program as coming to work and it gives him a lot of satisfaction.

Think of everything as an activity.

If you think of the morning dressing and grooming routine as an activity, it may be easier to accept the time it takes to help the person do as much as he can for himself, even though you could get it done in half the time by doing it for him.

Remember, it's the process, not the outcome. If you think of it as a purposeful activity for your husband to empty the dishwasher, you may not mind so much if he puts some of the dishes in the wrong cabinet. You can move them later when he won't see you.

Exercise is extremely important.

It's important for persons with memory loss for the same reasons it's important for all of us. It keeps us feeling better,

tones and strengthens muscles, helps maintain mobility, promotes cardiovascular fitness, alleviates stress and depression, and reduces anxiety.

Essential Elements for Making Activities Work *Remember good communication techniques.* Approach from the front. Get and maintain eye contact. State your message in simple terms. Speak slowly, concisely and unambiguously. Give the person time to respond. Give both verbal and nonverbal cues. Use body language. Praise and reassure, being careful not to over praise. Communicate that you are enjoying yourself—it's contagious!

Daily planning and routine are important. Have a specific routine for each day and introduce and perform regular daily activities in the same way each day. Familiar routines provide a feeling of security.

Simplify the environment to minimize confusion. Remove clutter. Reduce noise.

Think about the person's social and medical history, likes and dislikes, strengths and needs, in order to capitalize on remaining interests and skills. If a person loved to cook, have him help you with dinner. A former golfer may enjoy hitting balls at a driving range.

Take all necessary safety precautions. An ounce of prevention is worth a pound of cure. Bingo chips may be misperceived as candy. At HOW, we use poker chips, which are much larger.

Criteria for Successful Activities *Activities should have a purpose or be productive.* When you set the table for dinner, ask for help. Have your husband

put the napkins next to the plate or lay out the silverware.

Activities should be fun. Games and sports can be adapted so the person can do them with success while keeping them adult in nature. Practice putting in the living room using one of those gadgets that shoots the ball back when you hit it into the center.

Activities should be ones that can be broken down into simple steps and adapted to the person's skills. Cooking is a great activity for this. There are many simple steps. It's familiar, adult and pleasurable.

As much as possible, activities should be failure-free. Keep things simple. You don't want to frustrate the person or make him feel badly because he can't do what you're expecting of him.

Activities should be repetitive. Repetition provides a feeling of competency.

Activities should rely on habitual skills. Skills learned in years past remain longer. Although the person will enjoy familiar activities, he can also enjoy new ones if they are presented well. Many men who come to our program have never cooked or helped out in the kitchen, yet they really enjoy these activities at HOW. I think it's because they do it with success, feel like they're accomplishing something and feel needed.

Activities should provide sensory stimulation. But, don't overstimulate. Loud music, bright colors, and a lot of movement are stimulating. Soft music, slow movement and quiet activities have a calming effect.

Late Stage Activities With advanced dementia, the person will lose the ability to participate in many activities, but he can still feel and we're not sure how much he is able to take in. It's important to continue to talk to the person, use lots of touch and provide sensory stimulation. Take the person out to sit in the sun. Read to him. Give him a hand massage or back rub. Listen to music.

Successful Activities Following are activity ideas that work well for adults with memory loss.

Helping with daily routines and chores With supervision and step-by-step instruction, a person can help with most household tasks—indoor plant care, arranging flowers, gardening, folding towels, dusting furniture, drying dishes, setting and clearing the table.

Cooking and baking This is a favorite activity because there is a product at the end to be eaten and enjoyed, and the smells of things cooking are nurturing and familiar. Cut up vegetables for soup or fresh fruit for a salad, make applesauce, bake simple drop or bar cookies, or roll out dough and use cookie cutters. Try zucchini, cranberry or banana breads and easy cakes and pies.

Music This is one of the most successful activities for persons with memory loss. Memory for music seems to last longer than other memory. It also tends to stimulate positive, meaningful feelings and thoughts. The music most people remember seems to be that which was popular in their late teens to late twenties. Do sing-alongs, movement or dancing to music. Play

Name-That-Tune, Singo, music trivia, reminisce about music, or plan short musical programs. A trained music therapist brings a special expertise to music activities.

Games Many familiar games can be adapted or simplified. Try Bingo with numbers, colors or holiday pictures; dominoes; card games such as Blackjack or Pokeno; dice games like dice poker, Bunco, Bowl and Score; and block games such as Blockhead or Jenga. Try a puzzle map of the United States, large-piece puzzles (not juvenile), or matching games.

Word Games Using A-Z, fill in with specific categories, for example, countries of the world. Or use a particular letter such as "s" and name all girls' names beginning with that letter. Try hangman (Wheel of Fortune) or simple Pictionary. Complete proverbs or familiar poems ("The Night Before Christmas" or "Casey at the Bat"). Do simple crossword puzzles or adapt Scrabble. Use Elder Trivia questions.

Pets If the person is comfortable, holding and petting friendly animals can be a good activity. Pets can provide companionship and unconditional positive regard. A fish tank or bird feeder can provide interesting observation. It can also stimulate reminiscence.

Exercise and Active Games Plan a daily routine of seated and/or standing exercise. Take walks and window shop. Toss and/or catch beanbags in a waste can. Throw bean bags onto a hopscotch grid with numbers for scoring points, slide them down a long table at thread cones, or play Toss Across—a bean bag

tic-tac-toe game. Play balloon volleyball, indoor basketball, bowling or practice putting. Play indoor or outdoor plastic horseshoes or ring toss. Bat nerf balls back and forth with wooden paddles, tennis or badminton rackets. For larger groups, try parachute activities.

Reminiscence Since long-term memory lasts well into the illness, activities that rely on it have a good chance for success. During conversations, bring up topics from the past that are familiar. "Reminiscence boxes" are collections of items in various categories (tools, sewing, household articles, men's "things," women's "things," etc.) Bring them out to handle and discuss and old memories will be stimulated. There are a variety of nostalgia books that can be used. Photos of old movie stars and famous people and places are popular. Individual photo albums or "memory books" that include a life history can make a person feel special.

Discussions Look over the newspaper and discuss current events avoiding items that may be disturbing. Discuss sports. Read your horoscopes and advice or opinion columns, and ask for their advice or opinions. Enhance discussions using the encyclopedia or the Internet for more information. Use slide shows and travel or nature tapes. Have discussions around a particular topic, such as first dates, first cars, summertime, the Depression, weddings, WWII—the possibilities are endless. Talk about yourselves, family and friends, being sure to include the person in conversation. Really listen to the person and show interest in what he

is saying. Help him express himself and acknowledge his feelings.

Manicures and grooming

Combing hair and putting on makeup contribute to self-esteem. Nail care and hand massage provide pleasant feelings. Shoulder massage or a back rub can be relaxing. Remember to think of all areas of personal care—dressing, bathing, etc.—as an activity.

Art/Art therapy Do unstructured painting with washable tempera paints or watercolors. Do mosaics using ceramic tiles or paper squares or try modern art designs using various paper shapes. Make figures or ornaments from baker's clay. Make "quilts" with squares of wallpaper samples or collages from magazines or dried leaves and flowers. Make place cards, get well and birthday cards. Art activities of all kinds work well if well-planned, that is, not too complicated and presented one step at a time if there are multiple materials and steps involved. A trained art therapist adds a special dimension to art activities.

Celebrating Holidays/Seasons/Special Occasions This can provide gentle orientation to the season and time of year. More important, it is also a normal, fun part of life for us all. Make holiday decorations, a holiday or seasonal collage, cook and eat special holiday foods and reminisce about past holidays. Adapt your holiday celebrations so the person with memory loss can manage and enjoy them—that is, keep them simple and avoid overstimulation. Birthdays and other special occasions are also important, but celebrations may need to be

adapted so the person with memory loss can be involved. Arrive early before it gets too crowded or leave early before your family member gets tired.

Language Arts Have the person with memory read to you or you read to him. Write a poem or a story together. *TimeSlips* (www.timeslips.org) is a creative storytelling method that works well in groups or can be adapted for a one-to-one activity.

Service Projects In group or residential settings, there can be group projects—assisting with preparing mailings, collecting for a food pantry, sending letters to soldiers, etc.—that provide a sense of meaning and satisfaction. You might also do something at home with your family member.

Spirituality Staying involved in your place of worship can be important for both you and your family member. Praying, bible study, acknowledging religious holidays and rituals, discussions on the meaning of life or the wonder of nature are all activities that can nourish the soul.

Humor This is obvious—it’s fun! It’s therapeutic. Watch comedies or old-time TV shows that rely on long-term memory. Tell jokes. There’s even a practice called “Laughter Yoga.”

Plan Intergenerational Activities With special planning, both the children and the adults will enjoy their time together and benefit from the experience.

Resources for Activity Supplies The following companies have games, books, and a variety of other supplies for activity directors. Some may also be good for home use. These are just a few suggestions—the Internet offers an unlimited supply of activity resources and ideas!

- Bifokal.org
- Eldersong.com
- Activityconnection.com
 - Online subscription
- Creativeforecasting.net
 - Monthly journal
- Flaghouse.com
- Geriatric-resources.com
- S&S Worldwide (ssww.com)



CARING FOR THE CAREGIVER

Studies have shown that caregiving for someone with memory loss is more stressful than any other type of caregiving. And, we all know that stress compromises our health. But, there's a lot to be done about the stresses of caregiving.

Caregiving can also offer opportunities for positive experiences, expressions of love and caring, deeper intimacy, and stretching of our spiritual selves. I remember reading a personal account of a caregiver who talked about “thriving” and not just “surviving.” Studies of caregivers who seem to do well indicate that they rely on their spirituality for a sense of the deeper meaning of their caregiving role.

Nevertheless, there are many challenges families confront.

Emotional Challenges Stress has a lot to do with how we feel about our situation. Families dealing with Alzheimer's disease have many reactions. They may wonder, "Why me?" Or, "Why my husband?" This wasn't what you expected in your “golden years.”

Knowing what the future might bring can be frightening and overwhelming. Caring for someone with memory loss requires constant vigilance. This is demanding and tiring and takes its toll emotionally and

physically.

There are many other feelings you may experience. Initially, denial that there is a problem can be protection from facing the illness and all that it implies. At some point, denial needs to give way to facing what is happening and taking appropriate and necessary steps.

You may feel anger. Sometimes it seems like the person is acting purposefully to annoy you. You know the person will not improve.

You may feel helpless. You just don't know what to do. Sometimes nothing works.

You may feel embarrassment about the diagnosis itself or the person's behavior.

You may feel guilt. There's guilt about these feelings. You may think you're not doing a good enough job. You may wish you could somehow escape from the situation entirely.

You may feel grief. You are losing your loved one day by day.

You may feel depression about this loss or as a result of the demands of caregiving.

You may feel isolation as friends and family drop away or you just don't feel like socializing.

You may feel like you have nowhere to turn or you don't want to

burden others with your problems. Perhaps you've never had to ask for help.

Physical Challenges You may experience fatigue. Caregiving is hard work. When there are sleeping difficulties, this can add to your fatigue.

You may experience illness. Some studies have indicated that caregivers of persons with memory loss have weaker immune systems and are more vulnerable to illness.

Economic Challenges Your family member may have to quit a job or retire early reducing family income. There are also the costs of care—medical care, home care, adult day services and possibly residential care.

I guess that's some of the bad news, but there is help and there is hope. You should not travel this journey alone. One of the positive experiences of this journey is the truly kind, caring and giving people you will meet along the way if you allow yourself to ask for and receive help.

Coping Techniques and Resources There are many ways to cope with the stresses of caregiving. We all have coping mechanisms that are comfortable for us and seem to work well for us. Following are some other ideas.

Recognize and accept your feelings. They are OK. It's also good to talk to someone and share your experiences and reactions—good and bad. **Support groups** can be helpful for this. A good friend, family member, minister or rabbi can help. **Professional counseling** is also available.

Learn about the illness and successful caregiving techniques. It can make a real difference. Knowledge is a powerful tool. There are pamphlets, books and educational workshops. Support groups are educational as members share their caregiving tips. Professional advice can also help.

Do some planning. There's legal and financial planning to be done. It can help to plan for the future. There's an old adage, "Hope for the best and plan for the worst." Think about what kind of care and help you will want or need. It's also vitally important to plan for emergencies. What will happen if you become ill? Who can respond in an emergency and take charge of the situation?

Take care of yourself. Practice the many stress management techniques effective for all varieties of stress including proper nutrition and rest, exercise, meditation, journal writing, and others. Workshops on stress management are offered throughout the community. There are many books on the subject. Be sure to get regular medical care for yourself. Plan time away from your responsibilities and attend to your spiritual needs.

Get concrete help with your day-to-day caregiving. I cannot overemphasize this suggestion. There are many resources for this—adult day programs, home care, and residential respite programs. **Adult day programs** offer you regular, predictable time on your own while offering therapeutic activity for your family member. **Home care** allows you to get out for an evening with friends or can assist you

when the care and supervision of your loved one at home is just too much to handle alone. **Residential respite** can allow you to take a vacation from which you will return refreshed and with renewed energy. No one should do this alone. It's not good for anyone involved.

Good medical care is imperative.

It is important to have a good initial evaluation and ongoing follow-up care for your family member by a physician who understands dementia. It is also important to get good medical care for yourself.

Keep your sense of humor.

Alzheimer's disease is no laughing matter, but it is important to be able to laugh at ourselves and at our situations. It truly can be the "best medicine."

Legal and Financial Planning

Planning ahead and anticipating situations helps avoid crises—another source of stress. On the one hand, it's important to have the attitude of "one day at a time" when caring for someone with memory loss, however there are some areas that require planning ahead. You need to look ahead and do legal and financial planning. Actually, all adults should have this planning in order no matter our age or health, as life is unpredictable. However, if it hasn't been done already, this planning should start early, while the person with memory loss can still participate in decisions and is competent to sign legal documents.

You should consult an attorney for counsel on these matters, but following are some things to consider. Two documents that are important to consider are durable powers of attorney

for health care and property. Executed while the person is still competent, they stay in force when the person is no longer able to make decisions for herself. There are trusts, living wills, do not resuscitate orders and other planning tools and documents. These are complex issues to consider, so you should consult appropriate professionals about your particular situation. What I want to emphasize is the need to think and plan ahead.

Financial Planning The power of attorney for property allows for money management and financial decision-making. This and other tools can help you avoid going to court for guardianship to manage financial affairs. Even if a person doesn't have abundant financial resources, arrangements need to be made.

Health Care Planning Health care planning becomes particularly important regarding end-of-life decisions. Whether or not to resuscitate, whether or not to use a feeding tube, whether or not to treat pneumonia or other infections or illnesses are some of the decisions to be faced. The issues are complex and involve personal beliefs, thoughts and feelings, as well as legal and medical issues and ethics. There is no simple answer and there is no one right answer.

What is important to remember is that we all have the right and, I would add, responsibility, to make these health care and end-of-life decisions for ourselves when we are competent to make them. That is why it is so vitally important to make these decisions,

discuss them with our relatives and physicians, and put them in writing. We should do it for ourselves and for the benefit of others who may, at some point, be put in the position of carrying out these wishes.

When someone is in the early stage of Alzheimer's disease or other dementia, she is probably still capable of discussing these issues, expressing wishes and signing documents. Do this with your family member while you have the opportunity. If you haven't and are faced with making health care decisions for your family member, think about what she would want. You are being asked to make the decision you think your relative would make, were it possible to do so.

Whatever the circumstances, these situations are difficult, emotionally painful and accompanied by feelings of grief and loss, sometimes doubt and guilt. Even if they are totally clear about what needs to be done or not done, family members have told me that making end-of-life decisions is still very difficult. The support and guidance of others during this time can help you cope with your feelings.

Autopsy Another end-of-life issue to be considered is autopsy. A diagnosis of Alzheimer's disease can only be confirmed by an autopsy of the brain. Brain tissue is also used for research. If this is something you are considering, speak with your physician or contact the Alzheimer's Association—Greater Illinois Chapter at 800-272-3900 for information on how to make arrangements.

Residential Placement At some

point, you may need to consider residential care. Residential placement is one of the most difficult decisions family members must make. People often ask me when a person is "ready" for placement. There is no formula. Every situation is unique and the decision needs to be made with regard not only for the person with memory loss, but the caregiver as well. There usually comes a time when the caregiver realizes it is necessary to make a change. That time is unique to that person and can depend on many factors including a caregiver's physical health.

Taking the time to plan ahead for residential placement allows you the opportunity to investigate your options and to consider financial issues. Many long-term care facilities have specialized Alzheimer's programs and there are also facilities that specialize exclusively in dementia care.

Even when caregivers have done a superhuman job, placement is difficult. There may be feelings of guilt. There are certainly feelings of loss. It's important to remember that when you place your loved one in a residential facility, you haven't given up your caregiving role. Your presence and caring continue to be very important. Just the fact that you visit regularly helps insure that your loved one will get good care. Many family members help with meals, laundry or join in on activities.

Hospice Care In some situations, keeping the person at home until she dies is an option. It may require hiring full-time help. Hospice services are also

available under Medicare for Alzheimer's patients. These hospice services can also be offered in long-term care facilities.

What's important to keep in mind is that your situation is unique and you need to do what is best for you and your family. Support groups or professional counseling are often helpful to people during these transitions.

See the Positive Look for positive moments. There are many. A memory stirred, a song sung together, a hug, a smile, an "I love you" at an unexpected moment. We must learn to live in the moment, because this is all the person with memory loss has. If something is enjoyed, even for a moment, it's worth it. Take the opportunity to provide a quality of life for your loved one and yourself. It may not be the life you expected or would have chosen, but it's all you've got.

Remember that you, as a caregiver, have a special role. It's certainly not one anyone would ask for, but it is special nonetheless.

Caregivers, Take Care Caregivers, family or professional, need to take care of themselves. Following are tips, "rights," and reflections that are good advice.

Taking care of yourself is not being selfish. You will be better able to care for your loved one.

Accept that you can't change everything about your situation, but you

can change your attitude.

Get help early and often. Don't go it alone. It's not wise or healthy for either you or your family member. Ask friends and family members. Give them specific ways they can help—taking your mother for a walk, staying with your husband so you can go out to eat with a friend or take in a movie, giving your wife a manicure, or bringing over a meal to share.

Pamper yourself from time to time. You deserve it, need it and your spirits will benefit.

Take it one day at a time. It's wise to think and plan for the future, but needless worrying is unproductive. Enjoy the moment and your special relationship with the person you are caring for.

Accept your feelings. They are yours and they are valid. Find a friend, confidant or professional to share them with.

Be gentle on yourself, especially at those times when you have lost your patience or feel like you aren't functioning at your best. No one is perfect.

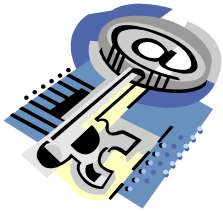
Say "no" sometimes.

Use your creativity. Try new solutions to ongoing, difficult problems.

Take a timeout in a quiet place.

Laugh, play and "smell the roses."

Be proud of your accomplishments as a caregiver. Your role is a valuable one.



RESOURCES

INFORMATION & REFERRAL

Alzheimer's Association—Greater Illinois Chapter, www.alz.org/illinois, Chicago, 800-272-3900 (help line) and 847-933-2413 (business line), provides information and referral, support groups, education.

Alzheimer's Association, www.alz.org, Chicago, 312-335-8700 (business line) and 800-272-3900 (help line), national office for above.

Illinois Department on Aging, Springfield, 800-252-8966, provides information and referral about community support services.

North Shore Senior Center, www.nssc.org, 847-784-6000, with offices in Northfield and Evanston, offers a wide range of in-home and community-based supportive services.

SUPPORT GROUPS

North Shore Senior Center's House of Welcome Adult Day Services, Northfield, 847-242-6250, offers an **Alzheimer's Family Support Group**.

For other support groups, call the **Alzheimer's Association at 800-272-3900** or visit www.alz.org/illinois.

MEDICAL

Consult with your primary healthcare provider for referrals or visit the website of your affiliated hospital. Below are several area programs that provide memory assessments.

NorthShore Univeristy HealthSystem Neurological Institute, 847-570-2570

Northwestern Alzheimer's Disease Center, Chicago, 312-695-9627

Rush Alzheimer's Disease Center, Chicago, 312-942-4463

LEGAL SERVICES

Chicago Bar Association website (www.chicagobar.org)

Lake County Bar Association website (www.lakebar.org)

National Academy of Elder Law Attorneys (www.naela.org)

ADULT DAY SERVICES

Visit www.iadsa.com for a list of adult day programs throughout the state that are members of the Illinois Adult Day Services Association.

HOME CARE SERVICES

The **Community Care Program** provides state-funded in-home and adult day services for financially eligible administered through local Case Coordination Units. Respite care and other services are also available. For information, call the **Illinois Department on Aging at 800-252-8966; or North Shore Senior Center**, 847-784-6040, for Maine, New Trier, and Northfield townships and 847-864-3721, for Evanston and Niles townships.

Home Care Agencies provide a variety of in-home services.

RESIDENTIAL PROGRAMS

Residential Respite A residential facility may be used for a short-term stay while you take a break, travel, or if you become ill.

Special Care Dementia Units

Many facilities have units with special care programming.

Assisted Living Facilities offer a variety of supportive services. Some specialize in dementia care.

Retirement Homes may accept a person with early memory loss and may help you make arrangements for additional in-home care within their facilities.



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house of welcome adult day services *specialized programs for persons with memory loss*



THE DAY PROGRAM Persons with memory loss and their families can benefit from the North Shore Senior Center's **House of Welcome Adult Day Services (HOW)**, providing specialized programs for persons with memory loss from Alzheimer's disease and other dementias. HOW's day program offers structured, therapeutic, small-group activities in a comfortable, homelike setting. Participants with early, as well as more advanced memory loss, enjoy meaningful activities and friendships, while caregivers benefit from time on their own. Special services of bathing, hairdressing, massage therapy and podiatry are available. Family members are provided supportive case management services.



ALZHEIMER'S FAMILY SUPPORT GROUP HOW offers a support group for family members of persons with memory loss from Alzheimer's disease and other dementias.

EARLY MEMORY LOSS PROGRAMS

Supported by the Martin and Mary L. Boyer Foundation



Mind Matters is a group program for persons with early memory loss, focusing on socialization, stimulation and support.



Mind Matters Family Support Group is offered to family members of Mind Matters participants.



COMMUNITY EDUCATION


HOW publishes an *Alzheimer's Caregiver Manual*. Educational programs on dementia and related topics are offered.



VOLUNTEER OPPORTUNITIES

Volunteers are an integral part of our HOW team, bringing a rich diversity of talents, making a real difference in the lives of our participants!

The mission of the North Shore Senior Center is to foster the independence and well being of older adults, enhance their dignity and self respect, and promote their participation in and contribution toward all aspects of community life.

 **For information, call House of Welcome at 847.242.6250**

1779 winnetka road, northfield, illinois 60093 • fax 847.242.6275 • www.nssc.org



Community Services Coordination
Respite Services
Adult Day Services
Dementia Care Specialty Program

