

Working With Family Caregivers of People With Memory Disorders



A NORTH CAROLINA | Information & Assistance Toolkit: Working With Family Caregivers of People With Memory Disorders 2002

*For Questions or Requests
for Additional Copies of this North Carolina Information & Assistance Toolkit*

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A NORTH CAROLINA | Information & Assistance Toolkit
Working With Family Caregivers of People With Memory Disorders

By Lisa P. Gwyther & Edna L. Ballard



Of the Duke Family Support Program & the Bryan Alzheimer's Disease Research Center
Duke University Medical Center

For the
North Carolina Department of Health & Human Resources
Division of Aging



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With Appreciation, We Gratefully Acknowledge Our North Carolina Aging Network Reviewers

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WHY A TOOLKIT?

Federal, state and local Older Americans Act services changed in the 21st century. With the introduction of the National Family Caregiver Support Program, the family caregiver became a new "consumer" focus for Information and Assistance Services. At the same time, North Carolina was building a network of county or local Information and Assistance specialists.

Family caregivers for people with memory disorders are families most likely to seek information and assistance on behalf of their relatives. With suggestions from the information and assistance specialists in North Carolina, Lisa Gwyther and Edna Ballard compiled this basic desk "toolkit" for reference while assisting family caregivers of persons with memory disorders.

IS THIS TOOLKIT FOR ME?

Yes, if you are an Information and Assistance specialist, a family caregiver specialist with an Area Agency on Aging, or a care manager or community advisory board member of a public, private or voluntary agency like the Alzheimer's Association.

No, If you are a health, human service or aging service professional who thinks you will never need to assist a family facing care for a member with Alzheimer's disease or another dementia.

THE TOOLKIT Specific Aims

- Information in lay language to enhance communication over the telephone and in-person among information and assistance specialists, family caregivers and persons with memory disorders.
- Tips for both professionals and family caregivers, recognizing many of us are both.
- Brief bulleted information in HARD COPY with web resources for further information. The goal is the right information at the right time and specific to the request or need. The aim is to avoid "overdosing or overwhelming" people with too much personally-irrelevant information.
- Format to ease copying of specific materials to give to or mail to family caregivers. We acknowledge diversity of families and care situations and suggest a personally tailored response to individual questions. It is not helpful to universally suggest that families "go online" for information. Some people still prefer to seek information from individual telephone encounters. The telephone offers a "preview" of service responsiveness.

HOW TO USE THE TOOLKIT

There are three sections

- Memory Disorders |The Basics
- For Information and Assistance Staff and
- For Family Caregivers of People with Memory Disorders.

The first and third section pages may be copied and distributed to families as needed. The middle section is a desk reference to enhance communication between aging services staff and family caregivers.

At each section divider, there is a list of its contents in order. The pages are not numbered because page numbering would limit the usefulness of specific pages as copied documents. The book is bound to keep all pages together and accessible.

The back pocket of the toolkit contains two complimentary booklets, single and on-line copies of which are available free (see inside of both booklets). The first is a caregiver guide for families of persons with memory disorders and the second addresses decision-making about help at home. These booklets were added simply to increase awareness of their availability and relevance to family caregivers of persons with memory disorders.

AN IMPORTANT MESSAGE FOR TOOLKIT USERS

These materials are "abridged, condensed and summarized" from 20 years of collected materials for families and professionals caring for persons with memory disorders. It was impossible to cite or credit accurately all original sources, including our own work. When families or human services professionals have an immediate need for information, there should be no "limits on access" to good ideas. Feel free to copy these materials for people who need and want them. Questions about sources should be referred to the Duke Family Support Program.



Section 1

MEMORY DISORDERS |The Basics

[Alzheimer's Disease | Fact Sheet](#)

[Characteristics of Alzheimer's Disease](#)

[Symptoms That May Indicate Dementia](#)

[When To Seek Help | 10 Warning Signs](#)

[Common Changes in Mild Alzheimer's](#)

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[Common Changes in Severe Alzheimer's](#)

[Facts About the Alzheimer's Association](#)

[Duke Family Support Program Offers You](#)

[Memory Disorders | Finding the Answers](#)

ALZHEIMER'S DISEASE

Fact Sheet

Definition

Alzheimer's disease (pronounced Alz'-hi-merz) is a progressive, degenerative disease that attacks the brain and results in gradual losses, first in memory and thinking then in function and behavior. Alzheimer's disease is the most common form of dementia. Dementia is a loss of intellectual function (thinking, remembering and reasoning) so severe that it interferes with an individual's daily functioning and eventually results in death. A certain amount of memory loss is a normal part of aging. The symptoms of Alzheimer's disease are much more severe than simple memory lapses. Men and women are affected almost equally. Identified risk factors are age and family history. Most people diagnosed with Alzheimer's are older than age 65; however, Alzheimer's disease can occur in people in their 30s, 40s and 50s.

Symptoms

Symptoms of Alzheimer's can include gradual memory loss, decline in the ability to perform routine tasks, disorientation, difficulty in learning, loss of language skills, impairment of judgment and planning and personality changes. The rate of progression varies from person to person. The time from the onset of symptoms until death ranges from 3 to 20 years; the average is 8 years. Eventually, persons with Alzheimer's disease become totally incapable of caring for themselves.

Diagnosis

Early and careful evaluation is important because many conditions, including some that are treatable or reversible, can cause dementia. Potentially reversible conditions include depression, adverse drug reactions, metabolic changes and nutritional deficiencies.

There is no single clinical test to identify Alzheimer's disease. A comprehensive evaluation to establish diagnosis will include a complete health history, physical examination, neurological exam, and tests including analysis of blood and urine and tests of memory and problem solving. Documenting symptoms and behavior over time, in a diary fashion, will help physicians understand the person's illness. The physician may order additional tests including brain scans (CT or MRI), psychiatric evaluation, and/or neuropsychological testing. While this evaluation may provide a diagnosis of possible or probable Alzheimer's disease, confirmation of Alzheimer's disease requires examination of brain tissue, which is usually done by an autopsy.

Treatment

Although no treatment can stop Alzheimer's disease, good planning and medical and social management can ease the burdens on the patient and family. There are currently four FDA-approved drug treatments specifically for the memory symptoms: tacrine (Cognex), donepezil hydrochloride (Aricept), and rivastigmine (Exelon), and galantamine hydrobromide (Reminyl). These and other medicines may help with mood, behaviors and function.

From: Alzheimer's Association, 7/2001.

CHARACTERISTICS OF ALZHEIMER'S DISEASE

ALZHEIMER'S IS:

- A diagnosable brain disease
- The most common form of dementia
- Progressive—it gets worse over time
- More than memory loss
- A common disorder
- Variable in symptoms and duration

ALZHEIMER'S IS NOT:

- Normal aging or amnesia
- Limited to people over 65 or to a specific race, religion, ethnic, or educational group
- Diagnosed by a single blood test or x-ray
- Mental retardation
- A character flaw or laziness
- Contagious
- Currently preventable or curable

From: Caring For People With Alzheimer's Disease: A Manual For Facility Staff (2001) by Lisa P. Gwyther

SYMPTOMS THAT MAY INDICATE DEMENTIA

Does the person have increased difficulty with any of the activities listed below?

Learning and retaining new information

Is repetitive; has trouble remembering recent conversations, events, appointments; frequently misplaces objects.

Handling complex tasks

Has trouble following a complex train of thought or performing tasks that require many steps such as balancing a checkbook or cooking a meal.

Reasoning ability

Is unable to respond with a reasonable plan to problems at work or home, such as knowing what to do if the bathroom is flooded. Shows uncharacteristic disregard for rules of social conduct.

Spatial ability and orientation

Has trouble driving, organizing objects around the house, finding his or her way around familiar places.

Language

Has increasing difficulty with finding the words to express what he or she wants to say and with following conversations.

Behavior

Appears more passive and less responsive; is more irritable than usual; is more suspicious than usual; misinterprets visual or auditory stimuli.

In Addition

Failure to arrive at the right time for appointments, look for difficulty discussing current events in an area of interest and changes in behavior or dress. Positive findings in any of these areas generally indicate the need for further assessment for the presence of dementia.

AHRQ Guideline Panel 1996.

See also: Is It Alzheimer's Disease? 10 Warning Signs from the Alzheimer's Association.

WHEN TO SEEK HELP

10 Warning Signs

Alzheimer's or other memory disorders symptoms may develop slowly and go unnoticed for some time. First there is a gradual loss of "what just happened" or recent memory, thinking or reasoning ability. Families begin looking for help when there are changes in daily function or in the person's ability to manage safely on his/her own. Consider these 10 items from the Functional Activities Questionnaire (AHRQ, 1996) as indicators that it's time for a medical evaluation and help from community services.

1. Trouble writing checks, paying bills, doing simple math or the checkbook.
2. Problems with business records, taxes or personal papers
3. Difficulty shopping alone for clothes, household items or groceries
4. Trouble with a familiar game or remembering words from a familiar hobby
5. Difficulty heating water, making a hot drink or turning off the stove
6. Problems preparing or eating balanced meals at reasonable times
7. Problems keeping track of current events
8. Trouble paying attention to or understanding a TV show or book
9. Problems remembering family events, holidays, medications
10. Difficulty traveling out of the neighborhood



*HINT: Dementia is a **DECLINE** from previous abilities. If the person never did one of these activities, it is **NOT** a change indicating a problem.*

COMMON CHANGES IN

Mild Alzheimer's

- Loses spark or zest for life—does not start anything.
- Loses recent memory without a change in appearance or casual conversation.
- Loses judgment about money.
- Has difficulty with new learning and making new memories.
- Has trouble finding words—may substitute or make up words that sound like or mean something like the forgotten word.
- May stop talking to avoid making mistakes.
- Has shorter attention span and less motivation to stay with an activity.
- Easily loses way going to familiar places.
- Resists change or new things.
- Has trouble organizing and thinking logically.
- Asks repetitive questions.
- Withdraws, loses interest, is irritable, not as sensitive to other's feelings, uncharacteristically angry when frustrated or tired.
- Won't make decisions—"I'll have what she is having."
- Takes longer to do routine chores and becomes upset if rushed or if something unexpected happens
- Forgets to pay, pays too much, or forgets how to pay—may hand the check-out person a wallet instead of the correct amount of money.
- Forgets to eat, eats only one kind of food, or eats constantly.
- Loses or misplaces things by hiding them in odd places or forgets where things go, such as putting clothes in the dishwasher.
- Constantly checks, searches, or hoards things of no value.

COMMON CHANGES IN

Moderate Alzheimer's

- Changes in behavior, concern for appearance, hygiene, and sleep become more noticeable.
- Mixes up identity of people, i.e. thinking a son is a brother, or wife is a stranger.
- Poor judgment creates safety issues when left alone: may wander and risk exposure, poisoning, falls, self-neglect, or exploitation.
- Has trouble recognizing familiar people and own objects: may take things that belong to others.
- Continuously repeats stories, favorite words, statements, or motions.
- Has restless, repetitive movements in late afternoon or evening—pacing, trying doorknobs, fingering draperies.
- Cannot organize thoughts or follow logical explanations.
- Has trouble following written notes or completing tasks.
- Makes up stories to fill in gaps in memory. Might say, "Mama will come for me when she gets off work."
- May be able to read but cannot formulate the correct response to a written request.
- May accuse, threaten, curse, fidget, or behave inappropriately, such as kicking, hitting, spitting, biting, screaming, or grabbing.
- May become sloppy or forget manners.
- May see, hear, smell or taste things that are not there.
- May accuse spouse of an affair or family of stealing.
- Naps frequently, or awakens at night believing it is time to go to work.
- Has more difficulty positioning the body to use the toilet or sit in a chair.
- May think mirror image is following him or television story is happening to her.
- Needs help finding the toilet, using the shower, remembering to drink, and dressing for the weather or occasion.

COMMON CHANGES IN

Severe Alzheimer's

- Doesn't recognize self or close family.
- Speaks in gibberish, is mute, or is difficult to understand.
- May refuse to eat, chokes, or forgets to swallow.
- May repetitively cry out, pat, or touch everything.
- Loses control of bowel and bladder
- Loses weight and skin becomes thin and tears easily
- May look uncomfortable or cry out when transferred or touched.
- Forgets how to walk or is too unsteady or weak to stand alone.
- May have seizures, frequent infections, falls
- May groan, scream, or mumble loudly.
- Sleeps more.
- Needs total assistance for all activities of daily living.

FACTS ABOUT THE ALZHEIMER'S ASSOCIATION

The Alzheimer's Association is the premier source of information and support for Americans with Alzheimer's disease. The Association's mission is to eliminate Alzheimer's through the advancement of research and to enhance care and support for individuals, their families, and caregivers. The official name of the organization is the Alzheimer's Disease and Related Disorders Association, Inc.

Improving Care, Offering Support

Through its national network of chapters, the Alzheimer's Association offers a broad range of programs and services for people with the disease, their families, and caregivers. With more than 35,000 volunteers, more than 4,000 support groups, and more than 48,000 hours of programs for family caregivers, the Association and its chapters can provide assistance with the following needs:

- Learning about how the disease progresses and what to expect
- Finding emotional support
- Securing help for legal, financial, and living-arrangement decisions
- Learning about current care and treatment options
- Obtaining information about clinical trials of potential treatment
- Developing skills to provide quality care
- Accessing professional and community services
- Reducing stress and managing lifestyle changes

Key Programs and Services Of The Association Include The Following:

- Safe Return, a nationwide identification program to assist in the safe and timely return of individuals who have wandered from home
- Chapter-sponsored support and education programs for individuals with the disease, family members, and caregivers
- National and chapter Helplines providing information and emotional support
- Educational brochures and newsletters
- National and regional education conferences and programs for health care providers, residential care professionals, and other caregivers
- The Benjamin B. Green-Field National Alzheimer's Library and Resource Center, which has a collection of more than 5,000 books, audios, Videos, and CDs; 120 periodicals; a Web-accessible catalog; materials in 17 languages; and various research services, such as literature searches and topical reading lists

The Alzheimer's Association represents the interests of people with the disease and their families before federal, state, and local government and with health and long-term care providers. Contact the association for more information about program and services: Call (800)272-3900 or visit the Web site at <http://www.alz.org>; or e-mail info@alz.org.

Are You Concerned About Someone With A Memory Problem?

Do You Live in North Carolina?

Duke Family Support Program Offers You:

- Free confidential, personalized tips on caring for people with memory disorders
- Free telephone help with care decisions or coping strategies
- A current information packet on Alzheimer's disease
- Free Caregiver Newsletter mailed to your home or office
- Current research updates on memory disorders
- Help in selecting support groups, education programs, websites or books
- Help selecting and evaluating assisted living or nursing facility care

Duke Family Support Program
(919) 660-7510
Toll Free: (800) 672-4213 in North Carolina

MEMORY DISORDERS

Finding The Answers

ORGANIZATIONS >

- ◇ Alzheimer's Association (800) 272-3900 for local support and information
- ◇ ADEAR (National Institute on Aging) (800) 438-4380 research updates and care tips
- ◇ Duke Alzheimer's Family Support Program (800) 672-4213 NC clearing-house for families and professionals concerned about persons with memory disorders
- ◇ NC Seniors Health Insurance Information (800) 443-9354

BOOKS >

- ◇ *Moving a Relative with Memory Loss: A Family Caregiver's Guide* (2001) \$10 booklet from www.whisppub.com
- ◇ *Nursing Homes: Getting Good Care There* (2002) \$11.95 paperback from National Citizens Coalition for Nursing Home Reform (202) 332-2275 or www.nccnhr.org
- ◇ *The 36-Hour Day* (2001) paperback available in bookstores or Amazon.com Basic text on all facets of Alzheimer's and caregiver issues.
- ◇ *Another Country: Navigating the Emotional Terrain of Our Elders.* (2000) paperback in bookstores. For adults caring for aging parents.



MEMORY DISORDERS

Finding The Answers



WEBSITES >

- ◇ www.alz.org Alzheimer's Association overview, updates and tips
- ◇ www.alzheimers.org National Institute on Aging. Research updates & excellent patient and family information (*See 2002 Alzheimer's Disease Medications.*)
- ◇ www.adrc.wustl.edu/ALZHEIMER Online support group and great topical index
- ◇ www.benefitscheckup.org Free confidential check of elder's eligibility for state and federal assistance programs.
- ◇ www.agelessdesign.com Safety at home, products at www.alzstore.com
- ◇ www.caregiver.org Excellent overviews and tips for families of adults with brain disorders.
- ◇ www.fullcirclecare.org Excellent NC and Alzheimer's information.
- ◇ www.medicare.gov Prescription drug assistance, compare nursing homes.
- ◇ www.medicarerights.org/medicareanswersonline.html Medicare answers.
- ◇ www.stoppain.org/caregivers/resource_form.html Pain and palliative care tips for family caregivers.
- ◇ www.aoa.gov/caregivers/default.htm General and specific tips for family care.
- ◇ www.healthinaging.org/public_education/eldercare American Geriatrics Society home care guide.
- ◇ www.dhhs.state.nc.us/aging NC state and local services; great tips.
- ◇ www.law.wfu.edu/eclinic NC elder law consumer information.
- ◇ <http://adrc.mc.duke.edu> Bryan Alzheimer's Disease Research Center at Duke.
- ◇ www.alzwell.com Newsletter with tips emailed twice a month.
- ◇ www.caregiver.com See Alzheimer's safety and incontinence information.
- ◇ www.aarp.org/caregive Useful brief tips.
- ◇ www.ec-online.net See communication tips.
- ◇ www.buildingbetterhealth.com/topic/alzcomm Communication tips.
- ◇ www.buildingbetterhealth.com/topic/topic/alzuncoop Dealing with resistive or uncooperative behaviors.
- ◇ www.caregiversmarketplace.com. Group purchasing program for home care supplies. (866) 327-8340.
- ◇ www.carolinasendoflifecare.org Hospice, end-of-life care and advance care planning materials. (800) 662-8859.



Section 2

FOR INFORMATION & ASSISTANCE STAFF

Telephone Support | Why It Works

Helpful Reminders About Family Care

What Do Family Caregivers Need From You

Guidelines For Family Education About Memory Loss

When Feelings Get in the Way

Dealing with Denial

Family Decision-Making Hazards

How to Overcome Barriers to Family Use of Services

Helping Families Choose Appropriate Help

When Counseling Family Caregivers

Family Counseling | Do's and Don'ts

Themes in Working with Family Caregivers

Listening

Common Openers from Families Seeking Help

Sample Responses to Families

Practice Guidelines I and II

Warning Signs of Caregiver Stress

Memory Disorders | Tips for Improving Communication

Unraveling Challenging Behaviors

TELEPHONE SUPPORT

Why It Works

- Familiar Technology
- Low Cost
- Time and Energy Constraints
- Potential for Continuity/Repetition
- Confidentiality and Privacy
- Trust/concrete Giving
- One-to-One Time
- Family Sets Pace, Can Withhold Information or Ask Specific Questions

The Telephone Works Well as a Vehicle for Caregiver Support Because of:

A high comfort level

Since the telephone is a familiar technology, the comfort level of the caller is high. Consider the contrast of an unfamiliar situation--like visiting an adult day center.

Meeting time and energy constraints

Sometimes caregivers just cannot get out. Sometimes it is just too much trouble to try to get out.

The potential for a continuing relationship

Your helpful information may result in the caregiver calling back. Over time, a helping relationship develops with people you never see.

Confidentiality and privacy

Caregivers appreciate talking without needing to give their name, rank and serial numbers. Do not start taking assessment information the minute a caregiver calls. First give information, then ask questions. Family caregivers will be more open later.

The potential for repetition

Some caregivers will call and ask for the same information 25 times. They really need to hear it 25 times before they can accept it. Be willing to repeat.

Concrete giving

Over the phone, you can offer something specific to do right now, during a crisis or a point of pain or concern. If she is concerned about her mother wandering, tell her how to order a "Safe Return" bracelet. Offer to mail a sheet of care tips to someone who doesn't use computers.

HELPFUL REMINDERS ABOUT FAMILY CARE

- Family care is an adaptive challenge: The family is not necessarily the problem. Few incentives (financial, religious, or counseling) will make an unwilling family assume care. Few disincentives will keep a determined husband or wife from honoring his/her commitment.
- The "family" is rarely one voice. There is no perfectly fair and equal division of family care responsibility. Most chronic illnesses get worse over time and elders need more help over time. Families can expect a permanent imbalance in the normal give and take of family relationships. Families can still work toward a more equitable sharing of responsibility.
- Few families have the luxury of one person needing care at a time. There is much less manipulation by dependent elders than there is unmet real dependency needs. There is also more underreporting of burden and underutilization of services than the reverse.
- There is no one right or ideal way or place to offer family care. Many families are forced to choose between equally unacceptable options. Successful family caregivers gather information, take direct action when it is possible, and often reframe things they can't change in more positive terms, e.g. "It could be worse—at least I still have her. Tomorrow may be a better day."
- Successful family caregivers are flexible in adjusting expectations of themselves, the dependent elder and other family members to fit needs and capacity of all. Coping with family care requires a sense of humor, a strong faith, belief or value system, creativity, practical problem solving skills and support from friends and family.
- A family caregiver's knowledge of an available service, need for the service and access to the service do not necessarily lead to appropriate timely use of services. Remember, there are no bad defense mechanisms. Some people need to deny the inevitable outcome (like loss of a loved relative) in order to provide hopeful, consistent care.
- There is no perfect control in a care situation. Families are better off if they work on their reactions to stress or lack of control.
- A primary caregiver at home is efficient and preferred. Primary caregivers need breaks, backup people and services to supplement their personalized care. Even in ideal situations, contingency plans are necessary.

WHAT DO FAMILY CAREGIVERS NEED FROM YOU?

- Relevant information.
- Acknowledgment.
- Reminders.
- Absolution/forgiveness.
- Decisional support.
- Help in mobilizing other family members.
- Permission to be imperfect.
- Humor, compassion, fresh perspective.
- Concrete help e.g. let your fingers do the walking.
- Accompany or "be with" caregiver.
- Consumer guidance.
- Safe time to express feelings.
- Help with appraisal of options, adaptation, problem solving.

GUIDELINES FOR FAMILY

Education About Memory Loss

- Distinguish normal forgetting from dementing illness.
- Timing of information is crucial. Suggest legal/financial precautions early.
- Consider special needs: Sensory-impaired, children, minorities, non-English-speaking.
- Repetition Helps: Change medium, or use person with greater authority, credibility.
- Individualize the approach—What do you need to know?
- A Common understanding within a family will minimize conflict. Give similar information to all family members or talk to them together.
- Universalize or Normalize patient/family reactions, e.g., many patients are easily frustrated or irritable; even caring family members lose their tempers.
- Emphasize heterogeneity of patients/families/solutions, e.g., there are many successful ways to discourage driving.
- Focus on expectations, ambiguities, remaining strengths, fears.
- Offer an understandable framework, e.g., broken brain.
- What have they read, heard? Correct misconceptions, e.g., It is not contagious.
- Encourage peer/consumer input from support group interaction.
- Suggest continuing source for additional information, e.g., Alzheimer's Association, Alzheimer's Research Center, Duke Family Support Program.
- Present information in hopeful terms, e.g., research is accelerating; there is new national interest in quality care options.

DEALING WITH DENIAL

- Remember that denial is not a conscious decision and that it may be a helpful defense.
- Recognize that denial may be temporary and that you can help the caregiver to accept current realities.
- Make sure that all family members have access to enough information about Alzheimer's and related dementias.
- Give relatives and friends a first-hand chance to see changes in behavior and abilities. Let them experience the tasks of caregiving for themselves and for longer than a few minutes.
- Talk honestly about the disease and how it is affecting the family, the person with the illness, and others.
- Give the person in denial concrete ways in which they can help and support the primary caregiver. What appears to be denial may be uncertainty about what is expected.
- Make sure that issues of health and safety are resolved.

FAMILY DECISION-MAKING HAZARDS

- Unrelenting crises make for impulsive decisions
- Old promises – "I'll never put you in a nursing home."
- Chasing ghosts of the care receiver as s/he once was.
- Different perceptions of needs.
- Different expectations of each other and services.
- Control issues – "I won't give my husband to strangers."
- Too few good choices of affordable available services.

HOW TO OVERCOME BARRIERS

To Family Use Of Services

- First, acknowledge what is working in the family caregiver's plan.
- Seek informal, volunteer, low cost, subsidized or alternative payment source services first.
- Have physician, clergy or trusted family friend reinforce service use.
- If the caregiver is focused on the elder, suggest benefits to the elder.
- Let your fingers do the walking. Never refer without checking on service availability.
- Normalize initial reluctance to seek help—fears and stigma.
- Label benefits/personal relevance, pro-active aspects of service use and **WHY NOW?**
- Use culturally sensitive and jargon free service descriptions.
- Allow time for family to express fears and talk about barriers.
- Correct misconceptions about service use or eligibility.
- Don't oversell services or outcomes.
- Suggest only one change in service use at a time.
- Suggest family talk to current family caregiver user of the service.

HELPING FAMILIES CHOOSE APPROPRIATE HELP

My Problem Is...	You May Need...
<i>"I need help bathing him."</i>	Personal care, home health aide
<i>"I just want time to run errands."</i>	Respite care or adult day center
<i>"I was looking for something that would give my father a reason to get up in the morning. He's a people person. If I keep him home with just me, it's boring for him. He needs stimulation and I need a break."</i>	Adult day center program, student or volunteer companion/escort to senior center program or other community activities
<i>"I Need help getting him to the day center"</i>	Transportation, escort
<i>"I need someone to teach me caregiving skills."</i>	Home health nurse or class for family caregivers
<i>"He calms down when he's riding in the car. I want someone to take him for rides to his old neighborhood."</i>	Private companion, senior companion, student
<i>"I was looking for someone with patience and understanding to work with my husband."</i>	Private companion or sitter from church, neighborhood or newspaper ad
<i>"What I needed was someone to help with the washing when I was sick."</i>	Chore worker, homemaker service or private maid service
<i>"I have live-in help, but we both needed respite. My husband is such a high-demand man that there is no respite. Even when he goes to the hospital, he still requires both of us to be there."</i>	Home care agency private duty companion, aide or Licensed Practical Nurse
<i>"I was looking for help so I can keep him home. Our home is a better environment than a nursing home."</i>	Private or agency home aide or home health service
<i>"I was looking for the expertise of others."</i>	Social workers, Area Agency on Aging, Alzheimer's Association support group or family physician
<i>"I was looking for somebody I could trust and somebody that I knew would take care of my husband while I run errands. I would like to go out to lunch with friends without worry."</i>	Senior companion program, church volunteer or any of the above
<i>"I feel burnt-out and depressed."</i>	Caregiver support group, physician or counselor

WHEN FEELINGS GET IN THE WAY

Why Caregivers Hesitate To Get Needed Help

"I don't want to be a bother. What's the use?"

"No one cares for him the way I do."

"I should be able to do this myself. He's my husband till death do us part."

"We're saving for a rainy day."

"Getting help with this feels like another irreversible step."

"The doctor didn't say we needed day care."

"Her Alzheimer's is the least of our problems."

"We have daughters for that."

"My husband told me never to let strangers work in the house—they steal."

"If I turn to social workers, they will put her away."

"He doesn't want to go to an adult day care."

"Those people are unreliable—they never showed up for my grandma."

"He would never forgive me."

"All that red tape is an invasion of our privacy."

"He's ok to drive—he sees better than I do."

"Can I trust these people to appreciate what a wonderful man he was?"

"It will seem to her that I am giving up on her."

"I can't stand to think what this new step will mean to her and to me."

"I have put years of my life into taking care of her. What will I do if I give up?"

"It's too much effort to get relief for just a short time."

"He can't protect himself. It's my responsibility to protect his image, his dignity. You would not believe some of the things he does."

"I can't afford the service and I don't qualify for anything. We're not a charity case."

"It's so frustrating just trying to get information about services. Everybody has a different rule, a different requirement."

"The people who talk to you are not always nice. They can make you feel stupid and behave as if they are doing you a favor. Why should I put up with that?"

WHEN COUNSELING FAMILY CAREGIVERS

Pay Attention To

AMENITIES

Comfort, privacy to talk, initial polite small talk, undivided quality time focused just on the family caregiver.

FEELING TONE

Hesitation, energy level, pressured rushed speech, disorganized thoughts, anger, sadness, grief, silences, tears, non-verbal appearance.

ETHNICITY

Race, culture, education, literacy, age, income, social class and regional differences MATTER.

VALUES, EXPECTATIONS

Clues to desired outcomes e.g. "We won't consider nursing homes."

MYTHS

Distortions, partial or incorrect information e.g. "I thought all old people were just like that."

RED FLAGS

Subtle hints of impending trouble "We won't tolerate "those people" in our house" or "Before he totaled the car..." or "after my cancer surgery..." or "Sometimes I wish she would just go away."

FAMILY COUNSELING

DOs

- Listen—does not imply agreement or endorsement.
- Know aging, chronic diseases, medications, health and service options.
- Accept secrets, silences and anger without judgment.
- Be whoever they need you to be: comforter, peer, authority, expert, coach, advocate.
- Ask open-ended, reflective but non-leading questions.
- Clarify meanings/Use metaphors for descriptions of respite like "recharge" a battery.
- Fill in partial or incorrect information discreetly.
- Create choices by re-framing the problem.
- Break down issues into doable steps.
- Prioritize and be pragmatic e.g. *"First, let's get the guns out of the house"*
- Offer tentative suggestions/short term trials.
- Lend energy and positive attitude.
- Offer tangible help. *"Can I make that call for you?"*
- Ask what else? Did I miss something?
- Summarize with realistic expectations.

DO NOT USE

- Jargon, hype, psychobabble.
- Loaded words (mental health, vegetative state).
- Assumptions.
- Pigeon-holing or trivializing.
- Rapid probing of family secrets.
- Self-revelations (it's NOT about YOUR mother)
- False promises

THEMES IN WORKING WITH FAMILY CAREGIVERS

- Normalize variability
- Address safety and security
- Mobilize other family members, friends
- Help with decision-making and transitions in care or caregiver
- Deal with accepting help and "letting go"
- Capitalize on elder's remaining strengths, capacities
- Acknowledge feelings and loss

LISTENING

When I ask you to listen to me and you start giving me advice, you have not done what I asked.

When I ask you to listen to me and you begin to tell me why I shouldn't feel that way, you are trampling on my feelings.

When I ask you to listen to me and you feel you have to do something to solve my problem, you have failed me, strange as that might seem.

Listen! All I ask is that you listen. Not to talk or do, just to hear me.

Advice is cheap. Fifty cents will get you "Dear Abby" in the newspaper.

And I can do for myself. I'm not helpless. Maybe discouraged and faltering, but not helpless.

When you do something for me that I can and need to do for myself, you add to my fear and inadequacy.

But when you accept that I do feel what I feel, no matter how irrational, then I can quit trying to convince you and get to understanding what's behind my irrational feeling. And when that's clear, the answers are obvious and I don't need advice. Irrational feelings make sense when we understand what's behind them.

So please listen and just hear me. And if you want to talk, wait a minute and I will listen to you.

Solving problems is easy. It is living with the solutions that is tough.

-Anonymous

COMMON OPENERS FROM FAMILIES SEEKING HELP

"Nobody understands...They don't even believe me."

"I don't know if you can help me—I never had to talk about my husband this way before...I never called one of these numbers before..."

"It's not fair..."

"I bet you heard this 1,000 times."

"It wasn't supposed to be this way—I never expected this."

"I'm so mad—I can't get satisfaction anywhere. I can't be the first person who needs this help."

"My father was just diagnosed with AD. I'm helping Mom explore options for his care."

"I'm going to tell you something you won't believe, but maybe you will..."

"You just don't know what it's like to live with someone like this."

"Is this normal? Is this normal for AD?"

"Sometimes I get so cross with him it scares me..."

"It's like I don't even know who she is anymore...She's different—certainly NOT the woman I married."

"How can I take driving away from him?...He's lost so much already."

"How old do you have to be to get AD? Does stress cause it?"

"Doesn't this run in families? Can I be checked now?"

"What about sex...well, can it be affected by AD?"

"I'm sure she could do it if she tried—she just wants attention, right?"

"She never wants to do anything anymore. She's getting lazy."

"He follows me everywhere—won't let me out of his sight."

"She seems more interested in her dead "Daddy" than her husband!"

SAMPLE RESPONSES TO FAMILY CAREGIVERS

"Does this sound familiar? Am I on the right track?"

"I bet you have been thinking about this for some time—Have you considered, read, been told...?"

"Sounds like you are between the devil and the deep blue sea? Maybe there are no "ideal" choices...?"

"I have known some people in your situation who said they felt (insert: angry at God, sad, confused, hopeless, overwhelmed). Do any of these feelings describe you at this point?"

"Your daughter said to call? I wonder what she thought we could help you with?"

"You are wise to call now when you have time to consider options."

"Did something happen recently that prompted you to call now?"

"Most people like you say this is uncharted territory. I can tell you that many families surprise themselves with their success in figuring things out."

"I was just talking to another retiree who mentioned how hard it was to ask an agency for help. Perhaps you, too, did not know that all tax-paying people in this country are entitled to this sort of help when they need it."

"Sometimes it helps to talk to someone who isn't a relative or friend. I know you wonder whether there's any point in talking about it or whether anyone else can help. But, if you are that uncomfortable or it is interfering with your work, relationship, or ability to enjoy life, it may be worth a try. Counselors don't take away your problems, but they can help sort them out. Just realize, no one can know enough about you and your situation to run your life better than you do after one conversation...".

"Sounds like suspiciousness is harder for you than his other symptoms?"

"Services and agencies are confusing. That's why we are here. Many benefits are based on income. With your permission, I could check on whether or not there is a middle income sliding scale. I could give you the income range and you could tell me whether or not it is worth pursuing."

"You will undoubtedly have other questions or run into other snags. My name is Lisa. Let me know if other things come up."

PRACTICE GUIDELINES

To Assist Families In Making The Best Choices For Everyday Care

- Focus expressly on values and care preferences as part of the assessment process to facilitate mutual understanding of what care receivers and caregivers need and prefer.
- Start talking as soon as possible about preferences for everyday care and for handling daily activities, such as finances and living arrangement—before problems arise, a crisis occurs or the person with cognitive impairment becomes unable to express wishes.
- Support the active participation of the person with cognitive impairment in developing the care plan. Whenever possible, involve family members other than the primary caregiver.
- Recognize the strengths of the person with cognitive impairment and encourage him or her to express his or her own values and preferences.
- Keep in mind that persons with memory loss and other cognitive impairments can often make decisions about their care or state specific preferences for everyday activities even though they are unable to answer seemingly simple questions about themselves (e.g., number of children, birth date).
- Recognize the family caregiver's need for information, emotional support and practical help. Time constraints, sadness over loss and the stress of new and difficult tasks can be a great burden to the family member involved in care. The caregiver must provide hands-on care and supervision, try to determine what the care receiver wants and then balance these new roles and situations with other work and family responsibilities.
- Enter into the discussion among family members with an open mind. Take into account the wishes and preferences of the person with cognitive impairment and the needs and situation of the family caregiver.
- Encourage all family members to recognize one another's rights to make their own life choices even if there may be disagreement about these choices. If health or safety is at immediate risk, assist the family to reach agreement.

Adapted from: Factsheets: Helping Families Make Everyday Care Choices. Family Caregiver Alliance

PRACTICE GUIDELINES II

Questions That May Help Family Members Talk About Values and Preferences Include:

- How much is your family willing to spend for paid care?
- Who in the family will provide care and/or make arrangements for care.
- What sacrifice of money or time is too much?
- What kind of help do you need right now? What do you think you might want in the future?
- Can you get used to having a stranger in your home to help you? Can you adjust to someone who speaks a different language?
- Do you want some care to be provided outside of the home? What kind? How often? How long?

To Encourage Expressing Daily Care Wishes Of The Person With A Memory Disorder, Consider Asking:

- When do you like to bathe? Is a shower all right?
- Would you rather have someone you know help with bathing or someone you don't know?
- Do you mind if someone of the opposite sex helps you with baths?
- What do you like to wear at home? When you go out?
- Do you like to exercise? How often?
- Do you like to go outdoors? Do you prefer being inside, near a window?
- Would you rather be alone most of the time or have company? Do you like conversation? Radio or television? News or music?

Adapted from: Factsheets: Helping Families Make Everyday Care Choices. Family Caregiver Alliance.

WARNING SIGNS OF CAREGIVER STRESS

- Denial/neglect
- Anger at elder, family, doctors, services
- Withdrawal/feeling overwhelmed
- Anxiety/constant worry
- Depression/no pleasure in anything anymore
- Exhaustion/sleeplessness
- Worsening of chronic conditions
- Irritability
- Lack of concentration/disorganization
- Change in appearance of caregiver or environment



MEMORY DISORDERS

Tips For Improving Communication

Most individuals with memory disorders have difficulty with communication, and this is likely to get worse over time. The person may frequently lose a train of thought; have difficulty organizing words logically, have trouble finding words; use familiar words to replace lost words; and, in some cases, use slang or offensive words. Individuals whose native language is not English may revert to speaking a first language.

Some Approaches Which May Be Helpful:

Look like you're really listening

Although it can be difficult to slow down enough during a busy day, it is vitally important. Look the person in the eyes, be patient, and show that you're listening.

Focus on feelings, not facts

If you're not clear what the person is trying to say, try focusing on the feelings behind the words. Saying "It looks like you're really angry" may help a person who is having a tough time putting his feelings into words.

Address the person by name

Whenever it is appropriate and as often as you can, call the person by name. It is an act of courtesy as well as it helps with attention and orientation.

Treat the person with dignity and respect

Many individuals with Alzheimer's feel that the illness has robbed them of their "adult" status—their independence. Talking down to them or talking about them as if they were not present only serves to reinforce that feeling.

Turn questions into answers

Rather than ask "Do you need to go to the bathroom?" say, "The bathroom is right over there. I am going that way."

Ask one question at a time using a gentle, calm, relaxed tone of voice

Instead of asking, "Would you like to have lunch, play bingo and try the health check?" say, "Please join us for lunch now."

Choose your words carefully

Simplify your message. Avoid using expressions that might be taken literally. "Please get in the car" is clearer than "Jump in and we're off".

UNRAVELING CHALLENGING BEHAVIORS

Rethink

Is the behavior harmful or scary to the individual or others, or can you accept it? Let forgetting work for the individual. Don't remind, argue, scold, lecture, or confront someone after an outburst.

Redirect

If the individual is pacing, agitated, or scared, provide a more positive activity, such as a walk, a dusting job, or a memory box to sort through. Distract the person; observe recurring behaviors and avoid situations that lead to problems; or let the person vent his frustration or anger in a controlled, secure place.

Restrict

Stop the person from doing things that are harmful. Take dangerous objects from the room.

Reassure

Say, "I know you're upset. May I help you?" If the person is searching frantically, calmly join in her search while suggesting that you know you can find the lost item together. Let her know she is not alone and that you understand how important the missing item is to her. Nothing comforts better than standing by a person who is upset, offering sympathy, understanding, a shoulder to cry on, a tissue, or a knowing kind look. Do not ask a lot of questions.

Routines, Rituals, and Repetition

Knowing what will happen next reassures people with Alzheimer's. Rituals help, such as handing the person her favorite audiotape or cup of tea. Security objects can reassure and comfort.

Register The Person with the Safe Return Program Through the Alzheimer's Association

Safe Return is a national program to help identify people who wander and become lost. Registered individuals receive a bracelet and clothing labels with a toll-free crisis number. This bracelet alerts others to an individual with a memory disorder who may need assistance.

Remain Realistic

About the person's abilities. Concentrate on the person's remaining skills, not deficits. Plan activities for best times of day. Help her/him compensate by doing for him/her what s/he can no longer do with ease.

Remain Objective About Your Own Strengths and Limitations Caregivers vary in their ability to cope with and manage a person who has Alzheimer's. Know your limits as well as your strengths, and use support from others.



Section 3

FOR FAMILY CAREGIVERS | Of People With Memory Disorders

Alzheimer's Disease Treatment

Talking with the Doctor

Who Pays for Medical Care?

Prescription Drug Assistance

Talking with People with Memory Disorders

From the Perspective of Persons with Memory Loss

The Ten Absolutes

What is Agitation?

Behavior Basics

Personal Care Tips

How to Make Tough Care Decisions

Family Decision-Making

Personal Documents

Can A Person with Alzheimer's Live Alone?

Fraud Protection

Should Mom Move in with Us?

Fretting From Afar

Finding the Help You need

Long-Term Care

How to Get Service Information When You Call

Hospitalization Happens

Pain and Dementia

Successful Nursing Home Visits

Family Caregiver Affirmations

10 Signs of Caregiver Stress

Nine Things to Help You Cope

Why Try A Support Group?

Preparing for the Death of a Loved One

ALZHEIMER'S DISEASE TREATMENT

HOW IS ALZHEIMER'S DISEASE DIFFERENT FROM NORMAL AGING?

The symptoms of Alzheimer's disease involve more than simple lapses in memory. People with Alzheimer's have difficulties in communicating, learning, thinking and reasoning that can affect their work, social and family life. Alzheimer's is a disease that destroys brain cells – which is not a normal part of aging.

HOW DOES A PHYSICIAN KNOW IF IT IS ALZHEIMER'S DISEASE?

There is no single test that can diagnose Alzheimer's disease, but skilled doctors are 80 – 90% accurate. A full evaluation includes:

- An accurate medical and psychiatric history
- A neurological and physical exam
- Lab tests to rule out anemia, vitamin deficiencies, thyroid and other conditions.
- An evaluation of the person's ability to do common daily activities such as managing money and medicines.
- A mental status exam to evaluate the person's thinking and memory
- An interview with the family or someone who sees the person regularly
- A brain scan, paper and pencil testing and additional labs as needed

HOW CAN YOU HELP THE PHYSICIAN?

- Be prepared for an evaluation with a list of current prescribed medicines and doses, and a list of anything the person is taking or doing for his/her health.
- Bring a list of signs, symptoms or situations that indicate a change and a decline in the person's abilities, mood, personality or behavior. For behavior changes, be ready to describe when each behavior started, the frequency of the behavior, the time of day it occurs or what seems to bring it on, and what strategies you have tried already to handle the behavior changes.

WHAT CAN BE DONE IF THE DIAGNOSIS IS ALZHEIMER'S?

Although there is no cure or no stopping Alzheimer's in its tracks, there are ways to treat some of the symptoms.

- Use of cholinesterase inhibitors to treat memory symptoms. These medicines may improve quality of life, memory, thought, attention and reasoning. These medications work most effectively for people who are mildly to moderately affected by the disease. This is why early recognition and diagnosis is so important.

- Vitamin E is an option to help with some symptoms of Alzheimer's disease. Vitamin E is an antioxidant, and it may aid in the breakdown of free radicals that may be damaging brain cells in people with Alzheimer's disease.
- Referral to appropriate activities like exercise or adult day centers.
- Prompt treatment of medical or psychological conditions that may add to memory problems or symptoms of confusion.

WHAT CAN BE DONE FOR BEHAVIOR CHANGES?

At times, people with dementia may have changes in behavior such as wandering, paranoia, suspiciousness, hitting or resistance to help with personal hygiene. The doctor may suggest:

- Enrollment in the Alzheimer's Association Safe Return Program, an identification program for memory impaired adults.
- Modifying the person's environment to reduce confusion caused by overstimulation from noise, glare or other sources
- Explaining a task with step-by-step directions
- Providing a predictable routine at home, playing music during meals or bathing, insuring regular light exercise and sleep
- Providing reassurance to the confused person without challenging his/her accusations or misperceptions, just redirecting or distracting him/her.
- If these strategies aren't enough, the doctor may prescribe medicines for symptoms of depression, restlessness, hallucinations, hostility and agitation.

HOW CAN THE DOCTOR HELP YOU PLAN FOR THE FUTURE?

The doctor may suggest that you start planning now for future health care decisions with an advance directive. An advance directive is a legal document that a patient signs while capable of making sound decisions. It directs how healthcare treatment will be made in the event of future incapacity. There are two types of advance directives:



- *Living Will states the person's desire to die a natural death and not be kept alive by artificial means.*
- *Durable Power-of-Attorney for Health Care designates an individual who can make health care decisions on behalf of the impaired person if he or she is not able to give medical consent.*

The doctor may also suggest that the family caregiver maintain regular visits to a doctor to insure he/she is in good health.

TALKING WITH THE DOCTOR

YOU ARE ENTITLED TO

1. Answers to your questions
2. Easily understood explanations
3. Kind treatment
4. Appropriate referrals to specialists
5. Appropriate referrals to community services and support

WHAT SHOULD YOU ASK THE DOCTOR?

1. What is the diagnosis?
2. Which tests are needed and why?
3. What are the treatment options?
4. Should any foods, activities or other medications be avoided while taking medicine for memory symptoms?
5. What is the future course of the disease?
6. Do you have written information about the disease or treatment?
7. Are there services available to help or support our family?
8. Do we need to see another doctor or specialist?
9. Can we schedule a follow-up appointment?
10. What changes should I call you about? When is the best time to call?



YOU MUST

1. Be organized, clear and concise. Use visits to clear up doubts, worries and misunderstandings.
2. Prioritize your top three concerns for this visit.
3. Be prepared to both ask and answer questions.
4. Explain what you think is going on and ask for both written and verbal explanations.
5. Encourage the person with dementia to ask and answer questions as well.

WHO PAYS FOR MEDICAL CARE?

PRIVATE PAY

- Patient or spouse pays based on a contract with a professional, agency or facility.
- Long-term care: *Most families pay out-of-pocket or savings until money and assets (minus those excluded by law) are spent. A spouse's money and assets (minus spousal protections) must be used to pay for care.*

LONG TERM CARE INSURANCE

May pay a daily minimum for home or facility care for those who are eligible and able to pay premiums before need for care.

MEDICARE

Eligibility: Age 65, eligible for Social Security benefits. Adults qualified for disability for two years may be eligible before 65.

PAYS FOR

- Hospital care, skilled nursing or rehabilitative care in a "participating" skilled nursing facility
- Home health and hospice care
**But duration of care, amount of care covered and eligibility have restrictions and limits.*
- Physician's services given at home, in an office or clinic,
After required deductible & co-pay Medicare pays for:
- Medical and surgical care
- Certain x-rays, Diagnostic tests, Medical supplies
- Covered physical and other therapies
- Covered services provided by social workers, physician assistants and nurse practitioners.

DOES NOT PAY FOR

- Most home care or care in assisted living, adult care homes or nursing facilities
- Care not considered "reasonable and necessary"
- "Custodial care" like help with bathing or walking
- Routine check-ups and immunizations (some exceptions)
- Routine dental care, vision and hearing tests, glasses or hearing aids
- Prescription drugs



MEDICARE COVERAGE FOR PEOPLE WITH DEMENTIA

Until 2002, Medicare could deny coverage of people affected by dementia for speech, occupational and rehabilitation therapies just because of the diagnosis of Alzheimer's disease or a related disorder. A policy change allows families to appeal unfair denials of rehabilitation services, neuro-diagnostic tests, medication management and psychiatric treatment for people with dementia. This does not guarantee that all ordered services will be approved as "reasonable and necessary" or that all denials will be reversed. There are NO NEW SPECIAL MEDICARE services for people with dementia. This policy change just corrects an unjust and illegal discrimination against people with a diagnosis of a dementia.

MEDICAID

Eligibility is based on low income, spent down assets, but there are protections for the well spouse.

See County Department of Social Services for Eligibility.

PAYS FOR:

- Some skilled home care
- Personal care
- Day health services
- Most prescription drugs for those financially eligible for Medicaid and qualified for skilled nursing facility care.
- People who are eligible for Medicare and Medicaid can get help paying Medicare premiums, deductibles and coinsurance.
- Skilled nursing facility care after all assets, minus spousal protections, have been spent down.
- Adult care homes and assisted living in certain facilities under special conditions.

NOTE: LONG waiting lists for non-institutional services.

PRIVATE MEDIGAP INSURANCE POLICIES

Pay some Medicare deductibles and coinsurance and may cover services not covered by Medicare.

GROUP OR RETIREE INSURANCE

May pay for more services at reduced costs through an employer or retiree organization.

VETERANS BENEFITS

Eligible if you are a veteran over 65 and you live near a VA facility.

PAYS FOR:

- A wide range of doctors
- Home care and facility-based care for those eligible.

NC COUNTY SPECIAL ASSISTANCE FOR AGED AND DISABLED

Eligibility through county departments of social services

PAYS FOR:

- Limited home care, day care, adult care, family care and assisted living.

HOME AND COMMUNITY CARE BLOCK GRANTS

Eligible 60+ on a cost sharing basis through county Councils or Departments of Aging

PAYS FOR:

- Some respite, home and day care services

PRESCRIPTION DRUG ASSISTANCE

MEDICAID

Eligible: Medicaid low income and spent down assets

PAYS FOR:

- All prescription drugs with a small co-pay

PRESCRIPTION DRUG PROGRAMS

Contact NC Health Department for local programs

1-800-MEDICARE (800-633-4227)

TRICARE SENIOR PHARMACY PROGRAM

(800) 538-9552 (Press 1)

For retired military personnel and families



PRESCRIPTION DRUG ASSISTANCE PLAN

(800) 662-7030 (CARELINE) or www.dhhs.state.nc.us/prescriptionplan.htm

Eligible: 65+ \$17,180 individual and \$23,220 couple income and no prescription insurance.

PAYS FOR:

- 60% of drugs for specific conditions (up to \$1000 each year.)

ARICEPT (Free) 800-226-2072 or Pfizer Share Card (800) 717-6005

low income 65+ \$15.00 for 30 day supply

Eligible: patient lives at home, couple income under \$40,000 and no prescription insurance

** MD's office must request and receive medication with patient's last tax return as proof of eligibility*

EXELON (Free) 800-277-2254 or Novartis Care Card (866-974-2273)

25% discount

Eligible: Family financially responsible and no prescription insurance.

** MD's office must request and receive medications with proof of need.*

REMINYL (Free) 866-736-4695

Eligible: Family is financially responsible and no prescription insurance.

** Caregiver may apply with MD authorization and take card to any pharmacy. Must be renewed every 5 months.*

TALKING WITH PEOPLE WITH MEMORY DISORDERS

Strategies for Communicating with Your Relative

- Speak slowly, simply, and concisely, always being mindful of the tone of your voice. Use concrete, familiar words. Do not use baby talk.
- Give one direction or ask one question at a time. "Are you finished?" or "Here is the toilet."
- Don't offer too many choices that may make it hard for the person to make a decision. Say: "Mary, would you like to wear the red dress or the green dress?"
- Don't avoid talking with the person who is having difficulty. Supply him with the right word or names and other information if you think you know what he is trying to say.
- Avoid instructions the person may take literally such as "run down the hall," or "hop into bed." Use direct statements to initiate action or an activity, i.e. "It is time for supper. Let's go to the dining room."
- Don't assume the person did not hear you if there is no response. It may take a while to process what you said and then form an answer.
- Watch for signs of restlessness and withdrawal indicating the person does not wish to communicate. Respect her wishes and try later.

Non-Verbal Communication: When Words Fail

When language becomes more difficult for the person with memory loss, you can help him or her with simple techniques that offer reassurance and encouragement. A smile, eye contact, and attentive listening help support and prompt the individual's efforts to communicate.

- Begin by eliminating distractions such as noise from a radio or TV that make it harder for the person to concentrate on what you are saying.
- Let the person see you on his level. If he is sitting, sit facing him. Use touch to get the person's attention. Holding hands or gently touching the individual's arm or shoulder may elicit trust and cooperation. However, be sensitive and respectful of the person who doesn't like to be touched.
- Learn to "read" the individual's behavior. The person with Alzheimer's disease may have a flat mood. He may show little expression or emotion. He may also misinterpret situations or the intent of others. Extreme or quick gestures may be seen as threatening. Move slowly and calmly.

FROM THE PERSPECTIVE OF PERSONS WITH MEMORY LOSS

How To Have A Good Conversation

Talking to an individual with memory loss represents a special challenge. He may have trouble organizing words into thoughts or lose his train of thought in the middle of a sentence; he may substitute or make up words that are incorrect; he may repeat favorite words or tactless curses; and he may misunderstand what you are trying to tell him. Yet, the person with memory loss can and wants to be involved in communicating with those around him. He asks that you be mindful of his difficulty and to remember things from his perspective.

Always treat the person with dignity and respect. He is an adult with adult feelings, still capable of embarrassment, humiliation, and of discerning when others are being condescending, impatient, or not interested in what he or she has to say. He is often aware of his difficulty in communicating. Patience becomes a virtue—patience to listen and the willingness to repeat your answers to his questions. Remember, it is the disease and not the person creating this new and difficult challenge.

- *"Don't lose patience if I ask something more than once. It is simply my way of letting you know that I don't remember what you said the first time."*
- *"Have a sense of humor. It will help me lighten up about things I may have trouble with."*
- *"I am not less of a person because I have Alzheimer's. Don't feel sorry for me."*
- *"I am what I am and that's all that I am. I think of myself as normal."*
- *"Please don't ignore me as though I don't exist. I am a human being. I am not invisible."*
- *"I think I have to feel like I'm useful."*
- *"Let me do what I can. Give me a try."*
- *"Consideration! Be considerate of me and of my feelings. I still have feelings."*
- *"Just because I have Alzheimer's does not mean that I should not have a voice in what affects me. Don't shut me out of decisions that I can still help to make."*
- *"I still enjoy hearing what goes on in the family. Don't be afraid to report to me all the happy details. I can also sense when something's wrong and feel worse when you hide things from me. Don't be afraid if I cry or become upset. It is better than not knowing."*

THE TEN ABSOLUTES

Talking To People With Memory Disorders

Never ARGUE, instead AGREE

Never REASON, instead DIVERT

Never SHAME, instead DISTRACT

Never LECTURE, instead REASSURE

Never say REMEMBER, instead REMINISCE

Never say I TOLD YOU, instead REPEAT

Never say YOU CAN'T, instead say DO WHAT YOU CAN

Never COMMAND, or DEMAND, instead ASK or MODEL

Never CONDESCEND, instead ENCOURAGE and PRAISE

Never FORCE, instead REINFORCE

Jo Huey, from the book "Caring for People with Alzheimer's Disease: A Manual for Facility Staff" by Lisa Gwyther, 2001.

WHAT IS AGITATION?

Irritability, frustration, excessive or uncharacteristic anger

Restlessness, constant pacing, searching or rummaging through drawers

Blow-ups out of proportion to the cause

Constant demands for attention and reassurance

Repetitive questions, requests or telephone calls

Stubborn refusals to go somewhere or do something expected

Insistence on going home immediately after leaving home

Yelling, screaming, cursing, threats

Hitting, kicking, biting, spitting

AGITATION | Helpful Talk

May I help you?

Do you have time to help me?

You are safe here. I'll check the locks for you.

Everything is taken care of. It's all squared away.

I will get right on it.

You can count on me.

I apologize. (Even if you didn't do it)

I am sorry you are upset.

I know this is hard.

I will stay until you feel better.

We're in this together.

BEHAVIOR BASICS

1. Behavior changes are responses to a confusing world. These changes are often beyond the person's control.
2. People with dementia may not know why they are angry, frustrated or suspicious. Don't take it personally.
3. The caregiver is a symbol of security and safety in a shrinking and "scary" world. People with dementia want a family member close by. They are easily upset by a tense, angry or rushed caregiver.
4. People with dementia are trying as hard as they can. Reasoning, pleading or punishing won't change unwanted behavior.
5. Most disruptive behaviors occur because the person is afraid, overwhelmed, forgets what is appropriate public behavior, loses control of impulses or is uncomfortable and unable to express pain, confusion or needs.
6. Brain damage makes it more difficult to plan, start or switch activities. Tailor activities to fit the person's capacities and energy level and help start the activity. People with dementia will try to avoid embarrassment by refusing to do things they perceive as too difficult or too childish.
7. Use humor, flexibility, acceptance, reassurance and tolerance for best results.

BEHAVIOR|Problem Solving

1. Pick your battles. Which behavioral symptoms are most disruptive to family life at this point?
2. Describe the behavior. Is it harmful to anyone? Can you accept it, change expectations or increase tolerance for it?
3. Is there any pattern, trigger or time of day that sets it off? (Caffeine, alcohol)
4. Does your reaction make it worse? Can you just repeat what is asked?
5. Can you change your response to calm or reassure? (Apologize, sympathize or suggest a walk to a person who is restless or searching)
6. Is the person hungry, tired, scared, overwhelmed, or in pain?
7. Will a change in the environment help? (Turn off TV)
8. Will distraction (ice cream), diversion (ride in the car) or reassurance with calm, relaxed approach, eye contact, gentle touch or soothing music, familiar pleasant activities or security objects help?
9. Is the person cold, over-sedated, hungry, constipated, searching for the toilet, depressed or frustrated by uncomfortable clothing? Try comfort measures.
10. Can routines be adapted to prevent future occurrences? (Frequent breaks, change time of bath)

PERSONAL CARE TIPS

Step-By Step Basics of Daily Care

The individual may vary from day to day in what she can do. Planning ahead, remaining flexible, and providing a predictable routine will help with personal care tasks that can be frustrating for her and for the caregiver. Many tasks, however, can be made easier and in some cases, enjoyable.

BATHING

Respect lifelong routines, habits, and preferences in taking a bath. Does the person prefer a bath or shower, in the morning or before going to bed? "Gather everything you will need ahead of time: towels, bath mat, washcloth, soap, shampoo, comb, lotion, and powder. Make sure the room is warm and comfortable." Be sure the water is at a safe and comfortable temperature. A hand help shower and a shower bench may provide a safety edge for many persons. Recognize that bathing two or three times a week is enough unless the person is incontinent.

If privacy is an issue, drape a towel over your relative's lap or shoulders and use a washcloth to clean under the towel. If she seems frightened, distract her by talking, singing or asking her to hold things.

It is often necessary to be directive at bath time using such phrases as, "Your bath is ready" instead of asking "Are you ready to take a bath?" Give step-by-step instruction:

1. "It's time to brush your teeth."
2. "Come with me."
3. "We're going to the bathroom."
4. "I will help you."
5. "Here is the toothpaste."
6. "Take the top off."
7. "Squeeze the toothpaste on the brush."
8. "You're doing great!"
9. Start the motion for him/her by guiding his/her hand.



Pay attention to oral hygiene. Daily attention prevents sore gums and infection. If you find the task unpleasant, using disposal plastic gloves may help. Healthy gums are critical for nutrition.

DRESSING

Evaluate the kinds of clothing used as skills decrease. For example, if a woman is having difficulty putting on a bra and the family does not object, don't bother with it. Also, women may find pantyhose or garter belts frustrating. Socks are a good substitute, especially if she paces a lot, increasing the chance of blisters. Clothing that fastens in the back may keep the person from disrobing in public.

Men who have trouble with zippers may do well with elastic waist pull-on pants. Consider jogging suits, slacks with elastic waistbands, shirts that pull over the head or snap up the front. Shoes that slip on or fasten on with Velcro may be easier. Tube socks are excellent because the person doesn't have to find the heel.

Limit choices. Some persons continue to dress themselves if you hand them one article at a time. For some, it is helpful to lay out the clothing in the order that they are to be put on, with underwear on top..

Give the person a clue if it is necessary, "Here is your shirt." Or help by demonstrating or guiding the person, i.e. putting an arm into the sleeve of the shirt. Allow plenty of time for this activity and let the person do as much as he or she can. Respect privacy to the degree possible.

Compliment the person when he is done. You may need to change your standards in allowing the person some freedom while supporting her self-esteem. If your mother is happy wearing an orange blouse with pink pants, let her. In the words of one caregiver, "I finally had to ask myself, 'What difference does it make?'"

If the person insists on wearing the same clothes or seems attached to a particular article, try to have multiples; this solves the problem on washday when he or she refuses to give up the favorite piece of clothing.

Select a short, easy-to-care hair style. If the person cannot shave himself, ask the barber for tips, including the best shaving tool. Many grooming tasks may be pleasurable and can be considered activities. Women in particular may enjoy make up, manicures, or having their hair done.



TOILETING

Sometimes the person with Alzheimer's will be unable to find the bathroom, unable to position her body to sit, unable to undress to use the toilet or will void in his clothes or other inappropriate places (like waste baskets or outdoors).

Clearly label bathrooms to make them easy to locate even if the person has lived in the same house for many years.

Watch for cues—fidgeting with clothing, pacing, agitation which may indicate the need to use the bathroom.



EATING & NUTRITION

Serve meals at a consistent time. A calm, comforting atmosphere encourages concentration on the task at hand.

If the person refuses to eat, too many choices on his plate may be the problem. He may not know how to begin the process. Model the eating process for him. Once the process begins, he may continue on his own. Allow him enough time to finish his meal.

If the person eats all the time (or under eats) prepare nutritious finger foods that he can eat throughout the day. Fresh fruits and vegetables are good choices.

Sore gums, poorly fitted dentures, or the food's lack of visual appeal or familiar smell can contribute to the refusal to eat. Correct any of these problems.

Use color and textures as visual clues. Choose dishes, for example, that contrast sharply with placemats or tablecloth.

Remove inedible materials, condiments, and hazardous items when the person loses discretion about use or appropriateness.

Give back some limited control—"Would you like to eat breakfast first or take your bath first? Don't rush or criticize how well the person does the task.

SLEEPING PATTERNS

Persons with Alzheimer's disease often appear to sleep less or more. Sleep problems may be caused by pain, medication, lack of exercise, or too much daytime napping.

Have the person evaluated for physical problems which may cause pain or discomfort.

Provide a night light for the person who is afraid of the dark. Fear, hallucinations and confusion may be worse with darkness. Sitting with the person for a while may help.

Is the room too warm? Are the sheets free of wrinkles? Her bed clothes comfortable?

Try white noise which can be soothing—the hum of a fan, soft music.

When the person is restless, try a back rub, brushing his hair, talking softly.

Hunger may be keeping the person awake. Provide a snack but no food or drink with caffeine.

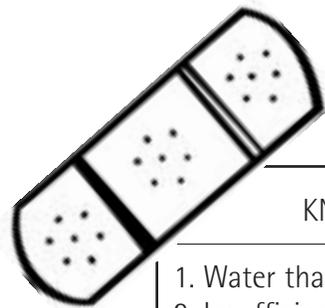
SAFETY IN THE HOME

Safety in the Home is important to the individual's well being: The person with increased confusion and disorientation because of memory loss is at a greater risk for falls and other injuries during daily personal care tasks.

Have the person checked for hearing and vision. Ask the doctor about medicines that may put the person at risk for falling or other injuries. Monitor the usefulness of the medication.

Take charge when the person can no longer manage his medications safely. Keep all medications (prescriptions and over the counter) locked. Each should be clearly labeled as to dosage, frequency and expiration date.

Keep all alcohol secured in a locked cabinet. Alcohol can increase confusion and present greater dangers if the person is on certain medications.



KNOW THE DANGER AREAS IN THE HOME

1. Water that is more than 120 degrees hot,
2. Insufficient lighting on stairways or hallways,
3. Missing labels on drawers, closets and other storage areas that help the person locate needed items,
4. Telephone numbers including emergency numbers when the person is left alone,
5. Urgent health information that is not readily visible to first respondents when the individual is incapacitated,
6. Electrical appliances and tools that the person cannot operate safely.
7. Many persons walk around in their home in socks. This is a major hazard for falls, particularly on smooth surfaced floors. Provide shoes or slippers that have non-slip soles or slipper socks that can be worn to bed if the individual is in the habit of wearing socks to bed. Getting up from the bed or chair presents its own danger. Encourage the person to get up slowly. Clutter in general creates danger as it adds to the person's confusion.

HOW TO MAKE TOUGH CARE DECISIONS

"She says she is "fine" and doesn't need any help, but she doesn't understand or remember all we do for her. She says "we don't need to bring strangers into our home—we have daughters." But how long can I spend 5 hours each day at her house?"

Should I make her see a doctor?

Should I start looking for home care or day programs?

Should I stop her driving or take over the checkbook?

Is it time to consider another living arrangement?

How do you make tough decisions when money is short, there are few affordable quality service choices, no time to look and she "doesn't want or need help"?

- **Ask: Is it my decision to make?**
If she is able or if she has a husband, you may feel responsible without the power to decide. Consider labeling it "your" need for help or reassurance rather than "her inability to do it herself."
- **Dare to think the unthinkable**
What would happen if your health takes a tumble? Change would be forced on you, and you would decide in a crisis. Look now while you still have control.
- **Listen to those who care about you**
If they think you need help, take them seriously. Move from "if" I need help to "how do I start?"
- **Decide when to start**
If you can't imagine keeping up this pace for 6 more months, start looking now.
- **Choose one issue**
Choose one need that, if met, will leverage other benefits. Don't be paralyzed by the magnitude of the task.
- **Experiment**
You don't know whether a care option will work until you try it. Experiment until you find a good fit. Offer your mother a few beauty shop visit coupons for a "Mother's Day" gift, rather than "because her hair is dirty."

- **Take one trial at a time**
Ask your dad to go with you for a visit to the day center rather than asking him to buy into a program.
- **Call in the allies**
If your relative resists, ask for help from someone she respects. Don't focus on her dependency, limits or needs but on the benefits to her.
- **Make a friend of crisis**
You may have to wait for a crisis, but prepare for the inevitable by considering a "Plan B". Check out services now.
- **Talk with a professional**
Call the Alzheimer's Association (800) 272-3900 or talk to a care manager who can help you clarify your thinking.
- **Remember**
Care decisions involve choices among imperfect options. Just do your best for your relative and yourself, and you will have acted responsibly

FAMILY DECISION-MAKING

Do We Really Need A Meeting?

A family meeting is chance for everyone, including the person with a memory disorder, to express concerns and acknowledge different perceptions. Although face-to-face meetings are preferable, don't delay if everyone can set aside time for a conference call or even an email chat. Be inclusive of all concerned, including non-local family members, children and teens who may be affected by decisions about elder care.

- Pick a place everyone is most comfortable. It could be the elder's home, a restaurant, or a hospital waiting room if it is an emergency.
- If the family is stuck in a disagreement, consider an outside facilitator, professional or expert.
- Clarify purpose and priorities: housing, medical care, safety, driving?
- Before the meeting, gather information on these areas from the Alzheimer's Association.
- Establish that "best care for Mom" is the focus, not long-standing family feuds.
- Brainstorm, allowing each family member an opportunity to be heard and submit an idea without criticism.
- Develop an action plan – what will be done first, second and third and ask for volunteers before divvying up responsibilities.
- Agree to follow-up by phone or email and acknowledge all contributions and good intentions.

PERSONAL DOCUMENTS

The Basics

When a family member has Alzheimer's, a family caregiver must know how to find important personal documents in an emergency.

1. Check the document list below
2. Have missing items created or replaced.
3. Review, update or change all existing documents as needed.
4. Safeguard the documents—
Make sure you have entry approved and know where the key to a safe deposit box is kept. Make copies of all documents to keep at home in case the bank is closed.

DOCUMENTS

Personal

Birth certificate, social security card, passport, marriage certificate, divorce, naturalization, military or guardianship papers.

Health

Health Care Power-of-Attorney—contact information for agent and alternate; Medicare (Medicaid) cards, Physician's contact information, current prescriptions, Living Will—where it is filed with addresses and phone numbers.

Legal

Durable Financial Power-of-Attorney, joint ownership deeds, will, cemetery, burial or funeral instructions.

Financial, Credit & Tax Returns

Tax returns, loan records.

Assets

Pensions, IRAs, Certificates of Deposit, bonds, stock certificates, annuities, brokerage accounts, titles or deeds.

Insurance

Policy numbers and phone numbers for life, health/disability, house, car, Medicare supplement, long-term care, funeral or burial insurance.

Household Items

Keep a list of and photos of valuables in a safe deposit box.

CAN A PERSON WITH ALZHEIMER'S LIVE ALONE??

The following questions may guide decisions about the safety of someone with a memory disorder living alone. It's best to observe the person doing these things rather than rely only on the person's report. Use only the questions that apply to your situation – for example, safe use of power tools may not be an issue for a woman living alone. Some of these questions apply to persons who are left alone during the day. If there are many "yes" answers, the person may need more supervision, support or a change in living situation.

SAFETY CONCERNS | Does The Person:

- Have driving accidents, even minor ones?
- Get lost driving or walking?
- Burn pots or forget to turn off burners or oven?
- Forget to extinguish cigarettes?
- Let strangers into the house?
- Lock him/herself out often?
- Forget to secure the house at night?
- Have mood swings and suspicious behaviors?
- Leave the house and get lost?
- Know there are firearms or dangerous tools in the house and how to use them safely?
- Know how to operate the thermostat and judge temperature appropriately?
- Know what to do in case of emergency?
- Have a recent history of being a victim of fraud, telemarketers or a crime?
- Risk injury from falls, vision or balance problems?

PERSONAL CARE/OTHER | Is The Person Able To:

- Eat well-balanced meals and drink enough fluids?
- Dress appropriately for the weather?
- Bathe and use the toilet when needed?
- Keep up with housekeeping and home repair?
- Pay bills on time, handle the checkbook, credit cards?
- Shop for, store and cook food correctly?
- Use the phone or answering machine?
- Take medicine on time and in the right amount?
- Know current address and phone number?

FRAUD PROTECTION

For Elders Living Or Staying Alone

- Remove his/her name from telemarketers' lists and junk mailings.
- Set up a P.O. box for mail delivery and screen mail.
- Arrange with the bank to allow access only to predetermined amounts of money. Ask the bank to call you if a request for a large withdrawal is made.
- Limit credit card access
- Look for unusual activity in bank accounts, bounced checks, "maxed out" credit.
- Look for checks or documents with signatures that appear forged.
- Screen phone calls
- Be sure the person's social security number does not appear on checks.
- Check the person's credit report yearly
- Look for unpaid or overpaid bills
- Be aware if someone isolates the person or talks excessively about finances
- Notice if a new acquaintance expresses inordinate affection and loyalty.
- Look for changes in a will, deed or Power-of-Attorney if the person is not able to comprehend such changes.

SHOULD MOM MOVE IN WITH US?

Moving Mom in with your family is an instinctive and generous response to her vulnerability, but it is not always the best option when she has a memory disorder that will get worse over time. A move is a serious commitment. Recognize that moves or changes are especially difficult adjustments for people who are confused or unable to learn as easily. Good intentions do not always guarantee good results.

Ask Yourself?

- How well do you get along now? How well did you get along in the past? Past problems and irritations can become pronounced when living together again.
- What do your spouse, children, brothers or sisters say about your plan? Will there be resentment from all sides?
- Is your home large enough for privacy and adaptable to your parent's changing needs?
- Are your lifestyles (television and temperature controls) and dietary habits compatible?
- Can your parent stay alone or with a paid companion comfortably and safely when you are out or on vacation?

If You Share Your Home

- You have limits. You will never be able to care for a parent exactly as s/he cared for you as a child.
- Be flexible within a predictable routine. Don't rush.
- Share household tasks with your parent by modifying tasks to fit abilities.
- Protect everyone's privacy and personal space.
- Choose your battles – everyone will have to compromise
- Give it time. It's a huge adjustment for all. Be patient but determined.
- Know when to quit. Another move will be smoother BEFORE resentment "runneth over".



FRETTING FROM AFAR

When Mom Is In Florida And You Are In Durham



If you are caring for someone who lives far away, you are not alone. These suggestions, from other long-distance caregivers, can help you to manage stress and to stay involved.

Assess the situation, identify what needs are being met, and hold a family meeting.

- Visit your relative to evaluate health and safety needs (clothes, food, hygiene), daily personal care, transportation, support, and financial needs.
- Meet with the primary caregiver, doctor, social worker, attorney, or other service providers while you are visiting.
- Establish a relationship with others caring for your relative.
- Call a family meeting to address concerns, prioritize needs and assign tasks.

Learn about local services. Services include volunteer helpers.

- Get in touch with neighbors, community organizations and churches/synagogues.
- Subscribe to the newspaper near your relative to identify new community resources.

Find a local contact to monitor the existing situation.

- With assistance from your relative (if possible), select a trustworthy individual to be your "eyes" when you are not there.

Address important legal and financial concerns.

- Know the location and contact information for your relative's documents.
- Consult with an attorney regarding durable power-of-attorney for health care and property, living will, and insurance coverage
- The Family Medical Leave Act (FMLA) entitles eligible employees to take up to twelve weeks of unpaid leave. Find out if you would be eligible.

Prepare for crisis situations. Crises can occur suddenly, so be prepared to respond.

- Install an emergency response system.
- Register your relative for SAFE RETURN through the Alzheimer's Association.
- Budget time and money for emergency care and urgent visits

Support the primary caregiver. He or she is the key to your relative's well-being.

- Call often, listen supportively, and ask about the person's condition and progress.
- Offer to help with bills, phone calls, or respite care.

Respect your relative and stay in touch.

- Do not underestimate your relative's capabilities.
- If phone conversations are difficult, just send cards and photos often.

Be kind to yourself. You can only do your best, given the present constraints.

- Find peers in a support group.

Help defeat Alzheimer's.

Become an advocate for the Alzheimer's Association.

FINDING THE HELP YOU NEED IN YOUR COMMUNITY

All services may not be available in your community. Begin your search before you think you may need the service.

HOME CARE

Home care may include a variety of care tasks depending upon the qualifications and abilities of the service or individual. Visiting nurses, home health aides, homemakers, private persons and volunteers can provide services at home such as bathing, dressing or companionship while the family is away.

Example: Mrs. G. has used a variety of home care services to support her care of Mr. G through the progression of his illness. Visiting nurses taught her how to lift him as he became bedfast. A volunteer continues to provide a few hours of male companionship to Mr. G each week. She hired a neighbor's daughter to do the heavy cleaning every two weeks.

RESPITE CARE

Refers to a short time of rest or relief. It allows caregivers a break from the day-to-day duties and provides the person with Alzheimer's opportunities to interact with others. Respite can be provided in the home, at an Adult Day Center, in a group respite program or in an assisted living or nursing facility as vacancy allows.

Example: With help from a trained respite worker, Mr. K was able to go back to golf on Friday afternoons. He knew his wife enjoyed doing household tasks with her new "friend," and that he would feel rested and refreshed when he got home.

ADULT DAY SERVICES

Adult day centers or group respite programs can give the person with Alzheimer's an opportunity to socialize with others, exercise and engage in meaningful activities. Hours of service may range from a few hours a day to a full-day program.

Example: Mrs. J found the adult day program in her town to be a lifesaver. Her husband enjoyed his day with "those guys" and she was able to keep working full-time.

MEDICAL SERVICES

"Families report they are most satisfied with a specialist who is well-informed about Alzheimer's disease. This may be a neurologist, geriatrician, psychiatrist or a family doctor who is experienced in treating people with the disease."

Example: Ms. M reports: "Mother's doctor has known her for years and insists there's nothing wrong with her. We know better but she trusts Doc Nielsen". Ms. M was able to get a consultation for her mother at a Geriatric Clinic and keep her mother's trusted relationship with Dr. Nielsen.

MOBILE MEALS

These programs deliver a hot noon meal to the home Monday – Friday. Costs vary widely, and there is usually some subsidy available. For the program nearest your family member, contact the county I & A Specialist.

Example: Mr. B is legally blind. Mrs. B's Alzheimer's disease has gradually erased her memory of how to cook. Mr. B finds that home delivered meals allow him and his wife to remain safely in their home together.

VISITATION PROGRAMS

Volunteers visit on a regular basis to shop, or visit with an isolated elder or couple. These programs are available from churches or voluntary community groups. Start with your church, an interfaith coalition, or your county aging specialist.

Example: Mrs. S is so isolated in caring for her sister with Alzheimer's disease. Few of their friends come by. Now, her church has found a young volunteer who comes weekly to visit. Both Mrs. S and her sister enjoy the young visitor and look forward to their time together.

TELEPHONE REASSURANCE

This program provides volunteers who make or receive a daily phone call from an older person living alone. Contact the county aging information specialist.

Example: Mrs. O lives alone and would like to continue to do so. Her son is concerned, but lives at a distance. The local telephone reassurance program calls her daily and her son registered her with the hospital's Lifeline program.

TRANSPORTATION SERVICES

These programs assist older people in need of medical transport (doctor's visit) and often provide rides for shopping, group meals, or recreation. Call the county aging department.

Example: Mr. N is not able to drive, but thanks to E-Z Rider, he never misses a doctor's appointment or lunch with his friends at the Senior Center.

CAREGIVER SUPPORT GROUPS

These groups are available throughout urban and rural areas. They provide information and support. For referral to a local support group, call the nearest chapter of the Alzheimer's Association at their national headquarters at 1-800-272-3900 or your county aging program.

Example: Mr. W credits the local support group with his becoming more patient with his wife. He was convinced that she just wasn't trying hard enough when she seemed so helpless. He learned good coping strategies for himself as well as good tips on how to take care of her.

SENIOR CENTERS & CONGREGATE MEALS

Senior Centers offer a variety of social, health, nutritional, educational and recreational services. A hot meal is served at noon and activities such as movies, crafts or guest speakers provide entertainment. Centers are usually open for several hours each day and meals are provided with donations based on the person's ability to pay. No one is turned away. Some centers provide free health checks and some offer transportation.

Example: Mrs. W was still a very outgoing person, even though her memory had failed. She looked forward to going to the Senior Center for lunch with friends once a week.

CHORE PROGRAM

This county social services program provides help in the home with laundry, house-keeping, cooking or shopping. Unfortunately, there are long waiting lists and strict financial eligibility.

Example: Mrs. G was in pain from her arthritis and spent most of her time caring for her husband with memory loss at home. Always a good housekeeper, she really appreciated the few hours on Thursday when the chore worker would come to help her with cleaning and laundry.

HOME HEALTH CARE

Home Health Care provides nursing services for maintaining or improving a person's health at home. Services may include skilled nursing care, help with bathing, physical therapy and speech therapy. The costs vary dramatically, depending on the service provided. It is best to call and compare public and private agencies. If the service is prescribed by a physician following a hospitalization, and is a "skilled" service, Medicare may cover the cost on a short-term basis. Some home health agencies are certified for Medicare and/or Medicaid and some are not. Some agencies will also accept private or work-related insurance. For this reason, it is very important to ask the agency about rates and whether they take third party payment.

Sources of Help

Try the local Health Department (for skilled care prescribed by M.D.). For a listing of home health agencies, call the county aging information specialist.

Example: Mr. K needed good, dependable care for his wife on an inconsistent basis. He found he could call the Home Health Agency in his community and schedule a private duty aide when he needed it on short notice. While he was out of town, he felt secure in the expert care with nursing supervision.

Medicaid CAP-DA Program

This Medicaid “waiver” program is for Medicaid eligible adults who need intermediate or skilled nursing home care—but prefer to stay at home. There are long waiting lists. Call the county Department of Social Services for more information.

Example: Mrs. S wanted to help her aunt stay home with her as long as possible, but they could not afford to hire help. Her aunt had mild memory problems and severe lung disease. The CAP Program provided a home care aide 20 hours a week.

Adult Care Homes, Assisted Living, Board and Care, Domiciliary, Family Care or Rest Homes

These homes go by a variety of names and can vary in the amount of care provided. They generally provide care for persons needing assistance in meeting day-to-day needs. They offer room and board, personal assistance, supervision of medications and social activities. Family Care Homes are for six or fewer residents. Most of these homes are private pay, and quality and cost vary widely.

Example: Mrs. P's relatives all lived at a distance and she had no children. When Mrs. P moved to a Family Care Home, she “perked up” around the other women. The family was relieved that she no longer had to cook or risk living alone.

Intermediate Care Level Nursing Home

This care level is for those who do not need skilled care, but usually do need some nursing assistance and supervision. Individual treatment plans are drawn up and followed under the direction of an RN. Intermediate care provides a minimum of 8 hours a day licensed nursing supervision and 24-hour coverage by non-licensed personnel like LPNs or Certified Nursing Assistants. Medicare does not cover these costs. Medicaid will cover cost, if prior approval is received and the facility is Medicaid-certified.

Example: Mr. B needed assistance with every activity of daily living. He could not bathe or dress himself, and he was incontinent. He needed help feeding himself. His wife was too frail to care for him at home and moved him to an intermediate care nursing facility wing. She could visit him to help with meals and to make sure he received appropriate care.

Skilled Nursing Care

This care level is for people who need intensive 24-hour care and supervision by a registered nurse under the direction of a doctor who is available for emergencies. Medicare, Medicaid and some private insurance policies pay for this level of care under certain conditions.

Example: Mrs. R. wandered for much of the day due to her advanced Alzheimer's disease. When she fell and broke her hip, she was placed on the skilled nursing facility floor of the nursing home to receive skilled nursing supervision and physical therapy.

HOSPICE/END-OF-LIFE CARE

This is a special program for the terminally ill. Hospice supports both patient and family with physical, psychological, social, spiritual and emotional care. Hospice can be provided in the home, assisted living or nursing facility. Medicare covers hospice care, if ordered by a doctor. Hospice staff make a home assessment to determine the appropriate level of care and service needs. Ask about hospice or palliative care services through your physician or county aging information specialist.

Example: Mr. D was determined to keep his wife at home, even when she stopped eating. With the help of a local hospice organization, he was able to make her comfortable, and receive support during her last days at home.

LEGAL SERVICES

Legal planning should begin soon after a diagnosis of Alzheimer's. An attorney familiar with Alzheimer's and aging issues can help draw up a durable power-of-attorney for health care and finances, a living will or guardianship if needed during the progression of the illness. Check listings of local private and non-profit legal services with the county aging information specialist.

Example: Miss A's father had a living will before his illness became severe. Knowing her father's wishes was reassuring in making difficult emotional decisions as his health care power-of-attorney when he was no longer able to speak.

FINANCIAL SERVICES

There are a number of professionals who can give advice on important financial decisions that will have to be made in caring for a person with Alzheimer's. To check eligibility for federal and state financial assistance, use www.benefitscheckup.org or call your county aging information specialist for referral to financial planners.

Example: Mrs. V was not aware that Mr. V was eligible for Veteran's benefits. Now his medical care and prescriptions are covered by the VA, leaving their minimal income for her medical needs.

LONG-TERM RESIDENTIAL CARE

The Basics For People with Memory Disorders

CONTINUING CARE RETIREMENT COMMUNITIES

Also known as Life Care, these large, campus-like complexes offer life-long care with activities and amenities. Middle to upper income residents must enter before a diagnosis of a memory disorder. Long waiting lists and age minimums. Requires buy-in (which may be partially, fully or non-refundable), entrance and monthly fees, and/or purchase of long-term care insurance. Provides multiple levels of care as needed for those deemed financially able. Have trusted attorney or financial advisor review contract.

ASSISTED LIVING, ADULT CARE, REST HOMES, FAMILY CARE

For persons with memory disorders who require supervision and/or assistance with personal care needs. Services include: assistance with bathing, dressing, grooming, scheduling and transport to medical appointments, administering medicines, all meals, snacks, limited help with eating and modified diets, group and individual activities, mail, laundry, telephone, personal lockable space, but there may be extra fees charged for personal care or nursing care. May include a special wing, program or whole facility dedicated to Alzheimer's or dementia care. May offer hospice or home health services to accommodate aging-in-place. Prices vary widely with limited funding for low-income persons in adult care and family care homes. Use Alzheimer's Association guide to evaluating residential care.

SPECIAL CARE UNITS OR FACILITIES

Wing, hallway or self-contained facility of an assisted living or nursing facility specifically for persons with memory disorders, and often for persons at a specific stage of impairment (moderately impaired but mobile residents). Most units separated by secured doors to insure safety of persons who live on the unit. SCUs should specify services that specifically address the needs of and benefits to individuals with memory disorders. Prices and services offered vary widely. Ask Alzheimer's Association for help in evaluating such options.

NURSING HOMES OR NURSING FACILITIES

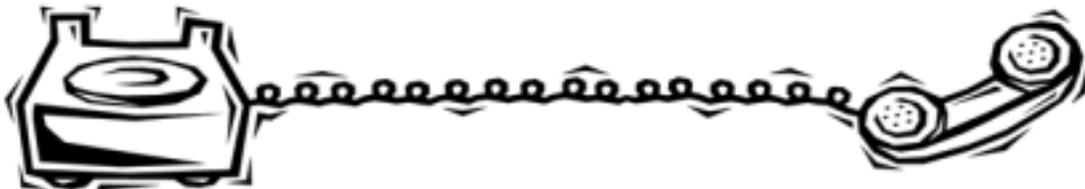
Provides short-term rehabilitative care, "subacute" post-hospital care, short or long-term skilled or intermediate level care with 24 hour RN on duty and physician supervision required. Hospice services may be brought in. Most expensive private, Medicare or Medicaid care. Check with long-term care ombudsman or www.medicare.gov information on evaluating nursing facilities.

HOW TO GET SERVICE INFORMATION WHEN YOU CALL

“It’s so hard to get through. I tried calling, but the line was busy more often than not. I didn’t know what number to press because I didn’t know what to ask for. When I did get through, I was put on hold and then told to call back later because the person I needed to talk with was out. I just gave up.”

When you call a service agency with a problem or request...

- Be specific and to the point.
- Be prepared with all the information you might need in front of you. (policy numbers, dates).
- Leave a message. If your call is not returned in a reasonable length of time, call back. After several tries with no luck, contact the person’s supervisor.
- Get the name of whomever you speak with. Ask by name for those you found helpful in the past.
- Be prepared for delays—the system works slowly. Plan ahead when possible.
- Try to call early in the morning or right after lunch. Avoid Mondays and Fridays when possible. If the lines are busy, do not give up.



HOSPITALIZATION HAPPENS

Limit Trauma of Emergency Room Visits

When a visit to the emergency room is unavoidable, the following suggestions can help families make the experience as non-threatening as possible.

Using these suggestions and taking certain steps in advance can greatly reduce the stress and confusion that can accompany a visit to the ER.

- Call a friend or family member to meet you at the emergency room. This person can focus on your family member while you are filling out forms.
- Be prepared to explain the symptoms, medical history, and recent events many times. You should also write down your relative's symptoms and problems. If you are asked the same questions, you can show what you've written instead of repeating.
- Inform the staff about the person's dementia. Provide communication tips; suggest that the staff members use eye contact and talk slowly and calmly.
- Be patient, and be prepared to wait.
- If your relative is discharged to home, make sure you understand ALL of the instructions before leaving. Ask questions, and review with your relative.
- Pack an "emergency bag", and have it ready in case of emergency.



The Bag Should Contain

- ◇ A sheet of paper listing the person's name, nickname, address, insurance companies (including policy numbers and pre-authorization phone numbers), physicians' names (including phone numbers) and list of current medications and doses
- ◇ A list of any allergies and previous bad reactions to medicines and foods
- ◇ A list of important phone numbers (relatives, friends, clergy person)
- ◇ Copies of advance directives, Health Care Power-of-Attorney, &/or a Living Will
- ◇ Extra adult briefs if your relative wears them
- ◇ A change of clothes and a plastic bag for soiled clothing.
- ◇ A card that says, "Please Understand – My companion has a memory disorder. Let me help with specific questions." Give this card to the health care professional during examinations. Avoid talking about your relative's memory changes or behaviors in front of him or her. This can be upsetting and embarrassing.
- ◇ Moist hand wipes.
- ◇ Reassuring object, portable radio/favorite tape with headset.
- ◇ A writing pad and pen to jot down information/directions.
- ◇ Pain medication for you, the caregiver.
- ◇ A sealed snack (i.e. crackers) and water or juice for you and your relative.
- ◇ A small amount of cash.
- ◇ Leave a note on the "Emergency Bag" to bring a cellular phone (if available).

PAIN AND DEMENTIA

Studies show that pain is often under-diagnosed and under-treated in people with dementia. They cannot always say how bad they hurt or where they hurt. Their discomfort may be expressed solely by changes in their behavior or observable physical symptoms such as sweating, a tight or tender abdomen, signs of redness or swelling in areas of the body, raised temperature, inability to perform normal physical tasks or decreased ability to concentrate.

Family members, must learn how to recognize non-verbal cues to insure that people with dementia receive the treatment and attention they need to maintain quality of life.

What To Look For:

- Noisy breathing or breathing that appears strenuous
- Vocalizations suggestive of pain such as moans or groaning or crying not typical of the person.
- Facial expressions such as a clenched jaw, grimacing, frowning, or distorted facial expression such as tightly closed eyes or mouth or widely opened eyes or mouth
- Clenched fists, wringing hands or grabbing at a body part
- Fidgeting, pacing, rocking, restlessness, inability to keep still
- Changes in eating including loss of appetite and weight loss
- Changes in sleeping patterns
- Withdrawal or refusal to participate in usual activities
- Anger, yelling, striking out

Consider Causes For Pain:

- Pain from an undiagnosed fracture from a fall
- Severe constipation or fecal impaction
- Urinary tract infection which causes burning pain upon urination
- Appendicitis, gall bladder attack, or heart attack which may begin with unrecognized mild but discomforting symptoms the person does not report

How You Can Help

First, insist on adequate medication for pain.
Then, try the following tips for reducing pain and improving quality of care:

- Talk, listen to music, or review photo albums with the person
- Encourage the person to try deep breathing/relaxation exercises
- Apply a cold pack for inflammation
- Encourage frequent naps (Pain can cause exhaustion and depression in some persons.)
- Use warm tub baths
- Try massage as tolerated

SUCCESSFUL NURSING HOME VISITS

More than Just Conversation

Things to Do:

- Substitute shared activities for limited conversation: manicure, hairdo, massage, watching entertainment, looking at picture albums, writing letters, hand work, watching TV news, volunteer work, walks, outings.
- Reminisce: Your favorite Christmas? Your first car? The smell of a wood stove? Baking at the old home place?
Note: If your relative is very impaired, you need to reminisce further back in time.
- Bring a pet or favorite stuffed animal or watch birds, squirrels or children playing from the windows. Start your own visiting rituals of things you do each time.
- Use the arts and your skills: music, poetry, hymns, photos, videos or audios, art work, games (even if your relative can't play well, he or she still may enjoy the activity). One man found that the slapstick humor of old Jackie Gleason Honeymooners tapes calmed his wife's agitation.

Things to Remember:

- You don't have to be busy every moment. Silence can be golden—tender moments watching birds, listening to music, sermons or shared private meditation or prayer can bring enjoyment to your relative.
- Respect personal space, possessions, and limited energy. Knock before entering. Ask before moving things around or sitting on the bed. Go slow...keep pace with your relative's concentration and tolerance.
- This is your relative's home. Behave as if you were visiting in his or her home.
- Your presence is enough. Visit like you really mean it.

Things Not To Do:

- Rush in, standing at the door, as if you are on your way out.
- Give a litany of your problems or obstacles to visiting.
- Apologize or "castastrophize" your guilt or failure—it's not your fault and you and your relative are in this together.
- Change the subject when your relative expresses negative or sad feelings.
- Give advice, nag or use baby talk.

FAMILY CAREGIVER AFFIRMATIONS

- I did what seemed best at the time.
- My choices may be limited and beyond my control.
- There are no perfect elder care solutions and no perfect families.
- If I had selected another course of action, I might now be having doubts about that as well.
- Things probably would have been worse if I had done nothing.
- Many others in similar situations have come to similar conclusions.
- New problems are not necessarily related to what I did or didn't do.
- I know it's easy to second guess or criticize from a distance.

- It isn't possible to compare how one person handles things to how another relative would handle it, if their positions were reversed. Choices, options and lives are different from what they were 30 years ago.
- I can only do my best and be dependable. I can't do it all.
- I must consider "good-enough-for-now" solutions.
- Family members have competing needs and loyalties. Compromise is necessary for each to get some of what they need and want.
- My elder is not unhappy or upset because of what I have done. She/he is living with unwanted dependency, loss and/or pain. She/he still needs to feel useful, dignified and loved.

- We must continue to celebrate good times as a family and feel good about what we have been able to do for and with each other.

10 SIGNS OF CAREGIVER STRESS

1. **DENIAL** about the disease and its effect on the person who's been diagnosed.
I know mom's going to get better.

2. **ANGER** at the person with Alzheimer's or others; that there are no cures; and that people don't understand what's going on.
If he asks me that question one more time, I'll scream!

3. **SOCIAL WITHDRAWAL** from friends and activities that once brought pleasure.
I don't care about getting together with the neighbors anymore.

4. **ANXIETY** about facing another day and what the future holds.
What happens when he needs more care than I can provide?

5. **DEPRESSION** begins to break your spirit and affects your ability to cope.
I don't care anymore.

6. **EXHAUSTION** makes it nearly impossible to complete necessary daily tasks.
I'm too tired for this.

7. **SLEEPLESSNESS** caused by a never-ending list of concerns.
What if she wanders out of the house or falls and hurts herself?

8. **IRRITABILITY** leads to moodiness and triggers negative responses and reactions.
Leave me alone!

9. **LACK OF CONCENTRATION** makes it difficult to perform familiar tasks.
I was so busy, I forgot we had an appointment.

10. **HEALTH PROBLEMS** begin to take their toll, both mentally and physically.
I can't remember the last time I felt good.

NINE THINGS TO HELP YOU COPE

- 1. The desire not to think about what you are facing is normal but you can grow beyond it.**
Recognizing that this is a progressive, degenerative disease is painful. One of the biggest challenges you face is to accept what is happening.
- 2. The process of this disease is unpredictable.**
Your loved one will lose functional ability. While change is inevitable, the time line will vary as to when your relative becomes a danger to himself or others. At these times you may need to make decisions for his/her safety.
- 3. Your family member can still do many things.**
Celebrate and make the most of remaining abilities. Help them find enjoyment in the simple things that are still within their capacity. Provide them with as much dignity and control in their lives as possible within their own abilities and limitations.
- 4. Your relative is doing the best s/he can.**
Challenging behavior is a result of their confusion and disorientation. He or she is not doing these things on purpose just to upset or get back at you. People with Alzheimer's disease cannot "just try harder" and it is not realistic to expect them to do what they used to do.
- 5. Your emotional relationship with you family member will change.**
Established roles such as with a parent or spouse will change, but not reverse.
- 6. Try to put yourself in the position of your relative.**
Imagine not being able to remember what you have done, or are supposed to do, or how to do even the simplest things. Recognize the insecurity the person must feel. Often s(he) may feel perfectly normal. Try to remember that sometimes their actions are reactions to your stress.
- 7. You, not s/he will have to change.**
Your relative's ability to change is extremely limited and will diminish as the disease progresses. This means that you will have to learn to accept the behavior and learn how to alter your expectations and reactions.
- 8. Beware of the grief that accompanies that process of loss.**
You may feel denial, anger, guilt and depression before you can accept what is happening. Seek the support of a trained counselor.
- 9. Some families successfully care at home and many successfully place their family members under the care of others.**
Don't make promises you can't keep.

WHY TRY A SUPPORT GROUP?

"Where else can I say how I feel and have "fellow travelers" understand?

You mean I'm not the only one in the world going through this?

I can be angry at fate's blows, and no one says, "you shouldn't feel that way."

This group is my link to the outside world, adult conversation,
and practical tips.

Only these people know why I can't do this myself.

I never suspected there were so many "right" ways to get Dad into the tub.

Who would have thought that I would be laughing at the dark and crazy
things that happen to me?

I realized I was out without him, and I didn't have to be guilty about it.

Compared to these people, I'm doing rather well. Things could be a lot worse.

These folks know how to pace themselves...and go the distance.

My family is totally dysfunctional ...the group is the family I always wanted.

Compassion, laughs and camaraderie – that's why I keep coming back.

I'm an information junkie – these people know every advance and good deal.

I know we can't cure her mother, but I'm here because I know y'all can
do something for my wife.

Only here can I whisper, "Will I be next?"

Until I came here, I felt like I was always letting her down and she wouldn't
have let me down.

I never thought I would hear some dignified older lady say,
"Poop is the enemy"

I can see the headlines now – "MAN JOINS SUPPORT GROUP....AND LIVES"

This is the closest I have come to a healing spiritual experience."

◇ ◇ ◇

He, too, must cross in the twilight dim

Good friend, I'm building the bridge for him.

– Will Allen Dromgoole

PREPARING FOR THE DEATH OF A FAMILY MEMBER

The following signs and symptoms of impending death may help families understand the natural changes that happen during the dying process and how to best respond. As each person is unique, all of these signs and symptoms will not occur with everyone, nor will they occur in this particular sequence. This information is intended to help with the natural worry and fear that accompanies caring for an individual with end-stage dementia.

Decreased Food and Fluids and Related Effects.

As the body no longer desires or tolerates food and fluids, the person normally eats and drinks less. The person loses weight, and skin becomes thin and tears easily. Urine output decreases and urine becomes more concentrated. Swallowing problems and choking are common; proper positioning can reduce choking.

- Never force food or fluids.
- Use glycerin swabs to keep the mouth and lips moist.

Increased Sleeping and Withdrawal.

The person may spend more time sleeping at the end of life or withdraw by closing his or her eyes.

- Never assume that the person cannot hear what is being said in the room.
- Sit with the person, hold his or her hand gently; speak softly and naturally.

Incontinence.

People with end-stage dementia lose control of the bladder and of bowels.

- Reposition and change pads frequently to avoid use of disposable undergarments.

Breathing Pattern Change and Congestion.

Breathing may become shallow, irregular, fast, or abnormally slow. Changes in breathing patterns or irregular shallow breathing patterns may cause a moaning-like sound when individuals exhale. Congestion is common.

- Try elevating the person's head by raising the head of the bed or by using pillows.
- Turn the person's head to the side.

Changes in Temperature and Skin Color.

The person's arms and legs may become cold, hot, or discolored.

- Keep the person warm if they appear cold, but do not use electric blankets.

Restlessness and Disorientation.

The person may make restless and repetitive motions such as pulling at sheets or clothing or calling out repetitively. He or she may groan, scream, or mumble loudly. The person may have visions or call out to people long dead and become increasingly confused about his or her identity and the identity of loved ones.

- Hold the person's hand or gently massage the forehead.
- Talk reassuringly, read to the person, or repeat favorite prayers or music.

At the Time of Death.

At the time of death, breathing ceases, heartbeat ceases, the person cannot be aroused. The eyelids may be partially open with the eyes in a fixed stare, the mouth may fall open, and bowel and bladder contents may be released as the body relaxes.

- When the death occurs, take time to call a supportive person to be with you before making other calls.

