Introduction

Eldercare is an experience that for all its universal quality is unique for every family. We have learned that families often don't know where to turn or what kind of assistance is available when an older family member suffers a significant mental or physical decline. This Handbook is intended as a resource for family members who are involved in caring for older adults in North Carolina. Its purpose is to help the family caregiving experience to be as successful as possible by providing basic information on caregiving, normal aging changes, and community services which might be partners in caring for a loved one. The "language" of caregiving (terms that are used by professionals) will be introduced as well as the kinds of services that are available in many communities in the state to help caregiving families.

Unless a person is the only family member available to give care, family dynamics may be an important concern, and family members may not agree about how much assistance is needed or who should provide it. The <u>Handbook</u> contains suggestions and perspectives about working *together* with all of the other parties involved.

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GETTING STARTED: USING THE CAREGIVER'S HANDBOOK

It may be some comfort to know that you are not alone. Many of your friends are facing the same hard questions and making the same difficult decisions about caring for an older family member. In 1997 more than 33.9 million Americans, that's 12.8 percent of our population, were 65 and older. A child born in 1996 could expect to live 76.1 years, about 28 years longer than a child born in 1900. Statistics show that anyone who lives past age 65 has a pretty good chance of living to be 83. In fact, Americans over 85 are the fastest growing segment of the population. This may explain why the topic of "eldercare" crops up so frequently after church, at supper parties or at work. And why, when those of us over forty get together, it's sometimes the only subject we discuss. Despite what most people think, most care of the elderly is not provided by hospitals or in an institutional setting, but by family members at home.

The major caregiving tasks that you may have to face include: understanding and managing finances and housing; arranging health care and long-term care; and, planning for legal and financial needs. To make good decisions you need information and assistance with figuring out the physical, technical and emotional aspects of these tasks. The <u>Handbook</u> can help you:

REVIEW your strengths, capabilities and needs, as well as those relating to your family and the older adult;

COLLECT information about how to address those needs:

DIVIDE responsibilities between family members, neighbors, friends, or other sources of support;

REACH outside the family for community services;

REPEAT the above steps every six months or so, because circumstances usually change. Often they worsen, but sometimes, perhaps more often than you'd think, they improve.

The Handbook is divided into three parts:

- Part 1. Family Dynamics and Aging
- Part 2. Community Resources
- Part 3. Financial and Legal Issues

Each section has two things in common which makes the <u>Handbook</u> easy to use and consult as your caregiving situation changes:

- (1) A summary of the chapter to help you be sure that you are looking in the right section; and
- (2) A <u>series of questions</u> that are asked most often by caregivers like yourself. Answers are found in each section to help you identify your own needs and steer you in the direction of some likely solutions.

PART 1. FAMILY DYNAMICS and AGING

I. SUCCESSFUL CAREGIVING

SUMMARY: This section describes caregiving in North Carolina. While caregiving is often rewarding, it also involves many new responsibilities and can sometimes be stressful. Take a minute to read this if you are new to caregiving or feeling overwhelmed with your responsibilities.

AM I A CAREGIVER?

You are --- if you make it possible for a family member, friend or neighbor who is ill, disabled or frail to get the help they need --- or if you provide ongoing assistance to someone who is ill or otherwise impaired. Primary caregivers have the responsibility of arranging or providing most of the care for an elder.

Some primary caregivers assist with day to day activities such as shopping, help with bathing and dressing or preparing meals. Other caregivers manage services such as home health care, in-home aide services or nursing home care.

Here are some statements about caregivers in North Carolina. Check <u>all</u> the statements which best describe your caregiving situation.

	I am the primary caregiver (70% of caregivers).
	I am the sole caregiver (30% of caregivers).
	I am a female (72% of caregivers are women).
	I am married to the person I care for (Most caregivers are spouses).
_	I am concerned about my own health (Nearly 50% of older caregivers share this concern).
	I juggle work, parental and eldercare responsibilities (Over 30% of caregivers).
	I provide care seven days a week for an average of four hours per day (80% of caregivers).
	I work outside the home (60% of caregivers).

Did you check more than 2 items? Many people think that nurses and nursing homes provide most of the care for frail, ill or disabled people. In reality, **the vast majority of care is provided by family members like yourself.**

Studies have shown that **family caregivers provide 80 percent of all personal and medically related care** and about 90 percent of all in-home services. Most caregivers are women, the traditional family nurturers who frequently are expected to serve in that role for aging parents and other family members.

In 1900, Americans aged 65 or older accounted for about 4% of the population. Since then, the average number of children per family has dropped to 2, and life expectancy has increased from 47 to 76 years. **Increasingly, as Americans live longer, the role of caring for the elderly falls on families a bit later in life,** often when they're planning for their own retirement or as their own children begin leaving home.

Some couples find that their "carefree years" become something very different because their time, attention and resources have switched from their children to their aging parents. It is **not uncommon now for an 85 year old mother to be cared for by a 65 year-old daughter.** That's a dramatic shift from the past.

A half-century ago, families had few choices if an older relative became too frail or ill to live alone. The older person simply moved in with them. While that often presented opportunities for intergenerational sharing, it also resulted in financial and social stresses. In those days there were fewer choices for caring for elders. Most women did not work outside the home, there were almost no services to help, and people generally lived only into their mid sixties.

In contrast, now there are many single-parent families. Most women, still the traditional caregivers, work outside the home. With medical advances, far more people live long enough to suffer from debilitating diseases and often need help in their later years.

Certainly one of the biggest challenges you may face is managing your caregiving tasks along with the other demands on your time and attention. Family members coping with already busy lives frequently face some periods of confusion. At times, many live with guilt and anger over the growing demands an aging parent or spouse place on their time and energy. One caregiver we talked with shared:

"Some days I get so frustrated. Here is Mom, the woman who gave birth to me and raised me, and now she wants me -- not some stranger -- to do her shopping and help her get dressed in the morning. I find myself saying 'After all she did for me, I owe her this much.' But I can't find time to keep my own house clean, spend time with my kids much less talk with Bob, my husband. So I get angry with Mom. Then I feel guilty for being angry and I try even harder on my next visit. It's a vicious cycle."

WHY IS CAREGIVING OFTEN STRESSFUL?

While caregiving can be very satisfying, especially when it is an expression of love and care for someone important to you, it can also be psychologically and physically draining. When demands become overwhelming, your energy, good humor, and coping capacity are taxed.

This can make you feel very stressed out. The stresses you face probably vary from day to day because your caregiving responsibilities shift according to your family member's health and your own energy level.

Maybe you aren't even aware of how much you are doing. To figure out your caregiving tasks, take a minute to complete this list of activities.

CHECK WHICH OF THE FOLLOWING KINDS OF CAREGIVING YOU CURRENTLY PROVIDE:

 Household management (cooking, shopping, cleaning, housekeeping)
 Transportation
 Personal care (bathing, grooming, toileting)
 Medical care (help with taking medications, applying dressings)
 Emotional support and companionship
 Supervision for safety
 Financial management and decision-making assistance
 Coordination and management of care provided by others
 Other (list)

DID THE NUMBER OF ITEMS YOU CHECKED SURPRISE YOU?

Managing stress requires **balancing** the demands in your life with the resources that can help you cope. Learn to recognize, anticipate and offset the demands and stresses in your life with positive self-esteem, coping skills and adequate social support.

This means **taking care of yourself** as well as spending time and energy with the person(s) for whom you are caring.

Taking care of her father helped Nan Harris learn more about her own strengths and limitations. ''From the time I was in grammar school I've taken care of people---my brothers and sisters, nieces and nephews. It's very easy for me to give and give and with Dad I've had to learn to say no,'' she said. Part of that process happened when she was hospitalized twice for exhaustion last year.

HOW AM I DOING?

Caring for your older relative or coordinating services for them through community agencies can be overwhelming. Feelings of frustration, depression, anger or guilt are not uncommon. Many caregivers decide to join a support group to provide emotional comfort. These groups allow people to share feelings and information and relieve stress, resentment and anxiety. Others seek help from their clergy or call their local agency on aging for assistance. See Section III for some suggestions on how to get your informal support system, such as friends, neighbors and community groups, to work more effectively for you and your older relative.

The following questionnaire will help you to become more aware of the stresses that you may be under. For each statement, check the column that expresses your situation.

"Describes me" "Does not describe me"

I find I can't get enough rest.

I don't have time for myself.

I feel frustrated or angry.

I feel guilty about my situation.

I don't get out much anymore.

I argue with the person I am caring for.

I argue with other family members.

I don't feel I know enough to be an effective caregiver.

If the response to one or more of these statements is "describes me," it may be time to begin looking for help with caring for your older relative and help in taking care of yourself.

SIGNS OF TOO MUCH STRESS

PHYSICAL: headache, muscle aches, sleeping and eating problems, getting sick frequently.

EMOTIONAL: guilt, anger, loneliness, depression, and anxiety.

MENTAL: forgetfulness, difficulty making decisions, attention wandering.

INTERPERSONAL: withdrawal, blaming, irritability, impatience, and sensitivity to criticism.

SPIRITUAL: feelings of alienation, loss of hope, purpose, and meaning.

What caregivers need most, say professionals, is a clear sense of their own limits as caregivers.

THIS MEANS YOU MAY WANT TO TRY TO:

- Talk openly with your aging relative and other family members.
- Assess the problems.
- Figure out where to get help.
- Decide how much help you can realistically supply.

As you begin to assess your own situation keep in mind:

SIGNS OF SUCCESSFUL CAREGIVING

- (1) Caring for yourself is a priority.
- (2) Know and respect your limits.
- (3) Arrange for time for yourself (**to be alone**).
- (4) Arrange for time with a spouse, other family and friends.
- (5) Give yourself credit for things you do well.
- (6) Caregiving can be a partnership in which you share responsibilities with others.

All that sounds pretty straightforward, like a good business plan, but it's not always simple.

HOW DO I MANAGE STRESS?

Fortunately there are some things that you can do to help manage caregiving stresses.

The **FIRST STEP** is to reflect on how you spend your time each day.

Imagine a "typical" day. **Ask yourself, "How much time do I spend?"** (estimate the number or hours each day)

EATING	
SLEEPING	
GIVING CARE TO AN OLDER PERSON	
TAKING PART IN FAMILY ACTIVITIES	
WORKING AT MY JOB	
ACTIVITIES WITH FRIENDS & NEIGHBORS	
SPIRITUAL ACTIVITIES	
BEING ALONE	
OTHER	
Total Hours	

Now that you have sketched out how you spend your time, you can determine how much time you have for yourself and how much time you have with friends or other family members.

Nan Harris felt guilty about asking someone to stay with her father while she did errands but she couldn't find time to go food shopping or keep her own doctors' appointments. Even more troubling, she realized that the only person she was regularly talking to was her sister. Somehow, the challenges of arranging care for dad had taken a priority over keeping up with friends and her own interests.

The **SECOND STEP** may be to arrange for a substitute caregiver for short periods of time so that you can get some time away from your caregiving responsibilities.

Nan called her Area Agency on Aging for information about eldercare services in her county. She was fortunate because there was a respite program near her which provides trained volunteers to act as substitute caregivers for short (2-4 hours) periods of time once a week. Nan later related that the "time I spent alone revitalized and recharged me."

Listening to music, reading, taking walks and other forms of exercise, can help you to better handle the stresses you may experience during the day. Taking care of personal business also can help you feel more in control of daily pressures. While most caregivers feel that they can, should or must provide all the care to their family member, carrying the total burden is not helpful and probably impossible in the long run.

The **THIRD STEP** is to ask for other assistance from family, friends, churches, in-home aide services and community agencies.

Before you dismiss the idea of seeking help **consider these three points:**

- 1. Additional help allows you to be a more effective caregiver by giving you time away from the person you are caring for.
- 2. Your spouse or older relative benefits by seeing and being with someone other than you.
- 3. Community-based services often allow the older family member to postpone using a nursing home by providing the more difficult and/or skilled care that is needed and can be provided in the home.

II. AGING AND YOUR FAMILY MEMBER

<u>SUMMARY:</u> While chronic illnesses are more likely in older adults, many continue to live healthy and active lives. This section discusses the major changes that happen in the body with age and includes references and phone numbers to call for more information.

With her neatly coiffed silver hair and slow, deliberate way of speaking, Janet Coles at age 81 might appear to be an old woman to many. But not to her great-grandson, Henry. "She knows the best stories, and she can do magic with cards."

Dr. James Petree doesn't think Mrs. Coles is old either. "What is old? What's normal aging? It seems like everyone has an opinion about that, but a lot of them -- even among doctors - are wrong."

WHAT IS NORMAL AGING?

Many older people endure pain and discomfort simply because of stereotypes that equate aging with physical and mental disability. The problem is exacerbated when well-meaning friends and relatives become over protective and try to shield aging but competent people from bad news, hard decisions and the risks of everyday life.

While children mature at more predictable rates, aging among older people is far more variable. **Most older people are not depressed, will never get Alzheimer's disease and will not end their days in a nursing home.** However, like most stereotypes, the myths of aging have some basis in fact. Aging is neither a disease nor an illness and to get old does not mean to be sick or senile. As we age, we change, and sometimes that change is a slow decline in life functions.

"The body does age. Cells atrophy and die, making the body more susceptible to disease or injury," said Dr. Petree, a geriatric specialist. "I've seen people who are 55 with 85-year-old bodies, and 85- year-olds with more energy and pep than their adult children. The most common stereotype is that most old people are sickly, and sick old people no longer can enjoy life, make their own decisions or benefit society," Petree said. "That's simply not true."

Genetic makeup, diet, exercise and medical care make a huge difference in how people age. No two individuals age the same way, and not all elderly individuals experience similar health problems. After two heart attacks last year, Mrs. Coles takes it easier than she did 20 years ago when she taught 25 active second graders. "My greatest wish is for a double. There's not enough time to do everything I want to do," she says.

Every Tuesday she volunteers at the nearby Senior Center and twice a week she spends an afternoon reading and tutoring children in an after-school program. She drives her own car, entertains and takes care of older neighbors. Her life changed considerably when her husband of 57 years died in 1991. "It was very hard when Charlie died. I still miss him terribly. But I finally decided life must go on. Being a volunteer helps, and my friends and family need me. I tackle things a little slower now, but I still tackle them."

HOW DOES THE BODY CHANGE WITH AGE?

Moving, talking, even thinking a little more slowly are common as the body ages. The changes begin much earlier than retirement age. Starting at about age 30, the body typically begins to lose about 1 percent of its function per year -- sometimes called the <u>One Percent Rule</u>-- finally becoming noticeable among people in their 70s or 80s.

Skin becomes thinner and drier. The body looks more wrinkled and weight may shift. The brain, immune system, lungs and other systems lose billions of cells and become less efficient. But the human body has such reserves that most people continue to function relatively well despite these losses unless they suffer from acute illnesses such as cancer, strokes or heart disease. Many older people with acute diseases and with chronic ones, such as diabetes, arthritis, high blood pressure or osteoporosis, remain mentally active, mobile and fully able to enjoy life.

Older people are not served well by physicians who look upon aches and pains, incontinence, confusion or depression as normal aging. Older people are sometimes over or under medicated by practitioners who don't fully understand that older bodies process medicines differently than younger ones.

"What we want people to know is that there is a difference between being old and being sick," said Dr. Petree. "A changing body is a fundamental part of aging, but disease is not. People who age successfully learn to accept those changes and adapt. They are the ones who learn how to handle losses they can't control and recognize that there is still much that they can do."

In normal aging, countless changes in the body begin to affect an older person's physical and mental abilities. They include:

BRAIN: Billions of brain and nervous-system cells die during a lifetime, and the brain loses about 10 percent of its weight by age 80 or 90. As the nervous system becomes less efficient, older people often don't recall facts or respond to sounds, changes in temperature or sensations as quickly as before.

Cell loss in specific areas can interfere with smell, touch, hearing and sleep patterns. Thinking and language skills typically do not diminish significantly with age. Forgetfulness occurs at all ages, but is more common as the brain becomes less efficient, especially when under emotional or physical stress.

Memory loss caused by strokes or Alzheimer's disease is not normal. These problems affect about 10 percent of people ages 65 to 74 and about 45 percent of those older than 85.

Depression and emotional problems are not normal at any age. They can be caused by illness, chemical imbalance, improper medication or by life situations. All of these can be treated.

SKELETON: Bones become more porous and brittle as they lose minerals. Women are six times more likely to develop fragile bones because of hormonal changes after menopause. Exercise and a calcium-rich diet starting in middle age can prevent or delay the condition.

Cartilage and ligaments wear thinner and joints become more prone to arthritis, bursitis and other problems. The trunk shortens and becomes less flexible as backbones shrink. Muscles lose some mass and strength. All of these conditions can make body movement painful and posture more stooped.

<u>HEART and ARTERIES:</u> Heart disease is the leading cause of death among people over 65, although the rate has decreased because of medical treatments and lifestyle changes. The heart loses efficiency with the loss of muscle fiber and the thickening of valves. Under stress it may not pump sufficient blood to the organs. Arteries stiffen, causing a rise in blood pressure, and arteries can become obstructed by fatty buildup.

LUNGS: Loss of some elasticity and other changes decrease the amount of air inhaled and exhaled by older people, and the lungs become less efficient at oxygenating the blood. That can slow many body functions, but usually this is not a problem except during physical or emotional stress. Exposure to pollutants or tobacco smoke makes the lungs less efficient and increases the risk of diseases such as cancer and pneumonia.

EYES: Beginning at age 40 or 50, the eye lens becomes thicker and less flexible and the eye has difficulty focusing on close objects. Older eyes tend to take in less light and develop problems with peripheral vision and glare. About one-fourth of people over age 65 and half of those over 85 have vision problems even while wearing glasses or contact lenses.

Cataracts affect about half of people older than 75 as the lens loses proteins and becomes cloudy. Cataracts can be removed safely with surgery. Glaucoma has few early symptoms and can lead to blindness. It occurs when the eye's fluid thickens and can't drain effectively, increasing eye pressure that can affect peripheral and night vision. It usually can be treated with eyedrops or surgery.

EARS: Loss of nerve and sensory cells of the inner ear leads to a progressive hearing loss, especially an inability to hear high-pitched tones or distinguish consonant sounds such as `th' or 'sh'. Sometimes sound waves are blocked by scarring in the ear drum or by wax buildup, especially among older men as ear hairs grow thicker. About 25 percent of those in their 80s have some hearing loss, which can usually be helped with hearing aids.

GENITO-URINARY TRACT: Incontinence at some time affects about 25 percent of men and 40 percent of women over 65. It can be caused by infection, medication, depression and other problems. Many people delay or avoid treatment because of embarrassment. Most men older than 60 develop enlarged prostates and this can interfere with urination.

Sexuality typically remains an important part of older age, although both the intensity and frequency of activities may diminish or change with age. For example, men's erections may become softer and women's vaginal walls become thinner, drier, and more subject to irritation.

• At any age, touching, cuddling and affection are important.

"Everyone's body changes with age, although a lot of problems can be cured or controlled medically," said Dr. Petree. Sometimes older people need a little help, but they don't need pity. Mrs. Coles reminded us that "older folks need the same things I need: love, respect, attention, entertainment, intellectual and physical stimulation...and sometimes, someone to take care of me."

As people grow older, they have more acute episodes of chronic conditions. Research shows that four out of five persons over age 65 suffer at least one chronic condition and multiple conditions are commonplace.

WHAT ARE THE MAJOR CHRONIC DISEASES OF AGING?

The descriptions of the illnesses described below include their causes, symptoms and common treatments. There is also a toll free number to use if you wish to get further information about some of the conditions.

Remember: only a **physician** should diagnose and prescribe medication.

A good rule is to find a physician who is interested in the health care of older patients. Many doctors have not had specific training in geriatric health care. Contact your county medical society for a referral to a physician in your area.

ARTHRITIS: Arthritis is joint inflammation and it refers to many diseases. A joint is any place in the body where two bones meet. The most common types of arthritis in older people are osteoarthritis, rheumatoid arthritis and gout. Ninety-seven percent of older people have

some degree of osteoarthritis. Symptoms include localized pain, stiffness and swelling of joints. Most commonly affected joints are the hips, knees, spine, fingers and big toe.

Medical treatment can reduce symptoms and help manage the disease. A physical examination will determine the kind of arthritis present and what kind of drug or other medical treatment is necessary. Some people suffer severe impairment and need ongoing assistance. Many adaptive devices (Velcro fasteners, large zippers or buttons, elevated toilet seat, tub stool and tub rails for example) are available. Support groups can also be helpful.

For more information:

Carolina Chapter, Arthritis Foundation (800) 883-8806

CANCER: A malignant growth or tumor. All people over age 50 should have specific screening tests for cancer on a periodic basis. Screening tests are intended to identify conditions that are hidden; signs and symptoms are often not seen in the early stages of the disease. There are a number of treatments that can be used for cancer. These include surgery, chemo or drug therapy and radiation therapy.

For more information:

American Cancer Society (800) ACS-2345

CONGESTIVE HEART FAILURE: Occurs when the heart is unable to carry enough blood to the rest of the body. Symptoms may include swelling in feet and lower legs, accumulation of fluid in lungs and shortness of breath. Medication may include digitalis which slows and strengthens heart beat and/or diuretics (water pills) to help the body rid itself of excess fluid. If not taking potassium, it is a good idea to have a good potassium source daily such as orange juice, bananas or pears.

For more information:

American Heart Association of North Carolina (800) 284-6601

DIABETES: Prevents the body from using sugar properly. Symptoms may include itching or skin infections, slow healing cuts or bruises, blurred vision, unexplained weight loss, increased thirst, frequent urination. Diabetes is treated by controlling the amount of sugar and starch in the diet. Medication may include insulin and other drugs. Good skin care (especially feet) and weight control are also important.

For more information:

Diabetes Association of North Carolina (800) 232-3472

EYE DISORDERS: Cataracts and Glaucoma

Cataracts are the most common chronic visual disorder. Surgery is almost always the treatment of choice resulting in a 90-95% improvement in vision.

With Glaucoma, fluid pressure builds up in the eye and gradually destroys vision. Some early symptoms may include: blurred vision, loss of side vision, difficulty in focusing, and slow adaptation to darkness. Glaucoma can never be cured but loss of vision can be prevented or minimized with proper treatment.

For more information:

National Eye Care Project Hotline (800) 222-EYES

National Center For Vision And Aging (800) 334-5497

American Foundation For The Blind (800) AFB-LIND (232-5463)

National Eye Care Project Helpline (800) 222-3937

HYPERTENSION: High blood pressure often begins around age 30, but because there may not be any overt symptoms, it may be untreated for a long time. Another milder form may appear in middle-aged and older persons. Untreated hypertension can lead to stroke, heart attack, congestive heart failure or kidney failure. It can be treated with medication, diet and exercise.

For more information:

High Blood Pressure Information Center (301) 496-1809

STROKE: Occurs when blood supply to a section of the brain is cut off or temporarily reduced. The loss of blood flow destroys the part of the brain that is affected. The kind and amount of damage that occurs depends on which part of the brain has been affected. Physical, speech and occupational therapy can help to restore lost abilities. Many stroke victims recover fully, or with minimal signs of damage.

For more information:

(800) 787-6537

ALZHEIMER'S DISEASE and OTHER DEMENTIA: Memory loss caused by Alzheimer's disease is not normal. Individuals with Alzheimer's, for example, may forget events more frequently. They also begin to forget information about themselves and family members. Eventually, individuals with Alzheimer's or related disorders forget how to perform basic activities, such as eating and dressing.

The Alzheimer's Association offers these warning signs:

- Recent memory loss that affects job skills
- Difficulty performing familiar tasks
- Problems with language
- Disorientation to time and place
- Poor or decreased judgment
- Problems thinking abstractly
- Misplacing things
- Changes in mood or behavior

For more information:

- Changes in personality
- Loss of initiative

"Not all memory disorders are alike," said Dr. James Petree. "Families should consult a physician early in the development of symptoms for a medical diagnosis because some reversible problems mimic the symptoms of dementia."

For example, deep seated sadness, inactivity, difficulty in thinking and concentrating, feeling of hopelessness, and sometimes thoughts of suicide are signs of major depression. Certain medical conditions like brain tumors, poor nutrition, infections (AIDS, meningitis), drug reactions and thyroid diseases may cause problems with thinking or memory. Some of these conditions may be halted or reversed. Other dementias, such as the kind caused by strokes, can destroy areas of the brain and can produce symptoms similar to Alzheimer's.

It is important to distinguish dementia from normal forgetfulness. Depression and emotional problems are not normal at any age. They can be caused by illness, improper medication, chemical imbalance, or by life transitions. All can be treated. Although there is no medication that can halt or cure Alzheimer's, good information and planning can help families cope with the effects of the disease. The first practical step in determining if memory loss is treatable is a consultation with a doctor.

Alzheimer's Association (910) 722-0811 Piedmont Triad North Carolina Chapter (800) 228-9794

Alzheimer's Association (919) 832-3732 Eastern North Carolina Chapter (800) 228-8738

Alzheimer's Association (704) 254-7363

Western North Carolina Chapter (800) 522-2451

Alzheimer's Association (704) 532-7390 Southern Piedmont Chapter (800) 888-6671

National Foundation for Depressive Illness (800) 248-4344

HERE ARE SOME BOOKS ABOUT HEALTH CARE FOR OLDER ADULTS THAT YOU MAY FIND HELPFUL.

- * D.H. Solomon et al., *A Consumer's Guide to Aging*. Baltimore: The Johns Hopkins University Press, 1992. Offers ways to think and plan for a healthy old age.
- * American Geriatrics Society, *Complete Guide to Aging and Health*, 1995. Ed. by Mark E. Williams, M.D.
- * K. Dychtwald, *Wellness and Health Promotion for the Elderly*. Englewood Cliffs, NJ: Prentice Hall, 1986, Useful information about health care.

III. THE INFORMAL SUPPORT SYSTEM OF FAMILIES, FRIENDS, AND OTHERS

SUMMARY: The most important resource for older adults is that of family and friends. This section discusses how a caregiver can work with these helping individuals in caring for an older adult. Issues which are discussed include working with your own family, caregiving from a distance and negotiating your many responsibilities as a caregiver.

Families are rarely prepared for a crisis with aging parents or spouses. For example, Mom has had a stroke or gets lost while driving to the store. Perhaps you live across the state, and your siblings live across the country. You need to learn what is going on and proceed from there.

WHEN DOES AN ELDER NEED ASSISTANCE?

Sometimes it's hard to tell the difference between meddling and being a responsible son or daughter. Allen Smith doesn't know what to do. George, his 88 year old father, wants to continue living by himself despite growing forgetfulness and frailty. He's had several falls and refuses to see his doctor.

This is a really tough issue. There are no clear guidelines to follow. Imposing his own standards on his father may backfire, so Allen needs to take some time and think over his approach. Above all, he must remember that his Dad has the right to refuse help and make his own decisions as long as he has the capacity to understand the consequences.

THE FIRST THINGS TO ASK:

- What are your parents' goals? Talk with them about how they want to live, what is meaningful and valuable to them.
- How do they want to achieve their goals? What can they do for themselves and how can you or others support their efforts?
- Can they handle the tasks? Can they physically do the shopping, drive to the doctor, or mow the lawn?
- What's your responsibility? As long as your parents can assess risk, they are in charge of their own lives. However, it's OK for you to disagree with their decisions.

IF YOU ARE ASKED TO HELP:

Decide if you are able and willing to do what they ask. You or other family members may decide to set limits on what you can or will do.

IF THE ELDER'S HEALTH FAILS:

In an emergency, you may need to make decisions for your parent(s) on a temporary basis. If illness occurs and you discover the electric bill hasn't been paid, you may decide to pay it. Then tell them what you've done and why.

It isn't wise to do things that your parents don't want. If you take over tasks and decision making, you may undermine their independence. Ask them for permission to talk with their doctor(s) so that you can become knowledgeable about their health problems.

IN RISKY SITUATIONS:

If the elder is a danger to others or can't assess his/her own risk, seek help from professionals. If you must step in, it is wise to limit your actions to the areas you believe to be dangerous.

If you think your parent or another older or disabled adult is being <u>abused</u>, <u>exploited</u> or <u>neglected by himself or others</u>, contact the County Department of Social Services. A law in North Carolina gives the Department of Social Services the responsibility to assess the situation and offer help to older and disabled adults who cannot protect themselves.

Take over responsibility only as a last resort. Help keep your parents as active as possible in determining their own fate and making their own decisions. For example, they may be frail, but still know when and what they'd like to eat for supper.

Allen Smith started small. He suggested that his father attend a meeting with his physician to discuss the family's concerns. Allen could have enlisted the help of their minister, a certified social worker, or other respected authority to mediate the meeting. Allen was assertive. He said, "Dad, I am very concerned about your health. I worry about the choices you are making, and I would like your permission to talk with your doctor. Maybe the three of us could sit down together." Fortunately George Smith agreed.

Many experts think it is more important to maintain a relationship with your parent than it is to win an argument. However, respecting an older person's right to choose becomes more difficult as he enters the gray area between being fully capable, intermittently confused, and the early stages of dementia. It is never too <u>early</u> to begin learning and discussing what your older relative's wishes are.

Family conflicts can be minimized or avoided altogether if both parents and adult children acknowledge the influence of their own personalities, confront their changing relationships and determine their individual abilities to handle responsibilities.

HOW DO I GET MY FAMILY TO WORK TOGETHER?

Begin with the most obvious step of deciding who is the primary caregiver. In most circumstances, this person is neither appointed nor anointed, elected nor decreed. The primary caregiver is the person who most often helps by finding, managing and offering appropriate assistance. Typical tasks include assistance with housekeeping, finances, preparing meals, help with eating, bathing, dressing, shopping or transportation.

Since Allen's mother died, he has been the one who has worked the hardest at keeping the family in touch with one another. His sister Sarah lives in California and his father's siblings are either dead or have retired to Florida. Allen has been keeping a close eye on his father and for the past five years has increasingly helped out around his dad's house.

Allen's situation is somewhat unusual because according to a national study done in 1987, the typical caregiver is a 52 year-old married woman who provides 15.9 hours of care per week for a 76.6 year-old widowed mother or mother-in-law. However, recent studies suggest that as much as 28 percent of caregivers for older adults are male: husbands (13%) provide care most frequently, and sons (7%) are the next most often involved.

To prevent or minimize potential conflicts, a family discussion about caregiving responsibilities, including financial and legal planning, and roles for long-distance relatives, should start while parents are still healthy. A meeting can include all potential family members who may be involved with providing care, and perhaps a trained counselor or friend, clergyman or social worker.

Questions to consider:

- **♦ Who will assume primary responsibility for decisions about care when it is needed?**
- \Diamond Is everyone satisfied with that plan?
- **♦ What information is needed before duties can be divided?**
- **♦ What are the financial and legal ramifications?**
- ♦ Who will pay for what?

What extra financial burdens will be placed on the elder's or caregiver's budget?

Allen invited his sister, Sarah, and her husband to visit for a week so they could talk with Dad about his wishes and their concerns. Initially they involved George's physician and his minister. Later in the week, several members from community agencies that serve older adults joined the discussions.

Disagreements about caregiving are common, but all family members' opinions should be heard and respected if possible.

Sarah said, "I really want to help, but Allen, being older, has always made decisions without me. My husband and I are financially secure and we'd like to contribute."

Siblings often want to offer assistance, but sometimes their offers of help are refused. It is easier for the primary family caregiver to ask for specific help and not expect siblings to read his/her mind. In this case, Allen was able to ask that Sarah and her husband, with their Dad's permission, take a close look at the finances. Allen said, "even though they are in California, they can get a better handle on Dad's long-term financial health, and let me concentrate on the day-to-day responsibilities."

Families may avoid serious conflicts if they remain flexible about responsibilities and the roles they are willing to assume. This is true if the older adult lives with you, close by, or in another state. When distance is involved, communication becomes both critical and more difficult.

HOW DO I MANAGE ELDERCARE FROM A DISTANCE?

If you find yourself in the position of being a long-distance caregiver to an older family member, you may find it difficult to assess his/her needs, locate and monitor appropriate services, and stay in touch with other family members.

Here are some suggestions:

- Talk With The Older Adult About His Or Her Needs. Find out exactly what he or she wants from you and encourage them to take the lead in arranging services if possible. It's **OK** to disagree, but **respect** their decisions and keep lines of communication open.
- **Find a trusted observer.** Long-distance caregivers may find that information from a local family member is not always objective. Sometimes it is good to also have a neighbor or family friend, such as a member of the clergy, serve as your eyes and ears.

Sarah decided to call her father's minister from time to time, just to get the minister's perspective on her father's situation.

• **Keep the family involved in decisions.** The immediate family may benefit from holding occasional meetings or conference calls during which everybody's wishes are heard and respected. A discussion of the older adult's capacities and community resources that may help him/her to remain independent should include the older adult if possible.

Allen and Sarah agreed to talk every two weeks. After a few months they may decide to set aside more time, or less, depending on the circumstances.

- Ask the older adult for permission to talk with his physician. This will allow you to be a member of the "team" and help reinforce any plans made for care.
- Seek help early. If you are the primary caregiver, your employer may offer nationwide
 access to an information and referral service on eldercare, or you may be able to locate a
 care manager, nurse or social worker in the older adult's community to help arrange and
 monitor services.

Call the National Eldercare Locator at (800) 677-1116 for referral to help in all states.

Call the **Department of Health and Human Services Information and Referral Service/ CARE-LINE** at **(800) 662-7030**, a state-wide information and referral service which can refer you to public and non-profit agencies in North Carolina.

Refer to PART 2 for detailed information on services in North Carolina.

A good book on long-distance caregiving is *Long Distance Caregiving: A Survival Guide* for Far Away Caregivers by Angela Heath. (American Source Books, 1993.)

HOW DO I BALANCE CAREGIVING AND OTHER FAMILY RESPONSIBILITIES?

Families generally do a good job of taking care of their older family members. However, caring for an older adult can demand a large investment of time and energy. Eldercare will also affect your relationships with other family members and friends and it is possible that your marriage may suffer from the strain of caregiving.

At 49, Alice feels she is in a "good" place in her life. Her sons are getting good grades in high school; her marriage to Robbie is happy, and she was recently promoted to Vice President for Human Resources at a textile company. But recently she started to look at things differently: "Mom had a stroke last month and now it looks like she's going to need more than just temporary assistance. I'm an only child and Dad isn't able to do much around the house."

Caregivers like Alice can consider these following points:

- Put your spouse and young children first in your *priorities*. Try not to let caregiving responsibilities for your *parents*, *siblings* or other *relatives* take so much of your time and energy that it causes resentment in your marriage.
- Discuss care options with your spouse before making decisions or promises to parents or other family members. As the situation changes, and it will, keep the lines of communication open.
- If you and your spouse agree to take on the role of caregiver, try to work out an understanding about how your time and activities will be divided. Make caregiving a mutual challenge rather than a competition among the needs of the older family member, spouse, and children.
- Plan some "time-out" for you and your spouse.
- Talk honestly with your *children* about your older *relatives'* health.
- Make time for yourself. It will be hard to sustain your roles as spouse, parent or employed caregiver, unless you stay physically and mentally healthy.
- Consider joining a support group for family caregivers.
- Talk with a member of the clergy or another professional about the care related stresses on your relationships with family members.

HOW DO I BALANCE CAREGIVING AND EMPLOYMENT?

These days women caregivers, like Alice, are likely to be executives or valued senior employees. More than half the women age 45 to 64 (the time when caregiving responsibilities hit hard) work outside the home.

Two strategies can help you, if you are a caregiver, to set some realistic expectations:

- 1. **Explain** to your employer or supervisor, if possible, that you may need flexible work scheduling at certain times.
- 2. **Ask** for help. Seek out and use community services, both for yourself and the person you are caring for.

A growing number of corporations are helping workers to care for their older family members. Companies such as *NationsBank*, *SAS Institute*, *and Duke Power in N.C.*, see such efforts as the key to successfully managing an aging work force.

Seek out and use company sponsored resources for caregivers, which may include:

- ♦ Access to information and referral services.
- ♦ Flex-time or job-sharing for employees who need to be at home during certain parts of the day.
- ♦ Personal leave of absence to be used for caregiving responsibilities.
- ♦ Employee Assistance Programs to discuss family issues in a confidential manner and provide help in finding assistance for older family members.
- ♦ A geriatric care manager or social worker who is available to consult with families.
- ♦ Work-site support groups.
- ♦ Newsletters or caregiver manuals.
- ♦ Seminars for caregivers.
- ♦ Training for supervisors.

Alice's company doesn't have any of these eldercare programs, but as V.P. for Human Resources she is in a position to assess her company's interest in offering these services. In the meantime, she'll try networking informally with co-workers to see if others are caring for older family members.

Here are some suggestions for additional reading:

Virginia Morris, *How to Care for Aging Parents*. Workman Publishing, 1996

B. Silverstone & Helen K. Hyman, Growing Older Together: A Couple's Guide to Understanding and Coping with the Challenges of Later Life.

Nancy R. Hooyman and Wendy Lustbader, *Taking Care of Your Aging Family Members*. New York: The Free Press, 1988.

Throughout the first part of this handbook we've advised you to "ask for help" and use community resources. Since there isn't any **one right way** to manage the challenges of

caregiving, we encourage you to be creative and find out what works for you, your family and your older family member. An important part of that is being able to create a support network of family, friends and professionals.

HOW DO I CREATE A COMMUNITY SUPPORT NETWORK?

STEP ONE: Make a list of caregiving tasks that need to be done.

CONSIDER THE FOLLOWING:

- **Homemaker Tasks:** home maintenance, home repair, cleaning, cooking, laundry, food shopping, transportation, handling bills and finances.
- **Personal Care Tasks:** bathing, dressing, toileting, feeding, shaving, hair grooming, nail care, teeth brushing.
- **Home Health Care Tasks:** managing medications, changing dressings, physical therapy, skilled nursing care, nutrition counseling.
- **Quality of Life Tasks:** companionship, exercise, counseling, reading, religious activities, social activities, senior advocacy, civic involvement.

STEP TWO: Decide how often each type of service(s) is needed (hours a day or days a week/month). What can your older relative do? What services can you provide? You will need to look for assistance for those that are not currently being provided by the elder, yourself and others.

STEP THREE: Identify current informal caregivers and their supports, or the supports they provide. Create a system of keeping track of who helps now and may help in the future.

- **Current Caregivers:** family, friends, neighbors, co-workers.
- **Family:** spouse, husband, wife, in-laws, brothers, sisters, children, aunts, uncles, nieces, nephews, cousins, step-family, foster family.
- **Volunteers:** religious organizations, youth groups, neighborhood groups, schools, senior service organizations, fraternal clubs, women's organizations, hospitals, businesses, senior advocacy groups, senior centers, retirement organizations.

STEP FOUR: Find out the availability of other services by contacting agencies in your community. PART 2 of this <u>Handbook</u> has a listing of aging services. The *Appendix* lists Cooperative Extension Centers and County Departments of Social Services addresses and telephone numbers.

• Check to see if your county has a local directory of aging services by calling the County Aging Services Department or Council, Department of Social Services, Senior Centers, Health Department or library reference desk.

- **Contact** the Cooperative Extension Services in each county or the senior organizations listed above for information and publications about aging and eldercare.
- Call the nearest Area Agency on Aging for information about services.
- Call the Information and Referral Service/ Care-Line at 1-800-662-7030 for information about services in other counties in North Carolina.
- Call the National Eldercare Locator at 1-800-677-1116 for information about services in other states.

STEP FIVE: Gather information from local resources and services.

- **Ask** about hours of operation, fees, the application process, eligibility requirements, and waiting lists.
- Talk with someone who uses the services if possible.
- **Compare** the list of needs to the financial resources available. Some services are free, some are on a sliding scale and others are available for a set fee.
- **Involve** the older adult in the selection process. If possible, choose which services or agencies are most appropriate and necessary.

PART 2. COMMUNITY RESOURCES

IV. FINDING THE RIGHT COMMUNITY SERVICE PROFESSIONALS

SUMMARY: Being able to get the appropriate assistance that caregivers' need is crucial. However, it may be hard to figure out how services are organized in your community. This section can help the caregiver by explaining common ways professionals describe services and suggest helpful ways that caregivers can deal with professionals.

WHAT IS THE AGING NETWORK?

The most important resource for older persons is the support offered by family, friends and neighbors. Community and institutional services can supplement and strengthen, not replace, the efforts of family and friends.

The <u>Aging Network</u> is a way to think about the <u>many services that have been created to meet</u> the <u>physical</u>, social, and emotional needs of the elderly. These services are provided in a variety of locations:

- <u>In-Home Services</u> Provided in the older adult's home.
- <u>Community Support Services</u> Provided at senior centers, nutrition sites, adult day care
 centers, etc., where the older adult comes to the community site in order to receive the
 service.
- <u>Institutional Services (Out-Of-Home)</u> Requires the older adult to live at the facility in order to receive the service. This can be temporary, as in a brief hospitalization, or for a longer period of time, such as in a nursing home.

If you think that you need help finding the services you need, you aren't alone.

Sherry, the primary caregiver for her 85 year old mother, didn't even know where to start. She recalled, "I was overwhelmed. I asked my minister for assistance and he gave me a few numbers to call, but I wasn't sure if I was asking all the right questions."

HOW DO I ACCESS THE NETWORK?

If you haven't already done so, read the section called **HOW DO I CREATE A COMMUNITY SUPPORT NETWORK?** It will give you some good ways to think about assessing both your own needs and those of the older adult.

Sherry said, ''you don't know what is available unless someone else tells you, and unless they've made some of the difficult decisions themselves, most people can't really help you find the best services for your situation.''

Often caregivers find it helpful to consult with experts in the community to get both information and assistance.

Consider checking with one or more of the following people/places for help in locating appropriate services in your community:

<u>The Information and Referral and Case Assistance Specialist</u>: Each county has an aging agency (sometimes called a Council on Aging, Department of Aging or Office of Aging) with an information and referral specialist who can provide information about the Aging Network and can refer you to agencies that may help you. Often there is a Directory of Services. See Section VIII for a list of agencies.

Each region of North Carolina has an Area Agency on Aging (AAA) located in the Council of Governments office. There are 18 of these agencies which plan, monitor, and provide technical assistance and advocacy services in aging. They can link consumers with local service agencies. See Section VIII for a list of Area Agencies on Aging.

<u>The Discharge Planner</u>: Each hospital has a discharge planner who can help identify and locate services in the community when the older adult leaves the hospital. This person is often a social worker or a nurse.

<u>The Care Manager</u>: Some communities have care managers who can help find and coordinate services and help caregivers work out financial arrangements with service providers.

Because this is a relatively new field, care (sometimes called case) managers are not available in every county. They may be employed by area agencies, insurance companies, or by private agencies. Care managers are often social workers. However, other professionals sometimes act in this role.

The state-wide information and referral service/CARE-LINE can refer you to public and non-profit agencies in North Carolina. (800) 662-7030.

- * County or State Cooperative Extension Service: These agencies provide a variety of information and materials and offer programs on aging, family caregiving and health.
- * Senior Centers: Community facilities providing services and activities for older adults. A senior center would be able to give information about other services in the community.

WHAT INFORMATION IS AVAILABLE ON THE INTERNET?

If your computer is linked to the internet, there are many resources for information available to you. Here are a few web addresses to get you started:

- * U.S. Admin. on Aging Directory of WEB and Gopher Aging Sites: pr.aoa.dhhs.gov/aoa/webres/craig.htm
- * N. C. Department of Health and Human Services, Division of Aging: www.dhr.state.nc.us
- * Philadelphia Geriatric Center Directory of Internet and E-Mail Resources on Aging: www.aoa.dhhs.gov/aoa/pages/jpostlst.html

HOW DO I DEAL WITH PROFESSIONALS?

Dealing with any community service agency can be frustrating. You might want to keep an informal written record, a log or diary, for recording information that you might need later on. The following suggestions will help you cut through red tape and find the assistance you need.

♦ **Be specific.** If possible, know exactly what you want before you call a particular agency.

Talk to the older adult, to the doctor, clergy or other family members and get a clear idea of the type of services you want. If you are unsure of the exact type of service agency you need, contact your regional Area Agency on Aging or the Information and Referral or Case Assistance specialist in your county.

- **Be polite but firm.** Explain your problem or need as clearly and as often as necessary.
- ♦ Try to call in the morning or right after lunch. These are probably the best times to reach agency professionals.

- ♦ Write down or record the name of everyone you talk to. This is helpful for follow-up calls.
- ♦ Be prepared in case the agency requires an initial interview. Find out in advance if legal and financial documents are needed for application and if possible, take these to the interview. If you feel stressed, take someone along with you. If necessary, take notes during the meeting to be sure you are clear about what is going to happen and what responsibilities you have.
- ♦ **Be assertive.** You will more likely be successful or at least be on the right track.

WHAT SHOULD I ASK PROFESSIONALS?

As you interview several people at community agencies, you may wish to keep a work sheet so that you can compare their services.

Consider these important questions:

About Cost:

- 1. How much do your services cost?
- 2. Are fees/commissions negotiable?
- 3. Are fees available on a sliding scale?
- 4. Are initial consultations available free of charge?
- 5. What is the average cost for my needs?
- 6. What other costs can I anticipate?
- 7. Can special payment plans be arranged?
- 8. Does insurance or any other third party payer cover costs?

About Legal/Application Issues:

- 1. What documents are needed?
- 2. Will you put your fees/estimates in writing?
- 3. Will you provide written contracts or agreements?

About Quality Issues:

- 1. Will you provide references?
- 2. What are the qualifications of your agency staff?
- 3. To which professional organizations do you belong?
- 4. Are you certified? Licensed? Bonded?
- 5. What do I do if I have a concern or complaint about the service you provide?

About Care Issues:

- 1. Do you provide transportation?
- 2. Can you accommodate a wheelchair?
- 3. Are you located near public transportation?
- 4. What days/hours are you open for business?

After each interview, consider:

- 1. Did the agency answer your questions completely?
- 2. Did you feel comfortable with the people you met?
- 3. Did the agency give you a brochure or other written material covering services and costs?

Caregivers often find it difficult to overcome feelings that they have failed their elders if they ask for help. Margie White said, "as a care manager I know that most of us would rather live at home than in a facility. I work with the Aging Network and the informal support system to help older adults live as independently as possible. That's

where our programs can make a big difference. We can help people live the way they want to."

The next sections are descriptions of services that you might find helpful in your caregiving situation.

Section V. describes specific information services that can enhance the lives of older adults.

Section VI. describes services that can assist older adults to remain in their homes.

Section **VII**. provides detailed descriptions of alternative living arrangements, both with and without services, for seniors.

Please keep in mind that not every service is available in every community, and they might have a slightly different name. For help in finding the services in <u>your</u> community, refer to Section VIII for phone numbers and agency lists.

V. INFORMATION AND ENRICHMENT RESOURCES

SUMMARY: These are services that can help preserve or enhance the quality of life of older adults.

RESOURCE AND SERVICE DESCRIPTIONS:

- Congregate Nutrition
- Employment Services
- Financial Counseling
- Health Promotion and Disease Prevention
- Housing Counseling
- Income Tax Assistance
- Information and Case Assistance
- Legal Assistance
- Mental Health Counseling
- Senior Center
- Volunteer Opportunities

CONGREGATE NUTRITION: Provides meals in a group setting which meet 1/3 of the Recommended Daily Dietary Allowance. This service promotes the health and well-being of older people by providing a nutritious meal and opportunities for health, education, social, recreational and other community services.

EMPLOYMENT SERVICES: May include client assessment as a basis for developing a plan for securing employment. Other services may include: testing, job counseling, education and training, job development, and job placement.

FINANCIAL COUNSELING: Provides advice and counseling to individuals and families on budget/money management. The programs also assist people with large debts in developing a plan to overcome their financial problems. These agencies do not provide money for paying debts.

HEALTH PROMOTION AND DISEASE PREVENTION: This can include health risk assessment and health screening, nutrition counseling and educational services, exercise and physical fitness programs, mental health services, drug education and management programs, smoking cessation, stress management, immunization, dental health, vision care, foot care, and other programs to enhance the health and wellness of older persons.

HOUSING COUNSELING: Advocacy, counseling and service efforts to assist older adults with locating and/or maintaining suitable living arrangements.

INCOME TAX ASSISTANCE: Trained volunteers are available in many communities to help or assist elderly citizens in filling out Federal and State income tax forms.

INFORMATION AND CASE ASSISTANCE: Assists older adults, their families, and others acting on behalf of older adults, to acquire information and to obtain appropriate services to meet their needs.

LEGAL ASSISTANCE: Services such as the preparation of wills, powers of attorney, deed changes, assistance with benefits (Social Security, Medicare, Medicaid) and other legal problems which do not involve criminal or personal liability.

MENTAL HEALTH COUNSELING: A service which includes care consultation, evaluation, and outpatient treatment to older adults who are experiencing mental problems.

SENIOR CENTER: A community facility designed for the organization and provision of a broad spectrum of services and activities for older adults and their caregivers including health, social, nutritional, recreational and educational programs.

<u>VOLUNTEER OPPORTUNITIES:</u> The service involves volunteers of all ages in providing services to older adults or others. Volunteering also provides community service opportunities for older adults.

VI. RESOURCES TO HELP ELDERS REMAIN IN THEIR HOMES

SUMMARY: These are services for the older adult who no longer can perform many daily tasks without help. Services may include light housekeeping, help with personal care tasks, nursing or any of the needs that individuals have in order to live in their own home.

RESOURCE AND SERVICE DESCRIPTIONS:

- Adult Day Care
- Adult Day Health Care
- Assistive Technology Equipment
- Care/Case Management
- Emergency Response System
- Financial Assistance
- Friendly Visitor
- Group Respite
- Home-Delivered Meals
- Home Equity Conversion
- Homestead Tax Exemption
- Home Health Care Services
- Home Maintenance, Repairs, Adaptations
- Hospice
- Information and Case Assistance
- In-Home Aide Services
- Long-Term Care Ombudsman
- Medical Equipment or Supplies
- Respite Care
- Telephone Reassurance
- Transportation Services

ADULT DAY CARE: An organized program of services in a group setting that provides weekly or daily support for older adults who need supervision and socialization. Services must include a variety of program activities designed to meet the individual needs and interests of the participants, and referral to and assistance in using community resources. Services for Adult Day Care and Adult Day Health Care must be provided in a home or center certified to meet state standards for Adult Day Care programs.

ADULT DAY HEALTH CARE: Similar to adult day care but services must include health care.

ASSISTIVE TECHNOLOGY EQUIPMENT: A variety of devices that can help the older adult function and live independently. These devices can also help to prevent injury from the elder over-extending him/her self.

<u>CARE/CASE MANAGEMENT:</u> Provides professional assistance for older adults and/or their families in accessing, arranging, and coordinating a package of services needed to enable the older adult to remain at home.

EMERGENCY RESPONSE SYSTEM (ERS): An electronic device linking an individual to a hospital, fire department or social service agency. Simply pressing a button triggers a device attached to the telephone which automatically dials the agency. This service is often called "Lifeline." There is usually a nominal monthly fee.

FINANCIAL ASSISTANCE: Various programs are available for short-term assistance with food, fuel or medicine for low-income elderly.

FRIENDLY VISITOR: A volunteer program with weekly visits to a home-bound elder to provide social contact, interaction and reassurance.

GROUP RESPITE: A program which provides caregivers and family information about community resources; participants, who do not require personal (hands-on) care, enjoy socialization and varied activities. It also provides short-term relief for the caregiver. The program operates on a scheduled basis for a period of less than six hours per day.

HOME-DELIVERED MEALS: Meals that contain 1/3 of the Recommended Daily Dietary Allowance to a home-bound older adult. These meals are to help maintain and improve the health of an impaired person and to enable him/her to remain in the home as long as possible.

HOME EQUITY CONVERSION: Allows the homeowner to convert equity into cash without losing his/her home. One type, called the Reverse Mortgage, is a loan plan whereby the older adult can borrow money from home equity. The individual is not required to repay interest or principal for many years - in some cases for the rest of the borrower's life. The loan is paid when the home is sold.

HOME HEALTH CARE SERVICES: Skilled health care prescribed by a physician which is provided in the older adult's home. Various levels of care may include: skilled nurse, certified nurses aide, licensed practical nurse, various types of therapists, medical social worker and nutrition care.

HOME MAINTENANCE, REPAIRS, ADAPTATIONS: Provides labor and/or materials for minor renovations and repairs to dwellings. Sometimes there are loan or grants available for housing rehabilitation and removal of barriers in the homes of persons with disabilities.

HOMESTEAD TAX EXEMPTION: North Carolina law allows a yearly real estate property tax exemption of \$20,000 of the appraised amount for a household with a person 65 or older, or disabled, and with an income of \$15,000 or less. Contact the County Assessor's Office.

HOSPICE: Offers a range of medical, social and psychological services for persons who are terminally ill. Hospice patients may be served at home, in a hospital or at a facility, such as a nursing home. Often an interdisciplinary team including a nurse, social worker, physician, chaplain, and volunteers provide patient/family comfort in the last phases of an incurable disease and bereavement following death.

INFORMATION AND CASE ASSISTANCE: Assists older adults, their families, and others acting on behalf of older adults, to acquire information or services and to obtain appropriate services to meet their needs.

IN-HOME AIDE SERVICES: Paraprofessional services which assist impaired older adults and/or their families with home management, personal care and/or supervision to enable the older adult to remain at home for as long as possible. These services may also be referred to as Chore, Homemaker-Home Health Aides and Respite Care.

LONG-TERM CARE OMBUDSMAN: Provides advocacy services on behalf of older individuals who live in nursing homes and adult care homes. Ombudsmen provide training and support to nursing home and domiciliary home advisory committees, ensure that patients' rights are protected, work to resolve grievances and complaints, educate the public on long-term care issues, and monitor federal, state and local laws, regulations and polices with regard to long-term care. Long-Term Care Ombudsmen are located at area agencies on aging.

MEDICAL EQUIPMENT OR SUPPLIES: Items to give the older adult mobility, safety, and independence in the home. These can include the purchase and installation of wheelchairs, safety rails, grab bars and non-skid surfaces.

RESPITE CARE: A service which allows the primary caregiver time away from the home by providing care for the disabled adult. Useful for family emergencies, planned special circumstances, relief from the daily responsibility and stress of caring for an older adult, or by allowing time for the caregiver to shop, run errands or other tasks. Respite can be in-home care, adult day services, group respite, or residential short term care.

TELEPHONE REASSURANCE: Provided by some agencies or volunteer organizations through regularly scheduled calls to homebound older adults. The volunteer will alert a friend or family member if something seems to be wrong. Phone calls ensure both personal safety and reduce social isolation by bringing personal phone contact to the older adult.

TRANSPORTATION SERVICES: Provides travel to and/or from service providers, nutrition sites, community resources, health providers and other designated places. This may include busses, vans, or personal vehicles. Appointments for services may be required in advance and there are eligibility restrictions. Some may charge a nominal fee.

VII. HOUSING OPTIONS AND LIVING ARRANGEMENTS

SUMMARY: This section examines issues related to living arrangements. Issues include examining the older person's needs, finances and family concerns. Descriptions for housing arrangements are divided into two parts: the first looks at housing without services; the second has detailed descriptions for housing with services.

HOW DO I EVALUATE HOUSING NEEDS?

Through a lifetime of hard work many older North Carolinians were able to accomplish their goal of home ownership. One's home is a source of pride and stability. Many older persons have no desire to change their living situation and they can make changes in their homes that enable them to maintain their independence.

The information in this section will give you an idea of the range of housing options for older persons. Keep in mind that not all options are available in every community. Caregivers may help the older adult determine his or her needs, evaluate finances and compare housing options. Since housing decisions are usually complicated and involve strong feelings, it is probably a good idea to check out options before the need arises.

SHOULD MY OLDER RELATIVE MOVE?

When evaluating whether or not to make a change in living arrangements, it is helpful to list the reasons for staying and the reasons for changing. Older people move for a variety of reasons: feeling that their present home is too big and requires too much upkeep; preferring to live in a situation that provides recreational and social activities; wanting a change of climate; wanting to be closer to their adult children; or, requiring housing with medical or other support services close by.

Some questions to consider when contemplating moving an older person:

♦ Are present housing expenses reasonable and will they continue to be?

- ♦ Can arrangements be made to hire help or make home improvements that would reduce upkeep?
- ♦ Is the present living arrangement convenient and safe? Consider stairs, space, laundry, bathroom, and storage areas.
- ♦ Does the neighborhood offer social, recreational, and religious activities?
- ♦ Is the older adult close to family, friends, doctors, and medical facilities?
- ♦ Is the older adult happy and comfortable with the living arrangements?

Ultimately, the decision to move or stay is influenced by many factors. Families should discuss the situation with the older person as circumstances change and help the older person clarify his or her housing needs.

HOUSING ALTERNATIVES

- **ELDERLY APARTMENTS:** Includes many types of apartments which are specifically intended for elderly, or elderly and disabled. May have special features or offer services such as transportation or housekeeping for older residents; or may be exactly like any other apartment building except for the age restriction. Apartments designated for elderly may be in public housing or other subsidized housing; or they may be non-subsidized (private pay) apartments.
- "CONGREGATE HOUSING" generally refers to a type of elderly apartments where supportive services are available, including the opportunity for residents to have at least one meal a day in a central dining area. However, the term is used to describe a wide range of independent housing where services may vary a great deal. Ideally, services are tailored to the individual's needs including recreational and social activities, housekeeping, laundry and transportation. Congregate housing may be either subsidized or private pay.
- **PUBLIC HOUSING:** Federally-supported housing units administered by local public housing authorities. Families or individuals pay 30 percent of their adjusted income in rent. Some services and activities <u>may</u> be offered for elderly residents, but this varies a great deal from one complex to another. Units or entire complexes may or may not be specifically designated for elderly and disabled residents.
- **SUBSIDIZED HOUSING:** Refers to any public housing <u>or</u> privately-owned housing where a government subsidy helps to make rents affordable for low- or moderate-income

people. In many, residents pay 30 percent of their adjusted income for rent. Others charge the same rent for all units of the same size, but rents are lower than rents in comparable non-subsidized housing. Some services and activities <u>may</u> be offered for elderly residents, but this varies a great deal from one complex to another. Specific units or entire complexes may or may not be specifically designated for elderly and disabled residents.

SECTION 8 VOUCHERS: <u>NOT</u> a type of housing, but a rental assistance program of the U.S. Dept. Of Housing and Urban Development (HUD) which can help make the cost of housing more affordable. Vouchers enable low-income people to rent a dwelling of their choice in the community if it meets certain standards set by HUD. Section 8 vouchers are provided to eligible individuals through the local public housing authority and HUD pays a portion of the rent based on the tenant's income. Vouchers are available to all ages of adults including the elderly. In many communities, there are waiting lists for vouchers.

CONTINUING CARE RETIREMENT COMMUNITIES (CCRCs) provide

independent accommodations that may include full or efficiency apartments, villas, cluster homes and other styles of independent housing. CCRCs offer a wide range of services and amenities which generally include community dining, house-keeping, transportation, recreational and social opportunities, and health-related services. Depending upon the individual community, some services and amenities may be included in the monthly fee or they may be purchased as needed. A substantial entrance fee is usually charged in addition to monthly fees. Generally, prospective residents must be capable of independent living when they enter the community.

In North Carolina, CCRCs must also include at least one of the following: **nursing home** care or **assisted living** (**adult care home**). These services are licensed by the N.C. Division of Facility Services. Because CCRCs include contractual requirements where, for certain fees, the facility agrees to provide health care coverage over a given period of time, they are considered an insurance product in North Carolina. CCRCs are regulated by the N.C. Department of Insurance.

CCRCs are sometimes known as "continuing care facilities" or "life care" communities.

FACTORS TO CONSIDER WHEN CHOOSING A CCRC:

• What is the range of housing provided and how much choice is available deciding upon decoration?

- What are the on-site services and arrangements for off-site services? This is
 particularly important for health care services such as nursing homes and health
 clinics.
- What are the entrance requirements?
- What are the services covered by the initial deposit and monthly fees?
- What is the policy for refunding the initial deposit?
- What is the history of fee increases?

ADULT COMMUNITIES: Not as common in North Carolina as in some other states, so-called "adult communities" are not, in reality, restricted to a certain age group. However, such communities are sometimes designed with the active retiree in mind, offering activities, recreational facilities, social functions and various services of interest to those of retirement age and attracting a majority of retirees by self-selection. These developments might consist of single-family (detached) dwellings; manufactured ("mobile") home parks; condominiums; apartments or other types of dwellings.

"NATURALLY OCCURRING RETIREMENT COMMUNITIES" are communities which are not intended for an older population, but still have a majority of older residents. They may attract an older population for various reasons such as location; services and amenities; proximity to health care, shopping and other needed services; affordability; or ease of upkeep. Some are simply communities of predominantly older adults where long-time residents have "aged in place." These often are not included in lists of elderly housing, since they are not formal retirement living arrangements.

SHARED HOUSING: The two basic types of shared housing are **shared group residences** and **home sharing.**

In **shared group residences**, none of the residents own the dwelling, but they have private space, such as a room and bath, and share common areas. Though not plentiful in North Carolina, shared group residences are usually sponsored by non-profit organizations. Each resident pays rent. Sometimes supportive services such as transportation and meals are also offered through cooperative agreements with human service providers.

In **home sharing**, two unrelated individuals live together in a shared home or apartment, each having private space yet sharing common living areas. **Home sharing** may be an informal arrangement among individuals. Just a few formalized home sharing

programs exist in North Carolina where people are screened and matched through an office on aging or other service organization.

ASSISTED LIVING

ADULT CARE HOMES These are also known as "<u>rest homes</u>." By state law, Adult Care Homes must provide 24-hour scheduled and unscheduled personal care services (such as bathing, dressing, grooming); and supervision. Extensive medical care is not provided. In N.C., most offer private or semi-private rooms with private or shared baths. Some may offer private or semi-private suites or other types of units. Adult Care Homes are licensed by the N.C. Division of Facility Services.

In some states, the term used for adult care homes is "<u>board and care</u>". In North Carolina, adult care homes were formerly called "<u>Domiciliary Care.</u>" Those with more than six beds in a facility were formerly called "Homes for the Aged."

<u>Family Care Home</u>: Adult Care Homes which are licensed for <u>two to six beds</u>. They provide group living arrangements with private or shared sleeping rooms.

QUESTIONS TO CONSIDER WHEN SELECTING AN ADULT CARE HOME:

- Does the home have a good reputation in the community?
- Is the home close to the resident's family, friends and community services and activities?
- What kind of services and activities are offered and carried out?
- What are the staffing requirements?
- What is the home's admission process? Are there waiting lists?
- Are there private or semi-private rooms? If semi-private, how are roommates selected?
- Does the home have a Resident's Council?

"MULTI-UNIT ASSISTED HOUSING WITH SERVICES" is a second category of "assisted living" effective in North Carolina as of July 1, 1996. This is a category of apartments or other independent residential arrangements where services are offered to enable residents with special needs to live in an independent, multi-unit setting.

At a minimum, one meal a day, housekeeping services and personal care services are available. Hands-on personal care and nursing care which are arranged by housing management are provided by a licensed home care provider, through a written care plan. Residents must not be in need of 24-hour supervision.

Like any independent apartment setting, a multi-unit assisted housing with services tenant commonly signs a lease agreement and pays monthly rent. Multi-unit assisted housing with services may be housing with or without subsidized rent (see **Subsidized Housing** in **A. Independent Living Housing**). Supportive services are optional to the

resident, and the resident must have a choice of care providers. Payments for personal or nursing care may not be combined with charges for housing.

"Multi-unit assisted housing with services" developments are not required to be licensed; however, they are required as of July 1996 to register with the N. C. Division of Facility Services and to provide a disclosure statement describing services offered; charges for services; financial/legal relationship with home care agencies; and other important information for consumers.

GROUP HOMES FOR DEVELOPMENTALLY DISABLED ADULTS: Adult Care Homes which have two to nine developmentally disabled adult residents.

NURSING HOMES

Nursing homes provide residents with 24-hour supportive care, nursing care, and other medically-related skilled services such as rehabilitation and therapy. Residents are admitted by a physician's order. Nursing homes are licensed by the N.C. Division of Facility Services.

FACTORS TO CONSIDER WHEN CHOOSING A NURSING HOME:

- How much time do you have before a placement is necessary?
- Will the older adult be placed from the hospital or from the community? The hospital/discharge planner will assist with placement into a nursing home if needed.
- Is there a shortage of nursing home beds in the community? If so, there may be very long waiting lists.
- Does the older adult have any behavioral problems that are difficult to manage?
- How will the cost of care be paid? Medicare pays for at least some nursing home costs for up to 100 days per benefit period for those who meet coverage requirements and require care in a skilled nursing facility. Medicaid pays nursing home expenses for individuals who meet income and resource eligibility requirements.

OTHER INFORMATION

Before moving in, prospective residents of any residential arrangement should have a lease, contract, or admissions agreement which has been carefully reviewed before signing. It is important to understand all terms of the written agreement: how rent or fees are assessed; what services are available and how they are arranged and paid for; what services are **not** included or available; terms, conditions, or penalties for breaking a lease or contract; and requirements for continuing residency.

Finding a facility that meets the needs of the older adult can be an overwhelming task for caregivers. The placement decision may come in a time of crisis, leaving little time for the selection process.

For information on housing or residential care options for older adults in your community:

- 1. **CONTACT** your Area Agency on Aging; local office on aging; local public housing authority or the N.C. Division of Aging, Caller Box #29531, Raleigh, NC, 27626-0531. Telephone: 919-733-3983.
- 2. **CONTACT** the state Office of the Long-Term Care Ombudsman or your Regional Long-Term Care Ombudsman housed in the area agency on aging office for assistance with advocacy, handling complaints and patient's rights. The State Office of Long-Term Care Ombudsman: (919) 733-3983.
- 3. **CONTACT** the North Carolina Department of Health and Human Services, Division of Facility Services for information regarding complaints.

Complaints Investigation

Nursing Homes (919) 733-7461

Adult Care Homes (919) 733-6650

Complaints regarding any facility licensed by the state: (800) 624-3004

Helpful resources: <u>Guide to Choosing a Nursing Home</u>, U.S. Department of Health and Human Services, 1993. Pub. No. HCFA-02174.

Burger et al, <u>Nursing Homes: Getting Good Care There</u>. National Coalition for Nursing Home Reform.

VIII. ACCESSING SERVICES

SUMMARY: This section has telephone numbers and addresses of agencies that either provide services for older adults or can help you locate the appropriate services in your community.

WHO SHOULD I TELEPHONE FIRST?

Check to see if your county has a local directory of aging services by calling the County Aging Services, Department or Council, Department of Social Services, Health Department or library reference desk. Information about aging and eldercare are available from the Cooperative Extension Service in each county. You can also call the nearest Area Agency on Aging for information about services (see list at the end of this section).

WHAT IS THE INFORMATION AND REFERRAL SERVICE/ CARE-LINE?

A program of the N.C. Department of Health and Human Services Office of Citizen Services which helps clarify information on human services and links clients in need of assistance with appropriate government and non-profit agencies and community resources.

This is an information and referral service for anyone calling within North Carolina. It also has a TDD (telecommunications device for the deaf) and a Hispanic Ombudsman for Spanish-speaking callers.

CARE-LINE for North Carolina

(800) 662-7030

WHAT IS THE NATIONAL ELDERCARE LOCATOR?

A nation-wide service to help families and friends find information about various community resources and services for older people. It will provide you with telephone numbers of appropriate state, regional, or local agencies in the United States, Puerto Rico and the Virgin Islands. When calling, have the zip code, name, and address of the older person you are assisting. This will help the service identify the nearest information and assistance sources.

ELDERCARE LOCATOR

(800) 677-1116

HELPFUL 800 NUMBERS

Alcohol/Drug Council of North Carolina

(800) 688-4232

Information and referral service for North Carolinians needing assistance with drug and alcohol abuse concerns.

Alliance for the Mentally III (N.C.)

(800) 451-9682

Advocacy, group and individual support, and education about mental illness.

Alzheimer's Disease (800) 272-3900

Provides information that can be mailed to you free of cost. Also can provide the phone numbers for Alzheimer's Disease chapters throughout the country.

American Cancer Society

(800) 227-2345

Provides information about local support groups. Can also tell you about existing programs in your community.

Arthritis Foundation, Carolina Chapter

(800) 883-8806

Provides written information about the disease, exercise programs, support group and self-help courses.

Cancer Information Service

(800) 4-CANCER

Provides questions to ask your physician, gives prevention and early detection information. Can also tell you where to locate physicians, and gives specific medical information on treatment for each stage of cancer.

Prevent Blindness- North Carolina

(800) 543-7839

Provides information on eye diseases, vision screening programs, and resources for assistance.

American Heart Association of N. C.

(800) 284-6601

Education and information about preventing cardiovascular disease.

Diabetes Information (National)

(800) 232-3472

Gives information about diabetes, medical treatments, diets, recent research findings, and local affiliates.

Hearing Aid Hotline (International Hearing Society)

(800) 521-5247

Provides consumer information about hearing loss and aides.

Better Hearing Institute (Hearing Helpline)

(800) 327-9355

Information on hearing loss and available treatments.

Information about Home Care

(800) 999-2357

Incontinence Information

(800) 23-SIMON

Discusses the various types of incontinence and provides informational phone numbers.

Lawyer's Referral Service for N.C.

(800) 662-7660

Provides referrals based on the county that the elder lives in.

Medicare Fraud and Abuse

(800)447-8477

Dept. of Health and Human Services Inspector General can be called if you suspect that a doctor, hospital, or other provider of health services is performing unnecessary or inappropriate services, or is billing Medicare for services not received.

Hospice Organizations

(800) 662-8859

Information and referral for hospice services.

American Lung Association of N.C.

(800) **LUNG-USA**

Information about respiratory disease.

National Parkinson's Foundation

(800) 327-4545

Literature, physician recommendations and phone numbers.

SHIIP - Seniors Health Insurance Information Program

(800) 443-9354

Volunteers help analyze health insurance coverage for older adults in North Carolina, and help consumers with Medicare forms.

Social Security Administration

(800) 772-1213

Open 7 a.m. to 7 p.m., Monday through Friday. Offers information and explanation of Social Security benefits and Medicare. If information about Medicaid is desired, contact the County Social Services Department.

Social Security/SSI Disability Hotline

(800) 638-6810

Operates 8 a.m. to 5 p.m., Monday through Friday. This service is part of the (North Carolina) Governor's Advocacy Council for Persons with Disabilities and provides information on disability benefits.

ALZHEIMER'S ASSOCIATION CHAPTERS IN NORTH CAROLINA

EASTERN NORTH CAROLINA CHAPTER 400 Oberlin Road, Suite 208 Raleigh, NC 27605-1351 (919) 832-3732 (800) 228-8738

SOUTHERN PIEDMONT CHAPTER

The Methodist Home, Inc., at Epworth Place 3420 Shamrock Drive Charlotte, NC 28215 (704) 532-7390 (800) 888-6671

TRIAD NORTH CAROLINA CHAPTER

200 N. Cherry Street Winston-Salem, NC 27101 (910) 722-0811 (800) 228-9794

WESTERN NORTH CAROLINA CHAPTER

3 Louisiana Ave, P.O. Box 1066 Asheville, NC 28802 (704) 254-7363 (800) 522-2451

ALZHEIMER'S DISEASE AND RELATED MEMORY LOSS RESOURCE TO ASSIST PROFESSIONALS AND FAMILY CAREGIVERS:

DUKE ALZHEIMER'S FAMILY SUPPORT PROGRAM Box 3600 Duke University Medical Center Durham, NC 27710 (919) 660-7510 (800) 672-4213

NC AREA AGENCIES ON AGING

A Southwestern NC Planning and Economic DevelopmentCommission

Post Office Box 850 Bryson City, NC 28713 (704) 488-9211

B Land-of-Sky Regional Council

25 Heritage Drive Asheville, NC 28806 (704) 254-6622

C Isothermal Planning and Development Commission

Post Office Box 841 Rutherfordton, NC 28139 (704) 287-2281

D Region D Council of Governments

Post Office Box 1820 Boone, NC 28607 (704) 265-5434

E Western Piedmont Council of Governments

736 Fourth Street, SW Hickory, NC 28602 (704) 322-9191

F Centralina Council of Governments

Post Office Box 35008 Charlotte, NC 28235 (704) 348-2711

G Piedmont Triad Council of Governments

2216 W. Meadowview Road Greensboro, North Carolina 27407-3408 (910) 294-4950

H Pee Dee Council of Governments

302 Leak Street Rockingham, NC 28379 (910) 895-6306

I Northwest Piedmont Council of Governments

400 W. Fourth St. Winston-Salem, NC 27101 (910) 761-2111

K Kerr-Tar Regional Council of Governments

Post Office Box 709 Henderson, NC 27536 (919) 492-8561

L Upper Coastal Plains Council of Governments

Post Office Drawer 2748 Rocky Mount, NC 27801 (919) 446-0411

M Mid-Carolina Council of Governments

Post Office Box 1510 Fayetteville, North Carolina 28302 (910) 323-4191

N Lumber River Council of Governments

4721 Fayetteville Road Lumberton, NC 28358 (910) 618-5533

O Cape Fear Council of Governments

1480 Harbour Drive Wilmington, NC 28401 (910) 395-4553

P Neuse River Council of Governments

Post Office Box 1717 New Bern, NC 28563 (919) 638-3185

Q Mid-East Commission

Post Office Box 1787 Washington, NC 27889 (919) 946-8043

R Albemarle Commission

Post Office Box 646 Hertford, NC 27944 (919) 426-5753

J Triangle J Council of Governments

Post Office Box 12276 Research Triangle Park, NC27709 (919) 558-9398

NC COUNTY INFORMATION AND REFERRAL SOURCES

In your county you can contact the agency listed below for information about services. Sometimes agency phone numbers change, so you can also call **CARE-LINE** of North Carolina at **(800) 662-7030** or the **Division of Aging** at **(919) 733-3983**. You can also contact your regional Area Agency on Aging (indicated by the letter after the county name).

ALAMANCE (G) Alamance County Eldercare PO Box 202 Burlington, NC 27216-0202 (910) 538-8080	BLADEN (N) Bladen County Division on Aging/ Senior Center PO Box 2102 Elizabethtown, NC 28337 (910) 862-6930
ALEXANDER (E) 590 7th St., SW Taylorsville, NC 28681 (704) 632-1717	BRUNSWICK (O) Brunswick County Department of Older Adults PO Box 219 Bolivia, NC 28422 (910) 253-2080
ALLEGHANY (D) Alleghany Senior Center PO Box 416 Sparta, NC 28675 (910) 372-4640	BUNCOMBE (B) Land of Sky Regional Council Area Agency on Aging 25 Heritage Drive Asheville, NC 28806 (704) 254-8131
ANSON (H) Council on Aging Rt. 3, Box 8 Wadesboro, NC 28170 (704) 694-6217	BURKE (E) Burke County Information & Referral PO Drawer 549 Morganton, NC 28655 (704) 439-2096
ASHE (D) Ashe Service for Aging PO Box 190 Jefferson, NC 28640-0190 (910) 246-2461	CABARRUS (F) Cabarrus Dept. of Aging PO Box 1005 Concord, NC 28026-1005 (704) 788-9899
AVERY (D) Avery Senior Services Department of Aging/Senior Center PO Box 447 Newland, NC 28657 (704) 733-8220	CALDWELL (E) Caldwell Senior Center Caldwell Information & Referral Lenior, NC 28645 (704) 757-8635
BEAUFORT (Q) Beaufort County Department of Social Services Aging Services PO Box 1358 Washington, NC 27889-4750 (919) 975-5500	CAMDEN (R) Albemarle Commission Area Agency on Aging 512 S. Church Street PO Box 646 Hertford, NC 27944 (919) 426-5753
BERTIE (Q) Bertie County Council on Aging/	CARTERET (P) Leon Mann Enrichment Center

Senior Center PO Box 644, 103 School Street Windsor, NC 27983 (919) 794-5315	3820 Gallantis Drive Morehead City, NC 28557 (919) 247-2626
CASWELL (G) Caswell County Parrish, Inc. 1038 Main Street Yanceyville, NC 27379 (910) 694-6428	CRAVEN (P) United Senior Services, Inc. PO Box 1114 New Bern, NC 28563-1717 (919) 638-3800
CATAWBA (E) Catawba County Council on Aging West Hickory Senior Center PO Box 835 Hickory, NC 28603-0835 (704) 328-2269	CUMBERLAND (M) Cumberland County Coordinating Council for Older Adults 339 Devers Street Fayetteville, NC 28303-4750 (910) 484-0111
CHATHAM (J) Chatham County Council on Aging P.O. Box 715 Pittsboro, NC 27312 (919) 542-4512	CURRITUCK (R) Albemarle Commission Area Agency on Aging PO Box 646, 512 Church Street Hertford, NC 27944 (919) 426-5753
CHEROKEE (A) J. Robert Penland Senior Center 105 Alpine Street Murphy, NC 28906 (704) 837-2467	DARE (R) Dare County Senior Center PO Box 1000 Manteo, NC 27954 (919) 441-1181
CHEROKEE RESERVATION (A) Tsali Manor Senior Center Route 1, Box B-5 Cherokee, NC 28719 (704) 497-4471	DAVIDSON (G) Davidson County Senior Services 935 N. Main Street Lexington, NC 27292 (704) 242-2290
CHOWAN (R) Albemarle Commission Area Agency on Aging 512 S. Church Street, PO Box 646 Hertford, NC 27944 (919) 426-5753	DAVIE (I) Davie County Senior Center 622 N. Main Street Mocksville, NC 27028 (704) 634-0611
CLAY (A) Clay County Senior Center PO Box 118 Hayesville, NC 28904 (704) 389-6301	DUPLIN (P) Duplin County Services for the Aged PO Box 928 Kenansville, NC 28349 (919) 296-2140
CLEVELAND (C) Council on Aging Senior Center 408 E. Marion Street Shelby, NC 28150 (704) 482-3488	DURHAM (J) Coordinating Council for Senior Citizens Senior Center 807 S. Duke Street Durham, NC 27701 (919) 688-8247
COLUMBUS (O) Columbus County Department of Aging PO Box 1187 Whiteville, NC 28472 (910) 640-6602	EDGECOMBE (L) Town of Tarboro Aging Director E.L. Roberson Center P.O. Drawer 220 Tarboro, NC 27886 (919) 641-4263

FORSYTH (I) Senior Services, Inc.	HALIFAX (L) Halifax County Council on Aging
836 Oak Street, Tobacco Square, Suite 320	159 King Street
Winston-Salem, NC 27101 (910) 725-0907	Halifax, NC 27839 (919) 583-1212
FRANKLIN (K) Franklin County Department of Aging 127 Shannon Village Louisburg, N.C. 27549 (919) 496-1131	HARNETT (M) Harnett County Department of Aging 309 Cornelius Harnett Blvd Lillington, NC 27546 (910) 893-7578
GASTON (F) Gaston County Senior Center 901 S. New Hope Road Gastonia, NC 28054 (704) 866-3800	HAYWOOD (A) Haywood County Council on Aging 1600 N. Main St. Waynesville, NC 28786 (704) 452-2370
GATES (R) Gates County Department of Social Services PO Box 185 Gatesville, NC 27938 (919) 357-0075	HENDERSON (B) Henderson County Council on Aging 304 Chadwick Avenue Hendersonville, NC 28792 (704) 692-4203
GATES (R) Gates County Health Dept. Rt. 1, Box 112A Gatesville, NC 27937 (919) 357-1380	HERTFORD (Q) Hertford County Council on Aging Route 1, Box 3-G Winton, NC 27986 (919) 358-7856
GRAHAM (A) Graham County Senior Center PO Box 575 Robbinsville, NC 28771 (704) 479-7977	HOKE (N) Hoke County Division of Aging 109 Cumberland Street Raeford, NC 28376 (910) 875-8588
GRANVILLE (K) Granville County Senior Service 120 Orange Street Oxford, NC 27565 (919) 693-1930	HYDE (R) Hyde County Focus on Aging/ Senior Center Route 1, Box 114 Swan Quarter, NC 27885 (919) 926-1956
GREENE (P) Greene County Council on Aging PO Box 36 Snow Hill, NC 28580 (919) 747-5436	IREDELL (F) Iredell County Council on Aging/Senior Center PO Box 344 Statesville, NC 28687-344 (704) 873-5171
GUILFORD (G) Senior Line PO Box 21993 301 E. Washington Street Greensboro, NC 27420 (910) 333-6981; 884-6981	JACKSON (A) Jackson County Department on Aging PO Box 596 Sylva, NC 28779-2998 (704) 586-8562

JOHNSTON (J) Johnston County Council on Aging PO Box 2235 Smithfield, NC 27577 (919) 934-6066	MECKLENBURG (F) Ageline 301 S. Brevard Street Charlotte, NC 28202 (704) 347-0400 Support Works Clearinghouse for Support Groups (704) 331-9500
JONES (P) Jones County Senior Center Post Office Box 694 Trenton, N.C. 28585 (919) 448-1001	MITCHELL (D) Mitchell County Senior Center 120 School Road Bakersville, NC 28705 (704) 688-3019
LEE (J) Lee County Senior Services 1615 South Third Street Sanford, NC 27330 (919) 776-0501	MONTGOMERY (H) Montgomery County Council on Aging PO Box 697 Troy, NC 27371 (910) 572-3757
LENOIR (P) Lenoir County Council on Aging PO Box 547 112 E. Blount Street Kinston, NC 28502 (919) 527-1545	MOORE (H) Moore County Department of Aging PO Box 487 Carthage, NC 28327 (910) 947-2881
LINCOLN (F) Lincoln County Office on Aging 115 West Main Street Lincolnton, NC 28092 (704) 736-8491	NASH (L) Nash County Department of Social Services PO Drawer 819 Nashville, NC 27856 (919) 459-9818
MACON (A) Macon County Department on Aging 125 Hyatt Rd. Franklin, NC 28374 (704) 349-2058	NEW HANOVER (O) New Hanover County Department of Aging 222 S. College Road Wilmington, NC 28401 (910) 452-6400
MADISON (B) Madison County Department of Social Services PO Box 219 Marshall, NC 28753 (704) 649-2711	NORTHAMPTON (L) Northhampton County Office on Aging PO Box 1034 Jackson, NC 27845 (919) 534-1668
MARTIN (Q) Martin County Senior Center PO Box 1023 Williamston, NC 27892 (919) 792-1027	ONSLOW (P) Onslow Council on Aging 105 Third Street PO Box 982 Jacksonville, NC 28540 (910) 455-2747
MCDOWELL (C) McDowell County Senior Center PO Box 338 Marion, NC 28752 (704) 652-8953	ORANGE (J) Orange County Department on Aging PO Box 8181 Hillsborough,NC 27278 (919) 967-9251

PAMLICO (P) Pamlico Senior Services/ Senior Center PO Box 184 Alliance, NC 28509 (919) 745-7196	ROCKINGHAM (G) Rockingham County Council on Aging Senior Line 105 Lawsonville Ave. Reidsville, NC 27320 (910) 342-9999
PASQUOTANK (R) Elizabeth City/Pasquotank County Senior Center 200 E. Ward Street Elizabeth City, NC 27909 (919) 338-3981	ROWAN (F) Rowan County Senior Services Department 1120-A Walnut Street Salisbury, NC 28144 (704) 636-2344
PENDER (O) Senior Citizens Services of Pender 312 W. Williams Street PO Box 1394 Burgaw, NC 28425 (910) 259-9119	RUTHERFORD (C) Rutherford County Department of Aging 193 Callahan-Koone Road, Suite 132 Spindale, N.C. 28160 (704) 287-6409
PERQUIMANS (R) Perquimans County Senior Citizens Center 300 Brub Street, PO Box 32 Hertford, NC 27944 (919) 426-5404	SAMPSON (M) Sampson County Department of Aging 303 Rowan Road, #C Clinton, NC 28328 (910) 592-4653
PERSON (K) Person County Council on Aging 121 A Depot Street PO Box 764 Roxboro, NC 27573 (910) 599-7484	SCOTLAND (N) Scotland County Department of Social Services PO Box 69 Laurinburg, NC 28353 (910) 277-2500
PITT (Q) Pitt County Council on Aging PO Box 7272 Greenville, NC 27835 (919) 752-1717	STANLY (F) Stanly County Senior Service Department 283 N. Third Street Albemarle, NC 28001 (704) 983-7334
POLK (C) The Meeting Place 500 Carolina Drive Tryon, N.C. 28782 (704) 859-9707	STOKES (I) Stokes County Senior Citizens Department PO Box 29 Danbury, NC 27016 (910) 593-8156
RANDOLPH (G) Randolph County Senior Adult Association Post Office Box 1852 Asheboro, NC 27203 (910) 625-0780 (1-800-380-4915 Randolph Call & Answer)	SURRY (I) YVEDDI PO Box 309 Booneville, NC 27011 (910) 367-7251
ROBESON (N) Robeson County Church & Community Center 210 E. 15 th Street Lumberton, NC 28358 (910) 738-5204	SURRY (I) Surry County Health Dept. PO Box 1062 Dobson, NC 27017 (910) 401-8050

SWAIN (A) State of Franklin Services to Senior Citizens Old Courthouse on Everett St. PO Box 356 Bryson City, NC 28713 (704) 488-3047	WASHINGTON (R) Washington County Senior Center Highway 45 PO Box 10 Plymouth, NC 27962 (919) 793-3816
TRANSYLVANIA (B) Home Care Transylvania Community Hospital PO Box 1116 Brevard, NC 28712 (704) 883-5340	WATAUGA (D) Watauga County Project on Aging 783 West King Street Boone, NC 28607 (704) 265-8090
TYRREL (R) Tyrrell County Focal Point on Aging 406 Bridge Street PO Box 449 Columbia, NC 27925 (919) 796-0365	WAYNE (P) Wayne County Services on Aging Senior Center PO Box 227 Goldsboro, NC 27530 (919) 731-1591
UNION (F) Council on Aging in Union Co. 16 N. Hayne Street PO Box 185 Monroe, NC 28111 (704) 289-1797	WILKES (D) Wilkes Senior Citizens Council 2 United Way Building 910 C. Street North Wilkesboro, NC 28659 (910) 651-7811
VANCE (K) Vance County Office on Aging/Senior Center 126 S. Garnett Street Henderson, NC 27536 (919) 430-0257	WILSON (L) Wilson County Office of Senior Citizens Affairs 2500 W. Nash Street Suite E, Office D Wilson, NC 27893 (919) 237-1303
WAKE (J) Resources for Seniors 1001 Navaho Drive, Suite 213 Raleigh, NC 27609 (919) 872-7933	YADKIN (I) YVEDDI PO Box 309 Booneville, NC 27011 (910) 367-7251
WARREN (K) Coordinating Council for Senior Citizens of Warren Co. Senior Center 435 W. Franklin Street Warrenton, NC 27589 (919) 257-3111	YANCEY (D) Yancey County Committee on Aging/ Senior Center 10 Swiss Avenue Burnsville, NC 28714 (704) 682-6011

PART 3. LEGAL AND FINANCIAL ISSUES

IX. FINANCIAL ISSUES

SUMMARY: This section discusses strategies for examining the older family member's financial situation. Both the issue of gathering information and making relevant decisions concerning paying for services, including long-term health care are considered.

In the course of providing or arranging care for an older person, you may be confronted with the need to know the financial situation of the older person. Your ease and ability to discuss finances depends in part on your past relationship with the older person <u>and</u> whether he or she feels comfortable discussing financial matters. Although it may be helpful to have as complete a picture of finances as possible, try to be sensitive to both the elder's independence and privacy. Ask for only the information you need and, keep in mind, that your involvement may change as the issue changes.

HOW DO I CREATE A FINANCIAL PROFILE?

Follow these three steps to create a good picture of the older adult's financial needs.

STEP ONE --- LIST INCOME:

ESTIMATE OR FIND OUT USUAL MONTHLY SOURCES OF INCOME.

Consider:	Taxable	Non-Taxable
Wages, Salaries		
Other Compensation		
Dividends		
Bonds		
CD's		
Interest		
Rental or Business Income		
Social Security		
Pensions		
Annuity		
Other		
TOTA	L	

STEP TWO --- LIST EXPENSES:

ESTIMATE OR FIND OUT AVERAGE MONTHLY EXPENSES.

Consider:	ESTIMATE or AVERAGE
Mortgage or Rent	
Utilities (gas/electric/fuel)	
Telephone	
Repairs or Maintenance	
In-home Services	
Legal/Accounting	
Equipment Rentals	
Insurance:	
Homeowners	
Life	
Automobile	
Disability	
Health Care (Medigap, other)	
Personal Care	
Food	
Clothing	
Automobile/Transportation	
Medical/Dental, Medicine (unreimbursed)	
Credit Cards	
Second Home	
Gifts	
Entertainment	
Charitable Contributions	
Federal Taxes	
State/Local Taxes	
Other Debt	
TOTAL	,

STEP THREE --- CONSIDER STRATEGIES

- Compare monthly income and expenses and develop a monthly budget.
- Look for ways to trim expenses and increase income, if needed, including programs that supplement income or provide food, transportation, medical care and other services.

- Consult a financial planner to determine if savings are invested to minimize risk but maximize income.
- Consult a social-service or credit-counseling agency (with fees based upon ability to pay) for help managing debt if this is needed.

REMEMBER: Unless the older adult is mentally incompetent, it isn't wise to take over. Consider this a joint problem-solving project to track expenses and income. Set goals and develop a plan to achieve them.

One of the largest financial expenses associated with growing old is long term care. Long-term care includes both home, community-based services and services in a facility (out-of-home care). Since Part 2 described home and community based options, the following section addresses financing out-of-home care. Adult care homes and nursing homes set their own rates for private pay customers, so the costs of care vary widely. To get information on the costs of care in your area, contact your county Department of Social Services or your Area Agency on Aging.

Two helpful resources which are available free from your county Cooperative Extension Service are "Health Insurance Fundamentals", FCS362-3, and "Health Care/Insurance Decisions", FCS-362-4.

HOW DO I PAY FOR OUT-OF-HOME LONG-TERM CARE?

Most people rely upon three ways to pay for their long term care needs.

- 1. **PERSONAL RESOURCES:** Often when a person first enters a nursing home, individuals rely on their own personal resources. However, due to the cost of such care, most people spend their resources to the point where they become eligible for Medicaid.
- PRIVATE INSURANCE: A fairly new product which covers nursing home and other long-term care. Often benefits are paid as a fixed dollar amount (per day or per visit). Certain conditions may be excluded or limited from coverage.
- 3. **MEDICAID:** A state/federal program available to eligible low-income individuals, who meet special age, disability, income and resource limits. Covers the cost of intermediate and skilled care. The facility must be Medicaid-certified.

Contact your county Department of Social Services to find out if the older adult qualifies for Medicaid.

Ask about the Community Alternatives Program for Disabled Adults. The program can provide personal care, nursing services, meals, adult day health care, medical supplies and other services for Medicaid recipients who would otherwise need to be in a nursing facility.

Check with your county Social Service Department for current eligibility guidelines and applications for this program.

WHAT IS MEDICARE?

MEDICARE is a federal insurance program for people aged 65 and older, some disabled people and people with kidney disease. Medicare has two parts: Part A and Part B.

- ♦ Part A is hospital insurance and it is free to most recipients. It covers inpatient hospital and skilled nursing services, home health care (under certain conditions) and hospice.
- ◆ Part B (Medical Insurance) covers physicians' services, outpatient hospital, medical tests, durable medical equipment and some other services not covered under Part A. Part B requires a monthly premium charge (usually deducted from one's Social Security check), yearly deductibles and co-payments.

For more information on Medicare contact the **Social Security Administration at (800)** 772-1213.

WHAT IS MEDIGAP (MEDICARE SUPPLEMENT) INSURANCE?

This is private insurance designed to supplement Medicare's benefits by filling in some of the gaps in Medicare coverage. Some Medigap policies provide coverage for Medicare's deductibles and most pay the coinsurance amounts (the portion or percentage of Medicare approved amounts for covered medical services for which the beneficiary is responsible). Some polices also pay for limited health services not covered by Medicare. This insurance is regulated by state and federal laws. There are 10 standardized plans which make it easy for consumers to compare.

For more information contact the **Seniors' Health Insurance Information Program (SHIIP)** at **(800) 443-9354**. Specially trained volunteers can help seniors with their questions about Medicare, Medicare supplement policies, long term care insurance and other health insurance.

WHAT IS A MEDICARE HMO?

A Medicare Health Maintenance Organization (HMO) is a way of delivering Medicare benefits through a managed care plan. A HMO is a combination of health care delivery system (doctor, hospital) and an insurance system. Like an insurance company, it covers health care costs in return for a premium. Each plan has its own network of hospitals, doctors, and other health care professionals. Services usually must be obtained from the professionals and facilities that are part of the plan.

You can get the names and information about Medicare HMO's by calling the **N.C. Dept. of Insurance Seniors' Health Insurance Information Program (SHIIP)** at (800)443-9354 or call **Medicare** at (800)638-6833.

WHAT IS LONG-TERM CARE INSURANCE?

Long-term care insurance covers nursing home care and increasingly covers home care as well. Because costs for long-term care policies vary widely, shopping and price comparison is important.

SOME IMPORTANT ISSUES TO CONSIDER:

- Determine if you really need the long-term care product.
- Understand the product. Go over each policy to see if it gives the kind of coverage needed.
- Don't buy more insurance than is needed. Duplicate coverage is costly and unnecessary.
- Find out what isn't covered.
- Check for waiting period and "pre-existing condition" exclusions.
- Ask how long the coverage will last. If it doesn't pay for the remainder of the policy holder's life, check the terms of renewal.

Finally, if you decide to purchase any policies, do some checking into the reputation and financial stability of the company offering the insurance.

If you think you have been a victim of illegal insurance sales practices contact the **N.C. Department of Insurance, Consumer Services at (800) 662-7777.**

For more information about seniors' health insurance contact the **Seniors' Health Insurance Information Program (SHIIP) at (800) 443-9354.**

X. LEGAL ISSUES

<u>SUMMARY:</u> Preparing for potential legal issues surrounding caregiving involves investigating issues, preparing documents and making difficult decisions. This section discusses legal issues and introduces important documents that may be appropriate for an elder's situation. Since under most circumstances the older adult is the decision-maker, the section is written with them in mind.

The vast majority of older people handle their own affairs throughout their lives. However, illness, chronic and debilitating conditions, or memory loss may make it necessary for someone else to handle their legal affairs. Being able to find important documents when they are needed saves time and money. Caregiving can be a stressful situation, and knowing where documents are located can help reduce the frustration.

HOW DO I CREATE A DOCUMENTS INVENTORY?

Here is a list of many different types of papers, documents and other printed materials that many people consider important to keep. Note the location of each item that you think is important to your caregiving situation.

<u>ITEM</u> <u>LOCATION</u>

- 1. Adoption papers
- 2. Apartment/house lease
- 3. Appliance receipts
- 4. Appraisals
- 5. Auto bill of sale (title, registration)
- 6. Auto insurance policy
- 7. Bank statements (canceled checks)
- 8. Birth certificate
- 9. Blood type records
- 10. Burial plot deeds, contract
- 11. Business records
- 12. Charitable contributions
- 13. Citizenship records
- 14. Copyrights
- 15. Death certificates
- 16. Debt records (credit cards, mortgage)

- 17. Deeds
- 18. Divorce papers
- 19. Driver's license
- 20. Health care power of attorney
- 21. Health records
- 22. Home improvement records
- 23. Income Tax records
- 24. Insurance policies (auto, homeowner's, renter's, health, disability, life)
- 25. Living will
- 26. Marriage certificate
- 27. Medicare card
- 28. Military service records
- 29. Personal property inventory
- **30.** Power of attorney (durable power of attorney)
- 31. Saving and investment documents
- 32. Social Security card
- 33. Trust
- 34. Wills and codicils

For more information about creating a document inventory, to learn how to obtain or create items you do not have, or to think through where to store documents contact the North Carolina Cooperative Extension agent in your county. They have produced a series called *Personal & Family Record Keeping*.

FCS400-1	Deciding What Documents & Records You Need
FCS400-2	Locating, Creating & Storing Important Documents & Records
FCS400-3	Organizing Personal or Family Filing Systems & Procedures

Single copies are free and available from your county agent.

WHEN DO I NEED TO INVOLVE A LAWYER?

An attorney might be helpful in preparing a durable power of attorney, estate plan, living will or living trust. An attorney may also be useful in assisting you with Medicaid and Medicare claims and appeals, Social Security disability claims and appeals, supplemental and long-term health insurance problems, and elder abuse cases. Sometimes an attorney will specialize in the area of elder law.

QUESTIONS TO ASK WHEN SELECTING AN ELDER LAW ATTORNEY:

- How long has the attorney been in practice?
- Does his/her practice have a specialty in the area of elder law?

- Is there a fee for the first consultation, and if so, how much?
- What information should you bring to the initial consultation?

If you cannot afford an elder law attorney, legal services will handle public benefits and consumer issues on a sliding fee scale and some services are provided free.

FOR ASSISTING IN LOCATING AN ATTORNEY:

- Ask for a referral to an elder law attorney from an attorney you already know.
- Contact the **North Carolina Lawyer's Referral Service** at **(800) 662-7660**. This service provides referrals based on the county that the elder lives in.

WHAT IS A POWER OF ATTORNEY?

The **power of attorney** is a legal device allowing one individual, called the "principal," to authorize another person, called the "attorney-in-fact" to act on his or her behalf. The attorney-in-fact may handle personal and financial matters of the principal to the extent authorized in the Power of Attorney document.

One disadvantage of the regular power of attorney is that it automatically expires if the principal becomes incapacitated or becomes mentally incompetent. A <u>durable power of attorney</u>, if it is properly registered, is effective even if the principal becomes incapacitated.

Regardless of which method is used, you should choose someone you trust completely to be your attorney-in-fact. The actions of the attorney-in-fact authorized by the power of attorney are considered legally to be your actions.

Ask the **Cooperative Extension Services** for a copy of the publication "Legal Authority", FCS-363.

WHAT IS A WILL?

Under North Carolina state law, a will determines how your estate is distributed after your death. Therefore, a will is an important legal document which should be drafted by an attorney who specializes in estate planning. An up-to-date will should be periodically revised in order to protect personal assets and loved ones in the event of death.

Failure to create a will may result in having to pay increased estate taxes and legal fees. Also, not having a will may increase the likelihood of other complications such as family disagreements over the distribution of property, delays in dividing assets, and the appointment of an outside executor.

Even though it may be a difficult subject to discuss, it is important that you make sure that your aging relative has a will. It will prevent unnecessary anguish.

For more information write the National Institute on Financial Issues and Services For Elders, 409 3rd Street, S.W. Washington, D.C. 20024.

For more information, see the **Cooperative Extension Services** series of ten publications, "Planning Your Estate", FCS273-(1-10)

For help in finding a lawyer, contact the **North Carolina Lawyer's Referral Service** *at* (800) 662-7660. This service provides referrals based on the county where the elder lives.

WHAT IS A LIVING WILL?

A living will is a legal document in which you declare your desire to die a natural death. This means that you do not want extraordinary medical treatment or artificial nutrition or hydration used to keep you alive, if there is no reasonable hope of recovery. A living will gives your doctor permission to withhold or withdraw life support systems under certain circumstances. A living will must be signed in the presence of two qualified witnesses and it must be notarized. The statutory Living Will form is duplicated at the end of the <u>Handbook</u>.

If you do not have a living will and you are unable to make your own medical decisions, someone else must decide for you. Your family may be burdened with this decision, and may not be able to agree on what action to take. A living will removes the decision from your family's shoulders and makes the decision yours.

- For more information get the pamphlet called <u>The Living Will</u>, FCS-364 from your county North Carolina Cooperative Extension Service agent.
- For help in finding a lawyer, contact the **North Carolina Lawyer's Referral Service** at (800) 662-7660. This service provides referrals based on the county where the elder lives.

WHAT IS A HEALTH-CARE POWER OF ATTORNEY?

A Health-Care Power of Attorney is a legal document that allows someone to make medical decisions for you if you cannot make them yourself. A health care power of attorney must be signed in the presence of two qualified witnesses, and it must be notarized. The statutory Health-Care Power of Attorney form is duplicated at the end of the Handbook.

You may appoint any competent person who is at least 18 years old and who is not providing paid health care to you. The person you appoint is called your "health care agent." In the

Health-Care Power of Attorney document you set out the authority of the health care agent and your wishes about your health care decisions.

A health care power of attorney is the best guarantee that your medical care will be handled according to your wishes if you become unable to make these decisions yourself. Choose your health care agent carefully because he or she will have the right to make life and death decisions on your behalf.

- For more information get the pamphlet called <u>Health Care Power of Attorney</u>, FCS-387 from the county North Carolina Cooperative Extension Service.
- For help in finding a lawyer, contact the **North Carolina Lawyer's Referral Service** at **(800) 662-7660**. This service provides referrals based on the county where the elder lives.

WHAT IS ELDER ABUSE?

The problem of abuse, neglect and exploitation of older adults is growing in North Carolina. Fortunately, there is something than can be done about it. The first step is to recognize abuse, neglect and exploitation when they occur and the second step is to seek help.

Abuse occurs in many places. It takes place in the older person's own home, in the home of a relative, in an adult care home or in a nursing home. Sometimes it may be intentional, but most often it is not intentional. Those responsible for the abuse may be family members, paid or volunteer caregivers, or owners or employees of facilities.

The term "abuse" is commonly used to refer to several types of mistreatment. Abuse may be physical, financial, psychological or emotional. Neglect by family members or paid or informal caregivers is also a form of elder abuse. The misuse of an adult's financial assets by someone else is the most common form of exploitation. However, exploitation of the person, such as being forced to work without pay, also occurs.

Elder abuse has serious consequences: It results in death, physical trauma, disability or decline, financial loss, mental anguish and loss of opportunity to live a full and meaningful life.

YOU SHOULD BE CONCERNED IF YOU KNOW A DISABLED OR OLDER ADULT WHO:

- Needs medical care and is not getting it.
- Does not have enough food or a safe home.
- Is not able to cook, eat, bathe, or dress, and there is nobody to help.
- Has unexplained bruises or other injuries.
- Has a change in the way he or she acts or looks.

Help is available through your county Department of Social Services. If you think an older or disabled adult has been mistreated or you believe someone is mistreating you and you are unable to protect yourself, you should contact your county Department of Social Services and ask to speak to someone about Adult Protective Services. A law in North Carolina gives the Department of Social Services the responsibility to assess the situation and to offer help to disabled adults who cannot protect themselves.

APPENDIX

PERSONAL CARE TIPS

ALZHEIMER'S DISEASE AND RELATED DEMENTIAS

LIVING WILL FORM

HEALTH CARE POWER OF ATTORNEY FORM

NORTH CAROLINA COUNTY DEPARTMENTS OF SOCIAL SERVICES

NORTH CAROLINA COOPERATIVE EXTENSION SERVICE COUNTY CENTERS

PERSONAL CARE TIPS

Personal care activities include: eating; bathing; shaving; caring for hair, skin and mouth; and transferring (moving to and from chairs, toilets or bed). These are activities which people have learned to perform by themselves since childhood.

During the course of our daily lives, these everyday routine activities are taken for granted until weakness or disability makes them hard to do independently and safely. Providing assistance requires knowledge, patience, skill and frequently physical strength.

BATHING

Bathing an older person may require strength, special equipment and learning special techniques. Ask the older adult's doctor, nurse or a therapist for help with bathing or instruction on how to safely help an older person with his bath.

SHAMPOOING AND SHAVING

Occasional visits to a barber or hairdresser can be very positive experiences for both men and women. Individuals who provide these services often will come to the home. Wetting hair with alcohol or conditioner helps remove snarls.

People who are diabetic or on medication to "thin blood" (anti-coagulants) should use an electric razor to reduce the risk of cuts. It is also much easier and safer to shave another person with an electric razor.

SKIN CARE

Keep skin clean and dry, especially if the person you care for is having problems with bowel and bladder control. When washing, use a mild soap, rinse and dry well.

Keep bed linens clean, dry and free of wrinkles. Disposable bed pads can be purchased at a drug store. These can be used to keep sheets dry so that the caregiver does not have to change sheets many times a day.

Help your older adult change his positions at least every two hours, particularly if he/she is confined to a bed or wheelchair. Encourage him to shift his weight between position changes to redistribute pressure onto other areas.

Use mattresses and chairs that are soft and form-fitting rather than rigid and hard. This spreads the weight over a larger skin area, decreasing the pressure over the bones.

Watch for possible sources of pressure or anything that would interfere with good circulation, such as tight hose, elastic cuffed socks or tight undergarments.

TOILETING

Consider installing safety features in the bathroom such as grab bars and raised toilet seats.

A commode or urinal may be necessary when flexibility and distance to the bathroom are a problem. These can be especially helpful at night.

Lack of control over bowel or bladder functions can be embarrassing and older people may try to hide it from caregivers. Be sensitive to your older adult's feelings. Loss of bowel and bladder function is not a normal part of old age and often can be prevented or controlled. Encourage the person you care for to talk to the doctor about this problem.

TRANSFERRING

Moving people who cannot move safely by themselves from one place to another requires skill, knowledge and some strength. For every type of disability, there is a specific technique to use in helping to move someone. Ask the older adult's doctor, nurse or therapist about the appropriate technique. In all cases, remember:

- 1. When lifting, do not add your own weight to whatever you are lifting --- get close and keep your balance centered.
- 2. Don't use weak back muscles to lift --- use your leg muscles.
- 3. Don't twist when you are lifting --- instead change the position of your feet so that you face the older adult and keep your spine straight.

ASSISTING WITH EATING

Eating can be a very time consuming activity, especially if the older adult must be fed. Encouraging independent eating saves time for caregivers, and promotes the independence and self-worth of the older adult. Consider these options:

- 1. Provide adaptive equipment such as plate guards or special silverware with built up handles.
- 2. Encourage the older adult to use a straw, cup with two handles or a glass with ribbed surface for independent drinking.

3. Because many older adults have limited vision, consistent placesetting of food and utensils helps them know where to find silverware, beverage, etc.

Remember to treat older adults who need assistance with eating as adults, not children. When a person lacks interest in food try to learn the reason. For example, being thirsty or perhaps not feeling well can affect appetite.

ENCOURAGING SELF CARE

Encourage the older adult to do as much as possible --- provide only as much assistance as is needed. Consider adapting the home to allow the older adult to do more things for himself. It is possible to install equipment such as grab rails in the bathroom, wheel-chair accessible sinks and mirror, a bath bench for the shower or tub and lights with switches that can be reached easily.

Try to include the older person in making plans for care. Whenever possible take his/her suggestions and feelings into consideration and encourage the person's involvement in his own care.

NUTRITION

Good nutrition is important for older adults. What is good nutrition? It is a balance of proteins, carbohydrates, fats, vitamins, minerals and water in the foods we eat.

A healthy diet helps to:

- 1. provide energy to maintain life;
- 2. build, repair, and maintain body tissues: and
- 3. regulate body processes.

When meals are eaten in the company of others, people not only benefit from nutritious food but enjoy the chance to socialize.

ADAPTING MEALS FOR PEOPLE WITH DIETARY RESTRICTIONS

If an individual is on a special diet such as low salt, diabetic or low saturated fat, certain foods may have to be eliminated, modified in their preparation, or limited in their intake. It is important that caregivers obtain specific instructions from a registered dietitian or the person's doctor on which foods are allowed, how much and how they should be prepared.

Certain medications and foods may interact to cause either the food or the medication to be improperly used by the body. Check with your pharmacist about food/drug interactions when buying medicine.

COMMON PROBLEMS INTERFERING WITH GOOD NUTRITION

Illness, disability and depression can affect the older person's desire and ability to eat properly. The following suggestions deal with common problems that interfere with good nutrition.

1. Food Tastes Strange

It might help to:

- Avoid alcoholic beverages; stop smoking.
- Marinate meat, poultry and fish in sweet fruit juices, Italian dressing, or sweet and sour sauces.
- Drink plenty of fluids or suck on candies to get rid of bad taste.
- Serve foods at room temperature or cold. (Serve hot foods hot 140 F
- or cold foods cold 45 F or below).
- Use stronger seasoning (flavor enhancers) when cooking.
- Try new foods.

2. Cramps, Heartburn, Bloating:

- Eat slowly, eat small meals frequently. (chew foods well)
- Avoid gas forming foods: cabbage, onions, nuts, beer, cola.
- Avoid fried, greasy and heavily spiced foods.
- Try bland, low-fat, easily digested foods.
- Chilled antacids may help.
- Stop smoking; lose weight if you are now overweight

3. Constipation:

- Eat plenty of high fiber foods such as: whole grains and raw fruits
- and vegetables. Drink plenty of liquids (eight to ten glasses of liquids daily).
- Avoid irregular meal intake. Get plenty of rest & exercise if possible.
- Drink hot beverages which act as stimulants.

4. Diarrhea:

- Eat frequent small meals.
- Drink clear liquids.

- Avoid high fiber and greasy foods.
- Replace fluid loss with liquids between meals.

5. Nausea, Vomiting:

- Avoid unpleasant odors.
- Eat frequent small meals.
- Sip cool, clear liquids between meals.
- Rest after meals with head elevated.
- Avoid hot, spicy, strong-smelling foods or fried, greasy food.
- Eat dry or salty food.
- Try fresh air and wear loose clothing.

6. Dry or Sore Mouth:

- Drink plenty of liquids.
- Suck on ice chips.
- Suck on popsicles made of milk or non-acid juices.
- Rinse mouth frequently.
- Suck hard candies or chew gum.
- Eat sweet or tart foods if there are no sores in mouth.
- Artificial saliva can be used.

GENERAL TIPS FOR HELPING THE OLDER PERSON TO EAT WELL

Plan meals and snacks to include the person's favorite foods.

Prepare foods that provide a variety in texture, color and, temperature, and new seasonings.

Provide a pleasant setting such as flowers, place mats, matching dishes and good lighting. Plan frequent, small meals.

The following section on Alzheimer's Disease is from <u>Home Is Where I Remember Things: A Curriculum for Home and Community Alzheimer Care</u>, by Lisa Gwyther. Available from Duke Family Support Program, Box 3600 Duke University Medical Center, Durham, N.C. 27710.

ALZHEIMER'S DISEASE AND RELATED DEMENTIAS

HOW DO YOU KNOW IF IT'S NORMAL FORGETFULNESS OR ALZHEIMER'S?

- Confusion, disorientation, and changes in personality and behavior are not normal signs of aging. The terms "senility," "organic brain syndrome," "hardening of the arteries," and "senile dementia" describe conditions in which a variety of such symptoms cluster together in one person, interfering with that person's ability to take care of him-or herself.
- Memory skills differ throughout life. Some people are never good with names or numbers, especially if they weren't able to attend school or if their work didn't give them many opportunities to practice what they learned in school.
- As we age we store more memories and it takes longer to remember things.
- If we don't pay attention to an event or fact, it's never stored in memory in the first place.
- It's more common to forget parts of an experience than the whole experience. We may forget what we ate for lunch, for example, but not whether or not we had lunch.
- People with normal memory changes use cues around them. They can look outside to see if their clothing is appropriate for the weather. They can connect fireworks with the Fourth of July or remember an appointment by looking at their calendar.
- Many people forget a name when they need it, but it may come to them later that day. They
 may forget why they went to the refrigerator, but looking in the refrigerator may remind
 them. The delay in remembering is simply normal forgetfulness.
- Illness, depression, stress, fear, or worry makes it hard for anyone to remember.
- Distractions-listening to many conversations going on at once, having troubled seeing or hearing, lack of sleep-can make normal forgetfulness seem a lot worse.
- Telephone reminders, notes, calendars, and lists can help people with normal forgetfulness.

EARLY SIGNS OF ALZHEIMER'S

PEOPLE IN THE EARLY STAGES OF ALZHEIMER'S MAY:

- Forget recent events (telephone call, just-eaten meal)
- Have trouble doing arithmetic, handling money, and making change
- Suddenly dislike familiar people or show less understanding of others
- Have trouble learning or coping with new things-new routines, new people, etc.
- Get lost going to familiar places
- Forget how things work--the washing machine or microwave, for example
- Ask repetitive questions
- Lose interest in hobbies and be unable to start or organize things
- Withdraw, worry, become cranky or silly, or show other personality changes
- Be indecisive or make bad decisions
- Take longer to do routine chores or become frustrated at the difficulties routine chores present
- Show changes in personal grooming
- Forget to pay bills or pay the same bill several times
- Forget appointments and holidays
- Lose skills, especially the ability to do detail work
- Lose, misplace, or hide things
- Arrive at the wrong time or place
- Constantly check locks, calendar, doors
- Become confused about time or abstract concepts, such as "in a minute"
- Look strong or healthy for their age and seem fine at times.

MIDDLE-STAGE SIGNS OF ALZHEIMER'S

PEOPLE IN THE MIDDLE STAGES OF ALZHEIMER'S MAY:

- Show changes in behavior, sleep patterns, and judgment of safety risks
- Mix up the identity of past and present acquaintances and family members
- Have trouble keeping a thought and talk in circles
- Have trouble with home safety or staying alone due to poor judgment
- Hoard things or urinate in strange places
- Make repetitive statements while following family members around
- Become restless (especially in the late afternoon and early evening), empty drawers or closets, or threaten, hit, or kick others
- Be unable to organize, plan ahead, or follow logic
- Have trouble following directions or staying on task
- Make up stories to fill in memory gaps
- Be unable to follow written signs, or write checks
- Be suspicious, curse, fidget, or behave inappropriately
- Sit and stare for hours, forget to eat, or eat only sweets
- Be sloppy or tactless, forget how to use utensils
- Show resistance towards dressing and bathing
- See or hear things that aren't there or believe things that aren't true
- Wander in search of an old job or long-deceased parents
- Accuse family of having affairs or stealing
- Nap frequently or awaken at night
- Have difficulty positioning their bodies to sit in chairs or attach seat belts
- Need help finding the toilet, using the shower, fixing food, remembering to drink, changing clothes, or dressing appropriately for the weather
- Talk to their reflections in the mirror or believe television stories are happening to them
- Show changes in sexual behavior
- Forget what is private behavior-- they may disrobe or masturbate in public

DEPRESSION IN EARLY-STAGE AD

People in the early stages of AD are often depressed by their loss of control and independence, sense of failure, and frustration at not being able to do things as well as before. Common symptoms of depression include withdrawal, feelings of hopelessness or uselessness, fatigue, restlessness, loss of pleasure in things, loss of appetite, sleeping a lot, and awakening early.

WHAT YOU CAN DO?

- Reassure depressed people that they are not going crazy or getting lazy
- Don't give pep talks or tell them to snap out of it
- Tell them they have a right to feel bad about their losses
- Remember that exercise helps; alcohol hurts
- Don't make false promises
- Let them talk about their feelings
- Limit your demands and over-stimulation: don't correct them, quiz them, or announce things too far in advance
- Try to increase their daily quota of pleasant events
- Give them a meaningful job and moments of fun and humor
- Encourage socialization but don't push
- Encourage them to participate in early-stage support groups

SLEEP PROBLEMS

Another problem persons in the early stages of AD may experience is troubled sleep. Brain damage disrupts the sleep-wake cycle--some people sleep more and some less than they used to. Because they have to concentrate so hard, people with brain disease tire more easily. Time distortions in AD make it impossible to relate time of day or night to sleep, and people with memory problems can't use cues like darkness to remind them it is time to sleep.

Adding to AD-related sleep problems, people experience less deep sleep and more frequent awakenings as they grow older. Pain, discomfort, medication use, depression, and an increased urge to urinate also interrupt sleep.

WHAT YOU CAN DO?

- Stick to predictable routines.
- Encourage regular, vigorous exercise or participation in an appropriately stimulating day center program.
- Don't expect the person to do too much. Plan shorter activities at his or her best time of day.
- Allow for frequent rests during the day and intersperse activities with breaks.
- Avoid caffeine, alcohol, and non-prescription sleep aids.
- Limit fluids after dinner except warm milk or herbal tea.
- Make sure the person gets help for depression, illness, or pain if they're interfering with sleep.
- Since darkness may increase the person's disorientation and fear of danger, try using a night light.
- Don't insist that he or she sleep only in a bed, but make sure that the bed, pillows, and nightclothes are comfortable.
- Create a safe space and quiet activity in case the person with AD can't sleep at night when his or her family is sleeping.
- If the person awakens, reassure and comfort him or her, change his or her position, and try
 using a radio, TV, or rocker.
- Change timing of medications that might interfere with sleep.
- Sleep medications are a last resort. Try them only after trying light snacks, back rubs, music, comforting nighttime rituals, cozy flannel sheets, and security objects. Also make sure lighting is ample and the temperature comfortable.

HOW MEMORY LOSS AFFECTS DAILY ACTIVITIES

 Daily care activities will take more time. People with Alzheimer's can't start, organize, or complete a task without step-by-step help. They can't keep track of time or wait long for anything. They may become frustrated, resist you, or wander off in the middle of the activity. They may even forget what you doing and why. You may have to pause between steps, so be patient and keep in mind that rushing makes them more confused.

- Abilities vary daily and hourly. You have to change your expectations if your client is having a bad day.
- Recognition is easier than recall: say "Here is your hair brush," not "What do think this is for?"
- Predictable daily routines-doing the same thing at the same time in the same way-- limit what people have to remember and make them feel more secure.
- You need to stay with the person throughout the activity—he or she may forget what is safe.
- The person may not remember something you just did-- he may ask you to do it again or tell someone else.
- Thinking exhausts people with memory loss. Allow rest or quiet time after each thought
 activity like bathing or going out. Use an afghan, soft music, or dim lights as a cue that it's
 quiet time.

STEP-BY-STEP BASICS OF DAILY CARE:

Here's a general outline of how you might help a person with dementia accomplish her daily care tasks:

- A predictable, structured routine can help you get started, but do remain flexible.
- Give her cues: say "Here's your shirt," point, demonstrate by putting the shirt on yourself, or guide his or her hand into the sleeve.
- Give step-by-step instructions:
 - 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. Start the brushing motion for her by guiding her hand.
- Begin the activity at the step where she can succeed. Encourage her remaining skills and help with her limitations. Respect her privacy to the degree possible.

- Give her back some control with limited choice: "Do you want to bathe first or eat first?"
- Without being bossy, approach her as if you expect her to agree. She may be embarrassed that she can't meet your expectations. Say, "I will do it with you but I need your help."
- Use smells, sights, sounds, and tastes to remind her of what you are doing "Smell that soup. Your lunch is ready."
- Organize materials for her bath or meals in advance.
- Concentrate on the task at hand.
- Allow plenty of time so she can do part of the job herself. When she has finished dressing, say, "Well, look how pretty you are today."
- Respect her lifelong routines, habits, and preferences: for example, choose her most relaxed time for bathing or prepare breakfast later than you normally would if she doesn't like to eat first thing in the morning.
- You may need to change your standards for activities like daily baths.

STEP-BY-STEP BATHING TIPS FOR ASSISTING PERSON WITH DEMENTIA:

- 1. Keep in mind the main causes of bathing problems, and alleviate them when you can:
 - Fear of falling, drowning, getting hurt, or being naked
 - Fear of being with a stranger in a private situation
 - Feeling overwhelmed by mechanics of bathing
 - Feeling embarrassed by needing help with something so simple and private
 - Feeling rushed or tired
- 2. Follow a regular routine which reflects her preferences: what time does she like to bathe? Would she rather take a bath or a shower?
- 3. Don't discuss why the person needs a bath. And remember that she might not need to bathe every day--washing her face, hands, and genital areas may be sufficient. Try to wash her face last, or before she puts on make-up (or during shaving if your client is male). If she

resists hair washing, try a simpler hair style, washing her hair separately in a sink, a regular beauty shop outing, or no-rinse shampoo.

4. Have everything ready before you start. Use plastic, not glass, containers. Hand-held shower heads, bath chairs or benches, non-skid surfaces on tubs, and grab bars attached to the tub are safer and less frightening. Avoid bath oils, electrical equipment.

UNDERSTANDING A PERSON'S BEHAVIOR WHO HAS DEMENTIA:

Alzheimer's causes people to act in different or unpredictable ways, to act in ways they wouldn't choose if they were well, and to lose the ability to change their behavior.

To better understand the person you're working with, ask the family or people who know him or her well about:

- Personality before and since the illness
- Typical ways he or she responds to stress
- What he or she remembers and considers important about his or her life
- Work or household routines and preferences
- What comforts him or her
- Details he or she still remembers about early life-- family, school, work, religion, hometown
- Food and music preferences, both before AD and now

Next, ask yourself:

- WHAT is the specific problem?
- WHY does it need attention?
- WHERE does the behavior happen?
- WHEN does it happen?
- WHO is around when it happens?
- WHAT usually happens next?
- WHAT does the behavior tell you about what the person can't say?

WHAT TRIGGERS BEHAVIOR CHANGES?

Physical Causes

Illness, medication, pain

Hearing or vision loss

Constipation, dehydration

Fatigue, depression

Too Much Going On:

Loud, busy places

Too much clutter, lack of routine

Anything that requires too much thinking, organizing, remembering

New Place or People

Situations which hold no cues to anything familiar

Situations which trigger fear of failure, embarrassment, or being lost

Complicated Demands or Jobs That Set Them Up to Fail:

Activities that require lost skills in planning, starting, organizing, and completing

Activities that involve too many steps

Activities that require new learning

Social Situations:

Frustrations of being unable to say what he or she means

Frustration of being unable to understand your directions

Feelings of being put down or nervous

Remember:

Not all people with AD exhibit the same difficult behaviors.

Most difficult behaviors do not last throughout the illness.

WHAT YOU CAN DO?

- Anticipate and meet the person's needs
- Change the person's situation
- Change your approach or reaction

- Assume the person is behaving that way because he or she is scared, frustrated, or embarrassed--not because he or she is out to get you.
- Tell the person you understand and will help.
- Treat him or her as a dignified adult who is not purposely trying to make you crazy.
- Don't confront, shame, scold, argue with, or reason with him or her.
- Be flexible and tolerant. Go with the flow.
- Know the person you're dealing with.
- Adjust your expectations according to the person's abilities. He or she will need more help over time.
- Name the person's feelings and strong points for him or her.
- Break down jobs into doable steps.
- Respect his or her limits. You can't teach the person to remember.
- Use humor or gentle teasing as often as it works.
- Repeat, structure, simplify, reassure.
- Know yourself and when you need help.

REDUCING DISRUPTIVE BEHAVIORS

RETHINK: It is harmful to the person with Alzheimer's or others?

Can you let the behavior roll off your back or change your expectations?

Is the person in pain, cold, hungry, sick, or over-medicated?

Is the behavior a problem in the privacy of his or her own home?

REDIRECT: Restlessness can be channeled into a productive activity: sweeping, raking, dusting.

Does music, dancing, exercising, or walking calm him or her?

Would giving him or her boxes of things to sort or pack help?

DISTRACT: With snacks, a ride, a walk, a cup of tea, or a request for help a failure-free job.

COMPENSATE: Protect the person from failure or embarrassment by doing the hard parts of tasks yourself or by giving him or her choices.

Guide the person to a private place if he or she is acting silly or behaving badly in public.

Hand her what she needs or do a job for him if he looks lost or confused.

REASSURE: The person needs to be reassured that you will keep him or her safe from danger, embarrassment, failure, and being lost or left behind.

AVOID: Noisy, busy places where people rush around

Complex directions; lack of structure or direction

Doing any one thing for too long

Confronting the person with a mistake

ROUTINES, RITUALS, REPETITION: Nothing comforts a person with Alzheimer's like the ordinary and expected. Let your client repeat favorite old stories.

SLOW DOWN AND SIMPLIFY WITHOUT PUTTING DOWN: Don't push her too far or too fast. Don't talk louder or use baby talk.

CELEBRATE THE PERSON'S GOOD DAYS AND REMAINING SKILLS: Let him help and thank him for doing it. Find out what she considers pleasant and do it often. Remind him of his success, family, skills.

CREATE FUN MOMENTS: Pleasurable activities and social events are great goals in themselves. The person will remember having fun even if he or she forgets what you did. Use music, massage, religious rituals, or stories if they calm him or her.

TAKE SAFETY PRECAUTIONS: Set up the house to reduce problems. Throw out spoiled food, lock up poisons, and keep extra keys, glasses, and dentures.

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