FAMILY CAREGIVER GUIDE

Caring for a family member or friend who has become ill or incapacitated can be a daunting task. Whether you became a "family caregiver" suddenly or over a period of time, you are probably overwhelmed with everything you need to do and to know.

The Western Connecticut Area Agency on Aging is a "single point of entry" provider of information, assistance, and services for seniors, the elderly, and family caregivers. The Agency and its partners have designed this packet to help you throughout your caregiving "career". Each page presents an individual topic and includes a list of additional resources. We put it in this packet form so you can use each page when it's most helpful to you.

NOTE: The terms "parent, spouse, Mom, Dad, husband and wife", etc., are all used interchangeably. They are intended to avoid more formal terms like "care recipient".

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For more information about caregiver assistance, call the Western Connecticut Area Agency on Aging at 1-800-994-9422 or 203-757-5449; e-mail at westernctaaa@sbcglobal.net.

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THE ROLE OF CAREGIVER

The National Family Caregiver Support Program defines a caregiver as "anyone who provides full or part-time care to older parents or relatives still living in their own home or now living with others". Caregivers come in all shapes and sizes and provide care in many different ways.

Often people who are assisting others with a variety of tasks do not identify themselves as caregivers because they think that a "caregiver" provides full-time, hands-on care. Or because the person being cared for is a spouse and that is simply part of the relationship – "for better or worse".

The following situations are those often faced by adult children of aging parents, the wife or husband of an ill or frail spouse, a family relative, or a close friend providing some help for a person age 60 or over living at home:

Does a parent or relative live with you? You're clearly a caregiver.

If your parent or relative still lives in his or her own home:

- Do you help with the yard work?
- Shop for groceries? Pick up the prescriptions at the drugstore?
- Clean the house? Take home the laundry?
- Pay the bills? Take Mom or Dad to the doctor?
- Spend more and more time visiting because your aunt is afraid to be alone?
- Arrange for a companion or homemaker to come in several times a week?
- Did you have a Personal Emergency Response System (PERS) installed because you're afraid your father might fall?
- Do you worry every time the phone rings that it will be another crisis?
- Feel guilt because you're not doing enough?
- Feel anger and resentment because no matter what you do, it's not appreciated?
- Feel manipulated because every time you try to get away for a day or two, Mom gets sick and you can't go?

If you are married to a spouse 60 or older who is beginning to fail, has a debilitating illness or disease, or has suffered a stroke or a fall:

- Do you find yourself waiting on him or her more than you used to?
- Have your wife's attitudes or behavior changed? Has your husband become more demanding or even belligerent?
- Do you find that you can't participate in your usual activities because you just can't get away?
- Do you find yourself exhausted with the additional responsibilities? Is your own health failing?
- Are you angry or resentful at having to play a new role in the relationship?

If you answered yes to any or all of these questions, you are a caregiver, whether you live with the person for whom you are caring full time, or you live in the next town or in another state.

ASSESSING YOUR CAREGIVING RESPONSIBILITIES & CAPABILITIES
TAKING CARE OF YOURSELF: MANAGING CAREGIVER STRESS

Although becoming a caregiver is a role you assumed by chance, it's important to step back and get a clear picture of your responsibilities and your capabilities. This checklist can help you to assess the situation and plan realistically for what's ahead.

- How much help does the person you care for need? Make a note about what they need and how much time you spend helping out with the following:
  - ❑ housecleaning
  - ❑ shopping
  - ❑ meal preparation
  - ❑ bathing or showering
  - ❑ laundry
  - ❑ paying bills
  - ❑ transportation to the hairdresser and doctors' appointments
  - ❑ other things____
- Is the housing situation safe and healthy in regard to:
  - ❑ appliances working properly
  - ❑ adequate lighting
  - ❑ clutter or scatter rugs removed that could cause a fall
  - ❑ sturdy handrails on stairs
  - ❑ doorways and thresholds not a hazard or barrier
  - ❑ bathroom fixtures easy to use, tub or shower easily accessible
- Is there a regular system of contact set up with family, friends, neighbors, and/or a phone reassurance program?
- Is company provided by family and friends, or is your mother alone most of the day?
- Is there a plan in place if the power fails or the phone goes out?
- Is Dad still driving? Should he be driving?
- Are medications being taken properly?
- Does Mom fall or have a medical condition that causes dizziness or fainting?
- Is your father still able to cook meals? Is he eating regular nutritionally well-balanced meals, or have you noticed some weight loss?
- Does your mother keep her financial information safe? Does she know not to give out any credit card or bank account information over the phone?
- Is the situation likely to change? Will it improve? Or will it deteriorate over time? Do you think your Dad is able to continue to live safely in his own home?
- Who provides the care now? Is it just you, or are there other people who are able – and willing – to help with care?

FINANCIAL TIPS FOR CAREGIVERS
Keeping Your Affairs in Order & Benefits Check-up Questionnaire

This information was prepared with the generous assistance of Patrick P. Bria, Certified Public Accountant and Certified Senior Advisor of the accounting firm of Patrick P. Bria LLC. Mr. Bria is a member of the Board of Directors of the Western Connecticut Area Agency on Aging. He can be reached at 203-830-4062 or by e-mail at patrick.bria@snet.net.

Caregiver's Check List for Getting Organized

It is important to help organize the personal papers of the person you care for before an emergency so that as a caregiver you will be able to find all of the documents that may be needed. Unfortunately most of us carry this information in our heads and never think of discussing it with our families. A failure to have the affairs in order can result in some of the assets going unclaimed, which may result in them being turned over to the government. State treasuries are currently sitting on billions of dollars of unclaimed assets!

Caregivers should know where important documents are filed. The "Keeping Your Affairs in Order" worksheet in this packet may help you get organized. Additional resources are listed at the end of this sheet.

Some of the documents that should be kept in a safe place where you as a caregiver can find them:

- Income tax returns
- Bank accounts – including account numbers, bank location, and the types of bank accounts. Also note the names of other(s) who are authorized to sign checks.
- Safe deposit box(es) – Note where the bank is located and where you have put the key(s). Also list the contents of the safe deposit box.
- Credit card information – including the names of credit card companies, the name(s) on the cards and the credit card account numbers.
- Insurance policies – such as life insurance, disability, health, auto, long-term care. Include the names of the insurance companies, policy numbers, location of the policies and any beneficiaries stated on the policies.
- Stocks, bonds, or money in mutual funds.
- Pensions, retirement accounts, or annuities, including the name and phone number of your broker or banker.
- Birth certificate, Social Security, and Medicare numbers (and Medicaid number if applicable).
- Legal documents – such as will, living will, advance directives, and Power of Attorney documents.
- Instructions for funeral services and burial along with name and location of the funeral home. Note if arrangements have already been made (and if there is a pre-paid burial plan). Do you want donations made to a specific charity? Do you want flowers sent?
- Deeds and titles to all properties or real estate you own.

LEGAL ISSUES FOR CAREGIVERS

This information was prepared with the generous assistance of Attorney Robert Fisher of the law firm Cramer and Anderson, which specializes in elder law and estate planning. Attorney Fisher is a member of the Board of Directors of the Western Connecticut Area Agency on Aging. He can be reached at 860-567-8718 or by e-mail at rfisher@cramer-anderson.com.

Talking with your parents about their wishes for healthcare decisions, their plans for giving away property, or leaving property to family members, can be a difficult discussion. If you're fortunate, your parents will be the ones to bring up the issue and tell you what their wishes are and what plans they have made. If they have never brought up the issue, you may want to find opportunities to introduce it.

There are several things that caregivers should be aware of when making legal arrangements. Your parents can make some arrangements on their own without legal advice; for others you will need to contact an attorney. ***Even for those documents that do not require an attorney, we recommend that you consult an attorney specializing in elder law and/or estate planning, especially if there are significant assets or complicated issues.*** Also, if your parents spend time in more than one state, they should have documents such as Powers of Attorney and Healthcare Directives drawn up for each state.

The following documents can be prepared without the help of an attorney, but they must be witnessed and notarized. If you are consulting with an attorney to prepare a Will or a Durable Power of Attorney, you might want to have the attorney assist you with the following documents as well. However, if you decide to prepare them yourself, forms can be found at local stationery stores, on the internet, or by calling the Western CT Area Agency on Aging.

- **A Power of Attorney** is a document in which a person names another person to be his or her "attorney-in-fact". The person signing the Power of Attorney in called the "principal" and the attorney-in-fact is called an "agent". A general Power of Attorney authorizes the agent to act on behalf of the principal. Depending on the language in the document, the agent's authority can be limited to certain transactions or may be limited in duration, including stating a specific expiration or termination date. A Durable Power of Attorney (see other side) is recommended over a Non-durable Power of Attorney as it continues in force even if the principal becomes incapacitated; a Non-durable Power of Attorney terminates if the principal becomes incapacitated. All Powers of Attorney terminate upon the death of the principal.
- **A Health-Care Agent (or Proxy) and Healthcare Directives** outline the healthcare decisions a person would make if he or she were capable of making them, and names the person(s) who will make those decisions if he or she is not able to do so. A Health-Care Agent designation can be included in a Durable Power of Attorney and a Living Will.
- **A Living Will** is used to express the wishes of the person as to medical treatment if he or she becomes comatose or otherwise incapable of communicating meaningfully with medical or hospital personnel. A Living Will typically spells out what types of treatment the person wants and/or does not want in the event that death is imminent or there is no reasonable chance of recovery. People often request that no heroic measures be used to sustain life, and that they be kept comfortable and free of pain.
- **A Do-Not-Resuscitate Order (DNR)** can be obtained through the doctor. A DNR spells out the person's wishes not to have CPR performed in the event the heart has stopped or he or she has stopped breathing. In Connecticut, for those wishes to be carried out when the ambulance arrives, the person *must be wearing* a DNR bracelet.

Copies of these documents should be given to family members, lawyers, doctors, hospital or nursing home staff – anyone who may be involved when decisions have to be made.

FINDING IN-HOME HELP

When the time comes that a family member needs a little help at home, there are several options for care.

First, decide what type of help is needed – does your Dad need a little help with his laundry? Shopping? Meals? A shower? Does Mom need someone to keep her company or provide a little social stimulation? The need will determine what type of assistance you will get and whether it will be a paid service or can be provided by volunteers.

If you are really not sure what is needed, you can arrange for an in-home assessment by a **geriatric case manager**. Case managers can help you develop a plan of care and can help you set up the needed services. The Western Connecticut Area Agency on Aging has an affordable case management program; call us at 203-757-5449 or 1-800-994-9422 to arrange for an appointment.

The following are services provided for a fee (see **PAYING FOR CARE AT HOME**):

- **Home Health Aides** – can do hands-on care such as bathing, showering, dressing, helping someone use the toilet.
- **Personal Care Assistants** – can do many of the same types of care as a Home Health Aide, but may be less expensive (not available at all agencies).
- **Homemakers** – cannot do hands-on care but can do housecleaning and laundry, run errands, help with meals, etc.
- **Chore Services** – can do inside and sometimes outside chores for seniors for a minimal cost.
- **Companions** – can stay with someone who will not need much assistance. Companions can read, play cards, take someone out to lunch or to shop.
- **Meals on Wheels** – meals delivered to the home, usually with a hot meal at noon and a sandwich for the evening meal.
- **Adult Day Care Programs** – a good option when in-home care is not practical. They offer personal care and socialization for the person you care for, and a good break for you as the caregiver. Most provide transportation and some operate seven days a week. Services include a noon-time meal, group activities, and many can do showers and hair care.

You can hire help through visiting nurse agencies (VNA's), home care agencies, nurses' registries, or you can hire privately. For VNA's and nurses's registries, look in the Yellow Pages, call your doctor's office, or the Area Agency on Aging. Most agencies require some license or certification in Connecticut (you can check with the Department of Public Health's Institutional Licensing Unit at 1-860-509-7444). To hire privately, check the newspaper or ask friends and colleagues if they know of anyone. If you decide to hire privately, be sure to ask for references; you may even want to do a background check (ask your local police department how to go about this).

PAYING FOR CARE AT HOME
(including applying for Medicaid/Title 19, Reverse Annuity Mortgages)

In-home care can be costly. Depending on your family's financial resources, there are a number of options to consider when looking for ways to pay for care. Many people have mistaken notions of what Medicare will pay for (see **MEDICARE: WHAT IT PAYS FOR; WHAT IT DOESN'T COVER** in this packet); in general, Medicare pays for very little in-home care.

NOTE: There are exceptions to every rule. The following list of payment sources may or may not apply to your family's situation. When significant assets and/or property are involved, consulting an attorney who specializes in "elder law" and/or "estate planning" is ***strongly recommended*** (see **LEGAL ISSUES FOR CAREGIVERS**).

- **Private pay** – for families with substantial income and assets (savings accounts, stocks, bonds, CD's, annuities, life insurance with cash value, etc.), paying privately may be the only option. (See note below about applying for financial assistance for care.)
- **Private insurance** – contact your insurance agent or insurance company to see if your health insurance plan provides for any in-home care.
- **Long-Term Care Insurance** – many long-term care policies (if you already have one) will pay for at least some in-home care. Consult your insurance company or agent. For more information about getting Long-Term Care Insurance, contact the Connecticut Partnership for Long-Term Care at 1-800-547-3443.
- **Reverse Annuity Mortgages (RAM)** – may be a solution for people who have substantial equity tied up in a home and/or property. There are different types of RAM's. Call the Connecticut Housing Finance Authority (CHFA) at 860-571-3502. **Also see attached page for more information about RAM's.**
- **Connecticut Home Care Program for Elders (CHCPE)** – appropriate for low- to moderate-income families caring at home for someone 65 or over, who would otherwise be at risk of nursing home placement. There are different levels of eligibility, based on income and/or assets. Please see the eligibility insert to determine whether your family member may be eligible for the program. (A couple should apply for Spousal Asset Protection.)

  For more information about the Connecticut Home Care Program for Elders (CHCPE), and to receive an application or make a referral, call the Alternate Care Unit at CT's Department of Social Services at 1-800-445-5394 or 860-424-4904. The Western Connecticut Area Agency on Aging can also give you some general information about the program; call 1-800-994-9422 or 203-757-5449.

  Depending on the income and assets (not counting a house or a car) of the person applying for the Connecticut Home Care Program, they may be expected to go onto **Title 19 (also known as Medicaid)**. Sometimes people are reluctant to go onto Medicaid because they

REVERSE MORTGAGES AND TODAY'S SENIOR HOMEOWNER

This information was generously provided by Joyce Kuhn, a Certified Senior Advisor and Assistant Vice President at Ridgefield Bank. She specializes in reverse mortgages, one way that senior homeowners can pay for care. Ms. Kuhn is a member of the Board of Directors of Western Connecticut Area Agency on Aging. To reach her, call 1-800-776-6518, extension 7540, or e-mail at joyce.kuhn@fcbankcorp.com.

Many Senior Homeowners' primary source of income is social security, followed by assets and then pensions. The asset with the highest worth is often the senior's home. So how can a senior tap into the equity of his or her home? The answer may be a reverse mortgage.

Basic Eligibility Requirements

The first step towards a reverse mortgage is determining if you are eligible. You must be at least 62 years old. The age requirement applies to everyone whose name appears on the title to the home. Secondly, you must have equity in your home. You may qualify for a reverse mortgage even if you have an outstanding balance on your first mortgage or a home equity line of credit. If this were the case, the balance of the outstanding loan would be paid off with proceeds from the reverse mortgage.

How Much Money Can You Get?

That leads us to the second step. How much money can I get? The answer is based on a formula governed by several factors: the borrower's age, appraised value of the home and the current reverse mortgage interest rate. Reverse mortgage lenders and counselors can provide the borrower with an estimate of how much is available to them. Although lenders may offer their own proprietary reverse mortgage programs, most reverse lending activity involves government-sponsored programs. In that connection, the borrower can select the **FHA-insured Home Equity Conversion Mortgage (HECM) or Fannie Mae Home Keeper**. Currently, the HECM is the most popular choice because it makes more equity available to the senior. This information will therefore focus on the FHA HECM.

Financial Counseling Required

Counseling is an integral part of obtaining a reverse mortgage. Before an application can be taken, the senior must participate in mandatory counseling. The counseling is most frequently done over the phone by a Fannie Mae or AARP certified counselor. The borrower may have a family member or trusted advisor participate in the counseling session. Counseling helps the borrower decide if the reverse mortgage is the right option to meet current and future financial needs.

Payment Options

A reverse mortgage offers several payment options to the senior. One can choose a lump sum at closing, a line of credit, a fixed monthly benefit (tenure) or a combination of fixed monthly benefit and line of credit (modified tenure). The borrower may also elect to receive the money for a fixed term. When the borrower chooses the tenure payment, it is paid on a monthly basis, for as long as the senior lives in the home. The most popular program is the combined monthly benefit with a line of credit.

MEDICARE: WHAT IT PAYS FOR; WHAT IT DOESN'T COVER

Many people are under the false impression that Medicare will pay for most health care when they reach the age of 65. Medicare does pay for some care under certain circumstances, but caregivers should be aware that there are many things that Medicare does **not** cover.

Medicare has **two parts – Medicare Part A (Hospital Insurance)** which most people get automatically when they turn 65 and do not have to pay for, and **Medicare Part B (Medical Insurance)** which most people pay for through deductions from their monthly Social Security checks. Medicare generally pays 80% of covered expenses. Many people opt to buy supplemental – or "Medigap" – insurance to cover the 20% that Medicare does not pay.

Medicare Part A pays limited coverage for:
(See eligibility insert in the front of the packet for current rates.)

- **Inpatient Hospital Care** – after the patient (or insurance) pays **a deductible**, Medicare pays the full amount of care up to 60 days. After 60 days, **the patient** pays partial cost per day for days 61 through 90, and a higher amount for days 91 through 150.
- **Skilled Nursing Facility Care (Nursing Homes or Rehabilitation Centers)** – following a minimum three-day stay in the hospital, Medicare pays the full cost for the first 20 days. After 20 days, the patient pays partial cost for days 21 through the 100. If there has not been a three-day hospital stay, Medicare will not pay any of the cost of nursing home care.
- **Home Care Coverage** – Medicare pays for some home health care under the following conditions: the doctor must sign a plan of care; the person must be "homebound" except in certain circumstances; the person must need a skilled nurse to visit periodically, or need physical or occupational therapy. The care must be provided by a Medicare-certified home health agency. (When the agency "discharges" you, ask your doctor to issue a new order.)
- **Hospice Care** – available when a person is determined by a doctor to have a terminal illness and is not expected to live more than six months. Hospice is not available to those who are pursuing treatment in hopes of a cure.

Medicare Part B pays 80% of the Medicare-approved cost (after an annual deductible) for:

- Doctors' visits (except routine physicals)
- Some home health care
- Diagnostic tests like X-rays and blood tests
- Diabetes monitors and testing strips
- Outpatient hospital care like radiation therapy
- Surgical dressings, splints and casts
- Prosthetic devices, therapeutic shoes, braces, trusses, artificial limbs and eyes
- Some ambulance services
- Kidney dialysis
- Some medical equipment for use in the home
- Some mental health services
- Some preventive services like colorectal screening, pap smears, mammography, diabetes screening, bone mass screening, prostate exams, some vision testing
- Certain vaccines like flu, pneumonia, and Hepatitis B

MAINTAINING GOOD HEALTH

Maintaining good health can be challenging as a person ages. Caregivers must pay close attention to be sure the person they care for is eating enough, consuming enough liquids, taking medications properly, maintaining good hygiene, and seeing the doctor on a regular basis. Improper use of medications, inadequate nutrition, and dehydration are leading causes of hospitalizations for older people. Caregivers should also be aware of signs that indicate possible neglect, self-neglect, or even abuse.

Doctor's appointments

- Be sure your Mom or Dad sees the doctor regularly and that the doctor takes the time to thoroughly check out what's really going on.
- Before the visit, **keep notes about any changes** and **make a list of questions** to ask while you're there. If you think you may need more time, **ask for a double appointment**.
- **Take any medications with you**, along with a list.
- **Be sure you are with the person in the examining room** (unless your parent refuses to have you there) and that your concerns are addressed. A second set of ears is important.
- **Write down what the doctor says**.

Medications

- **Know what medications your parent or spouse is taking** and why he or she is taking them. You can ask the doctor to have the pharmacy make a note on the medication label what the medication is for – especially helpful when a person is seeing more than one doctor.
- **Make a list of the medications**, doses, the times of day they must be taken, and whether they should be taken with or without food. **Keep a copy of the list on the refrigerator door**, or with the medications if they are in an easily identified location. Keep another list in your Mom's wallet and one in yours. **Update the list after any change in prescriptions** and **list any over-the-counter medications**, including laxatives, vitamins and herbal supplements. Also note whether there is any **alcohol use**.
- **Store medications properly**. Unless otherwise specified, store medications in a cool dry location, away from extremes in temperature. Do not refrigerate unless specified. Do not store in direct sunlight or in the bathroom "medicine chest" where steam and heat can affect the quality. If grandchildren will be visiting, store medications out of sight and out of reach.
- Be sure the medications are **being taken correctly**. Know how many pills are in the bottle and check often on the number remaining. Refill promptly when needed.
- If you detect a problem, **consider setting the medications out weekly in a pill box** (different types are available in the drug store). If there's still a problem, investigate the possibility of installing a Personal Emergency Response System (PERS, sometimes called a Lifeline) that has a daily reminder capability.
- **Be aware of changes** that may occur as a result of a new medication or a change in the dose. Dizziness, lightheadedness, fainting, confusion, and signs of delirium can all be caused by medication changes. Of course there may be something more serious going on, but be sure to tell the doctor, paramedics and/or emergency room staff about any changes in medications.
- Also tell the doctor about **severe constipation and/or urinary incontinence**, they could be the result of medications like iron pills (constipation) or diuretics like Lasix, which can cause frequent urination or even incontinence.

Call the doctor or pharmacist for *any questions* you may have about medications. HINT: You may find that the pharmacist is available to take your calls more often than the doctor.

MENTAL HEALTH CONCERNS IN THE ELDERLY:
Memory Loss, Depression, Delirium, & Dementia

The Alzheimer's Association and the Northwest Regional Mental Health Board have generously assisted with the development of this information sheet.

As we age, changes in the brain can lead to some normal minor memory loss. We may have a more difficult time remembering a person's name or where we left our keys, for example. However, more serious problems with memory loss, or confusion, anxiety, delusions, and profound sadness should not be taken as normal signs of aging. If you become aware of changes in the mental state of the person you care for, you should call your doctor for a thorough evaluation. If your doctor does not specialize in treating the elderly, you may want to request an evaluation by a **geriatric specialist** in order to get the most up-to-date information and treatment options. (Although some doctors call themselves geriatricians, you should find out if they are geriatric board certified.)

The three most common mental illnesses that affect the elderly are depression, delirium, and dementia (the 3 D's). The most common form of dementia is Alzheimer's disease, but there are many other illnesses with related dementia, including liver disease, Huntington's Chorea, AIDS, ALS, vascular dementia, Parkinson's Disease, and several Parkinson's-related diseases. These are some ways to distinguish among the 3 D's:

Depression – While everyone gets sad or feels blue once in awhile, prolonged depression in the elderly is a serious illness that must be medically treated. The **onset of depression usually is very gradual**, which means that the early stages are often overlooked. The good news is that depression is usually treatable with medication, psychotherapy, or a combination of the two. Depression should never be dismissed as something that the person can change if they just tried harder; a person who is depressed cannot just "snap out of it".

Signs of depression:

- Prolonged sadness
- Feelings of hopelessness
- Lack of initiative, lack of interest in hobbies
- Poor memory
- Inability to concentrate, make decisions, or get anything accomplished
- Changes in appetite which lead to weight gain or loss
- Changes in sleep patterns: insomnia or sleeping much more than usual

Delirium – Delirium is often a side effect of a physical problem and can be caused by infection (urinary-tract infections are a common cause), intoxication, metabolic conditions, or medications. **Delirium usually has a sudden onset**, over a matter of hours or days, and symptoms may fluctuate throughout the day. A person may be calm one moment and very agitated the next; they may be very confused or experience hallucinations, and talk about people who are not there or events that have not happened. Delirium can usually be reversed with appropriate diagnosis and treatment.

Signs of delirium:

- Confused about time and/or disoriented
- Inability to recall recent events
- Inability to focus
- Hallucinations

HEARING LOSS

This information was generously provided by Howard Raff, BC-HIS. Mr. Raff is a member of the Board of Directors of the Western Connecticut Area Agency on Aging. He is the owner of And How Hearing in Waterbury. He can be contacted at 203-754-2200 or by e-mail at howard@andhowhearing.com.

Hearing loss is one of the most common – yet neglected – health problems in the world today. The onset of hearing loss can be so gradual that a person with some hearing loss may not notice it right away. In fact, family and friends are often the first to become aware of it.

With hearing loss, a person still has the ability to hear, but certain sounds or tones – such as "sh", "th", and "f' – are more difficult to hear than others. As a result, the person may be aware that others are talking but may not understand what is being said.

Other signs of hearing loss include:

- Difficulty following conversations in crowds or at social events
- Difficulty determining which direction sounds are coming from
- Difficulty hearing everyday sounds like water dripping or the telephone ringing
- Difficulty hearing the television or radio at levels that others finds comfortable
- Missing all or parts of conversations

If the person you care for is experiencing any of these symptoms, he or she may be one of the 27 million people in the U.S. who suffers from hearing loss.

Effects of hearing loss

Studies have shown that hearing loss can affect more than just hearing ability. It can affect a person's quality of life. Untreated hearing loss can lead to:

- Increased sadness and depression
- Increased worry and anxiety
- Social isolation
- Emotional insecurity
- Strained personal relationships

Some things you may not know about hearing loss

- People with hearing loss wait an average of seven years before seeking help.
- 75% of people who could benefit from hearing aids are not using them.
- About 30 to 35% of adults between the ages of 65 and 75 have some hearing loss. It is estimated that 40 to 50% of people 75 and older have hearing loss.
- 60% of people with hearing loss are between the working ages of 21 and 65.

ACTIVITIES & COMMUNICATION

Caregivers are often frustrated when the person they care for loses interest or pleasure in activities or hobbies they used to find enjoyable. There may be many reasons for this decline: failing vision or hearing loss, inability to manipulate materials due to arthritis, loss of mobility, or some memory loss. Sometimes lack of interest is related to depression or the onset of dementia (see the sheet on **MENTAL HEALTH CONCERNS IN THE ELDERLY: MEMORY LOSS, DEPRESSION, DELIRIUM, & DEMENTIA**). While some decline in interest may be a normal part of aging, do not take it for granted. Rule out underlying conditions such as depression or early-stage dementia with a thorough evaluation by a geriatric physician.

The following are suggestions for a variety of activities. They are intended for people with different levels of functioning, including memory loss; use whatever applies to your situation. Most importantly, be creative!

Activities should be designed to provide stimulation and relieve boredom, reinforce self-esteem, and generally improve the quality of life. They should focus on using or adapting skills and interests the person has had in the past; avoid trying to teach complicated new skills. Focus on what the person can still do, but also be sensitive to limitations – hearing, vision, strength, and mobility, for example.

- **Reminiscing can involve all members of the family** and can be a very positive activity. Look at old pictures and family albums together. Do a family history project, including taping oral histories of older family members. Create a scrapbook together with old school pictures, articles, etc. This is especially helpful for families where memory loss is an issue; long-term memories tend to remain clear long after short-term memory loss becomes a problem. It is also an excellent way to divert attention away from complaints about current aches and pains.
- **Play games** that were family favorites in the past – another good diversionary tactic.
- **Listen to music together**, especially the music that was popular when your mother was young. Sing along together.
- **Develop a simple exercise plan** based on the person's abilities. Take walks if your Dad can still walk. Do seated activities with light weights with your Mom. Put on some music and dance.
- If vision is a problem, **read out loud**. Also look for **large print books** or **books on tape** at your local library or bookstore.
- **Birdfeeders** can provide hours of pleasure for someone who enjoys watching the birds – it often becomes a new hobby for someone who has not had the time before.
- **Plant a garden** with colorful, easy-to-grow plants. If bending and weeding is a problem, put pots of flowering plants on easy-to-reach tables where they can be seen from the window.
- For former pet owners who are no longer able to care for a dog or cat, have a friend or family member **visit with a well-behaved pet**.

SAFETY ISSUES
Home, Driving, Financial Safety; Assistive Devices

There are several safety concerns that family members should watch for when caring for an older person, especially for someone who lives alone. Keep in mind issues of home safety, driving safety, and the possibility of fraud and identity theft.

Home Safety

As people get older, they sometimes develop problems with weakness, balance, and/or judgment caused by illness, sensory impairments, or dementia. These can lead to falls, burns, or other injuries. Caregivers should be aware of the following:

- **Provide adequate lighting –** lightbulbs should be bright enough (without causing glare) to adequately light areas like staircases, hallways, porches, etc. Use nightlights to ensure good visibility when someone gets up at night.
- **Clean up clutter** – sometimes people keep too much stuff: newspapers, magazines, knick-knacks, unnecessary pieces of furniture, etc. Keep well-traveled areas clear. For those who are unsteady on their feet, be sure there is no fragile furniture to lean on.
- **Pick up scatter rugs** and **make sure extension cords are out of the way** – these are major causes of falls for older people.
- **Check the safety of appliances** and determine, for example, whether the person you care for should still be using the stove – if memory and/or vision are impaired, using a gas or electric stove can be a real hazard. Consider getting a toaster oven or a simple microwave.
- **Assess safety hazards in the bathroom** – be sure the floor is not slippery and that bath mats do not create a risk of tripping. Consider getting a raised toilet seat and/or grab rails that install around the toilet to allow someone to get up more easily. Get a bath or shower seat and install secure grab bars to help someone get in and out of the tub safely. A handheld shower can be a great help for someone using a bath seat.
- If stairs become a safety concern, **install hand rails, ramps, or stair glide systems** where appropriate. **Be sure that doorways are wide enough** if a person uses a wheelchair or walker, and that the thresholds do not pose a tripping hazard. Call the Western Connecticut Area Agency on Aging for a copy of AARP's ***Do-Able, Renewable Home***.

Driving safety

The same concerns that affect home safety can impact driving safety: changes in vision, strength, coordination, memory, and judgment can significantly impair a person's ability to drive. Because giving up driving often feels like the final blow to remaining independent, it is sometimes the most challenging issue that caregivers deal with.

Some ideas for limiting or stopping someone from driving:

- **Have the doctor do an evaluation** to determine whether it's safe to still be driving. Sometimes a word from the doctor can be enough to get Mom or Dad to limit driving or to stop altogether. If not, **the doctor can make a report to Department of Motor Vehicles**.
- **Take away the keys** (be sure you get all sets).
- **Disable the car** by dismantling the ignition switch or taking off the distributor cap.
- **Sell the car** (if you have Power of Attorney or Conservatorship).
- **Notify the local police**.
- In Connecticut, **Department of Motor Vehicles has an affidavit** that can be filled out and sent in to the DMV to report unsafe drivers (copies available at WCAAA by calling 1-800-994-9422).

DURABLE MEDICAL EQUIPMENT: ASSISTIVE DEVICES FOR INDEPENDENT LIVING

As a caregiver, you may have found a number of gadgets and equipment that help those you care for get safely around their homes. There are lots of items available that promote safety and stability for an older person who is having some difficulty with everyday tasks. The list below is a starting point for thinking about assistive devices, or durable medical equipment.

The **bathroom** offers the most challenges for a person with any disability; it is also the site of the most falls and injuries in the elderly. Consider these options:

- **Grab bars** to prevent falls in the tub or shower – they either can be screwed in to the wall or attached with clamps to the outside edge of the tub.
- **Shower chairs or tub transfer benches** – can be used to get into and out of the tub and to sit while bathing in case of weakness or dizziness.
- **Hand-help shower heads** – for bathing while sitting.
- **Special knobs and switches** – for turning water and lights on and off more easily.
- **Commodes or grab rail systems** which can be set up with existing toilets – they help someone who has difficulty getting up from the toilet.
- **Raised toilet seats** – placed on existing toilets, they are useful for someone who has trouble bending their knees to sit.

For someone who has trouble **dressing and grooming** because of weakness or lack of dexterity, consider:

- Long reach **shoe horns** to avoid bending to put on shoes.
- **Shoe aids** to remove shoes.
- **Sock aids** or **stocking pulls**.
- **Shoe lace fasteners, elastic shoelaces/coilers.**
- **Shoes with Velcro closures or that slip on** to eliminate the need to tie shoes.
- **Clothing with elastic waistbands or that pulls on over the head** to assist with dressing.
- **Clothing with Velcro closures** instead of zippers, buttons or snaps.
- **Zipper/ring pulls, button hooks, bracelet fasteners, and dressing sticks** to assist with dressing.
- **Collar/cuff/waistband/bra extenders** for more comfortable fit.
- **Reachers** for items out of normal reach.
- **Long-handled brush and comb** and **toothbrush with special grip** for personal hygiene.

There are several **devices to increase mobility**; Medicare may pay for some of them in certain circumstances.

- **Walkers**, standard or with wheels (some even have fold-down seats), with or without an additional basket to carry things around.
- **Canes** come in a variety of sizes and lengths and have different types of tips, including the quad cane, for more stability with walking. (Be sure the person is trained to use a cane properly; improper use can actually lead to greater instability).

RESPITE PROGRAMS TO PROVIDE A BREAK FOR CAREGIVERS

Respite (res'pit) *n.* A period of relief. *Syn.* Interval, pause, reprieve.
Family caregiver *n.* A person who provides care (emotional, custodial, health, legal, etc.) for a family member who is old and frail, chronically ill or disabled, or who simply needs some assistance with the activities of daily living.

The Western Connecticut Area Agency on Aging (WCAAA) administers three programs that provide respite for family caregivers:

- **The National Family Caregiver Support Program –** for families caring for a person 60 or over at home. Priority is given to those families with limited resources and high caregiver stress levels.
- **The Statewide Respite Care Program** – for those caring for someone with Alzheimer's disease or another form of dementia. There are some income and asset limits but they are fairly generous; those who are not eligible for other programs may be eligible for this one.
- **Private Case Management** – to help families manage care when they are not eligible for other programs. Our staff nurse can help you arrange for services and can provide ongoing monitoring for a modest fee.

Respite care under these programs **is intended to give a break to family members caring for someone** who either lives alone but who requires regular assistance, or for those caring for someone who lives in the same household. We can help arrange for assistance and can sometimes help pay for the following services in order to provide a break for the caregiver:

- ❑ **Adult Day Care Programs**: Having a parent or spouse attend an adult day program gives the family caregiver a "day off" to do errands, clean house, or just have some time alone. Day care provides stimulation for the person you care for, often relieving some boredom and depression. Day care staff also can usually provide showers and hair care, which can be a real help to caregivers for whom this is becoming difficult.
- ❑ **In-Home Assistance**: Hiring someone to help with showers or housecleaning can be a boon for the working caregiver caring for an older relative. This type of assistance can also be very helpful for a spouse who can no longer safely assist with a bath or shower. Sometimes the caregiver can use the opportunity to get out of the house for a few hours.
- ❑ **Temporary placement in an assisted living facility or nursing home**: Caregivers need vacations just like everyone else. Having someone go for a week to assisted living (or nursing home if they need a more skilled level of care), means that the family can go away knowing that Mom will be cared for while they are gone.
- ❑ **Temporary live-in help**: Families can also arrange for someone to come in to stay 24 hours a day while they are away. We always caution families that this is often less reliable than having someone go to assisted living or a nursing home (paid live-ins have emergencies like everyone else). If you decide to do this, you *must* have a Plan B – someone who can step in if the live-in has an emergency and can't fulfill his/her obligation.

HOUSING OPTIONS FOR OLDER ADULTS

There may come a time when the person you care for can no longer safely stay in his or her own home and you find yourself considering other living arrangements. There are many options for housing, based on the level of care needed and financial circumstances. ***It's important to plan ahead.*** Many older adults will have to move from their homes at some point in time. Waiting lists for other housing options can be long; it may take a year – or more – to get into the facility of your choice. For more information about types of housing and what's available in your area, call the Western Connecticut Agency on Aging at 1-800-994-9422 or 203-757-5449 for a copy of a **Guide to Housing Options for Older Adults**.

For someone still in relatively good health but who can't manage a big house any longer, consider these options:

Independent Living – complexes which are restricted by age, usually consisting of units with living space on one floor. They are intended for those who are still relatively healthy and mobile, and who require little or no assistance. Many offer one meal for a fee, and some have **resident service coordinators** on site to help residents set up additional services if necessary. Independent living complexes may be rental units or units owned by the residents (condominiums). Independent living options include:

- high-end retirement communities for those with adequate financial resources
- subsidized housing apartment complexes for low- to moderate income
- rental units in private homes
- mobile homes

When a little more help is needed, consider:

Assisted Living – for those with various levels of independence and those who may have chronic but stable conditions. Some assistance is provided; core services include laundry, meals, transportation, housekeeping, recreational activities and routine maintenance. Additional services, such as help with activities of daily living, nursing services and medication supervision, can often be provided – usually for a higher monthly fee. At this time, most assisted living facilities in Connecticut are an option only to those who can afford to pay privately. Some have special units for residents with dementia.

Congregate Housing – similar in some ways to assisted living facilities, but intended for those who with low to moderate incomes. Residents must be at least 62, have incomes of no more than 60% of their area's median income, and need some assistance with at least one activity of daily living. One main meal in a communal dining area, housekeeping, and 24-hour security are provided. Arrangements can be made for additional services.

Continuing Care Retirement Communities (CCRC's) – also referred to as "life-care communities". Offer various types of care that allow residents to stay in the facility and move from independent living to assisted living to nursing home care as needs change. Residents enter into a contract and must pay an entrance fee and ongoing monthly fees.

SUGGESTED READINGS & RESOURCES FOR CAREGIVERS

The following books have good practical advice for family members caring for aging parents or an ill spouse. These and many other books on caregiving are available in the Aging Resource Services Library at the Western Connecticut Area Agency on Aging. Also, check with your local library for books and other resources on caregiving.

Claire Berman, **Caring for Yourself While Caring for Your Aging Parents: How to Help, How to Survive,** Second Edition. 2001, Henry Holt and Company, New York.

Strategies for avoiding caregiver burnout.

Barbara Bender Dreher, **Communication Skills for Working with Elders**. 2001, Springer Publishing Company, New York.

An excellent resource for understanding how aging affects communication and comprehension; tips for how to improve communication with elders.

Joseph Ilardo, Ph.D., LCSW, and Carole Rothman, Ph.D., **I'll Take Care of You: A Practical Guide for Family Caregivers**. 1999, New Harbinger Publications, Oakland, California.

Includes exercises to help caregivers assess and cope with specific problems unique to their situations.

Grace Lebow and Barbara Kane with Irwin Lebow, **Coping with Your Difficult Older Parent: A Guide for Stressed-Out Children**. 1999, Avon Books, New York.

Especially for caregivers whose parents present specific challenges – dependency, clinging, not accepting help when they need it, always expecting more, etc.

Nancy L. Mace and Peter V. Rabins, **The 36-Hour Day: A Family Guide to Caring for Persons with Alzheimer Disease, Related Dementing Illnesses, and Memory Loss in Later Life**. 1999, Johns Hopkins University Press, Baltimore.

The "bible" for families caring for a person with Alzheimer's or other dementia.

Mathy D. Mezey, Editor-in-Chief, **The Encyclopedia of Elder Care**. 2001, Springer Publishing Company, New York.

The authoritative, comprehensive resource on geriatric and social care.

Virginia Morris, **How to Care for Aging Parents: A Complete Guide**. 1996. Workman Publishing, New York.

One of the classic books on caregiving.

Linda Colvin Rhodes, Ed.D., **The Complete Idiot's Guide to Caring for Aging Parents**. 2001, Alpha Books, Macmillan USA, Inc., Indianapolis, IN.

Don't let the title put you off; easy-to-read, practical information for caregivers.