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# what is caregiving?



## Your role as caregiver may have started slowly.

Occasionally, you would pick up groceries for your elderly neighbor. Then you started taking her to a doctor's appointment here and there. The next thing you knew, she was depending on you.

Or it started with a crisis, when your father had a stroke. He recovered, but now he cannot live alone anymore. Either way, you are now a caregiver, providing regular help to a person who needs you.

Caregivers can be sons or daughters, other relatives, neighbors, friends, or perhaps members of the same church. And caregiving can take place in your home, next door, across the state, or across the country.

Whatever your situation, the Prince George's County Area Agency on Aging wants you to know that you do not have to — and you shouldn't — face it alone. We've created this booklet to help you find the help you need so you can take care of your loved one the way you both choose.

## great difficulties great rewards

It's very difficult to see someone you care about become frail and dependent. You mourn for the person they used to be, and now have added responsibilities to your already hectic schedule.

The stress you feel can be constant and at times overwhelming. You have the physical stress of taking on extra housekeeping duties, helping with personal care, keeping track of medicine, doctors' appointments, and perhaps dealing with unpleasant behavior. You may also have to consider the costs of medical equipment, outside help, housing, and other expenses. Another stress of caregiving is the adjustments you must make to your family and social life, allowing less time and energy for other people, and less time and energy for yourself.

But this is also a time to find great rewards. As a caregiver, you can develop an amazing inner strength. You create a high level of trust between you and your loved one. You can get to know that person in a whole new or deeper way, take care of any unfinished business, and say a meaningful goodbye. Her journey will teach you new respect and understanding of life and death. This is also a chance to give a wonderful and lasting gift to the person you care for — helping her through a hard stage of life.



## what is the Area Agency on Aging?

The purpose of an Area Agency on Aging is to support older people so they can maintain the highest possible quality of life with independence and dignity. In Prince George's County, the Area Agency on Aging is part of the Department of Family Services, Aging Services Division. We are the first phone call you can make to help an elderly relative or friend. We help older people and their caregivers by planning, developing, and providing in-home and community services. We can give you information and referrals, and link you to services in your community. Our phone number is 301-265-8450.

# what is your situation

**contact people:** *your relative's doctor, the social worker, case manager, discharge planners at the hospital, neighbors*

Most people — the elderly especially — prefer to remain independent, and that option is often possible with cooperation, resources, and support. But it takes planning. Your first step is to look closely at your entire situation. We recommend bringing all concerned family members together for a conference to help answer some basic questions. From there, you can look into your options.

- What kind of care does your loved one need?
- What arrangements can be made to help the person stay as independent as possible?
- Where can this person live?
- Who can provide the care? When? How?
- How will this change affect your life as caregiver? The family? Housing? Finances? Who else are you responsible for?

*see chart on the following page*

## meeting your needs

Below is a list of needs you or the person you're caring for may come across, and how to find help. For most services, you can call the Area Agency on Aging first at 301-265-8450, or refer to the resource list enclosed in this booklet.

<i><b>The person I'm caring for</b></i>	<i><b>services &amp; where to find help</b></i>
has healthcare costs	services: help paying healthcare bills – reducing cost of quality healthcare resources: <i>Medicare - Social Security Office, Medicaid - Department of Social Services, Maryland Senior Health Insurance Program, Area Agency on Aging</i>
just sits around, doesn't care about things that used to be important, gets angry	services: mental health evaluation resources: <i>family doctor, County Mental Health Department, geriatric social workers, crisis intervention unit, psychiatric hospitals, Alzheimer's Association, Prince George's Health Department's Adult Evaluation &amp; Review Service (AERS)</i>
is acting strange, forgetful, wanders	services: complete geriatric evaluation that looks at medical, psychological, and social condition of older person resources: <i>family doctor, mental health professional, Alzheimer's Association, Prince George's Health Department's Adult Evaluation &amp; Review Service (AERS)</i>
cannot even take care of basic needs, needs 24-hour supervision	services: private nurse, assisted living or nursing home resources: <i>private nursing organizations, homes for the aged, Area Agency on Aging, hospital social services, ElderCare locator, Maryland Department of Aging</i>
is terminally ill and wants to return home instead of dying in the hospital	services: hospice care resources: <i>Prince George's County Hospice, Visiting Nurses Association, Cancer Society, local hospital social services department, places of worship</i>
needs to get out of the house and do something with other people	services: social and volunteer agencies resources: <i>nutrition sites, senior centers, adult day care, friendly visitors, Senior Employment Program</i>
can do light house cleaning but needs assistance with heavy tasks	services: minor house repair, window washing, lawn mowing, roofing resources: <i>Area Agency on Aging, faith community, fraternal orders, youth groups, neighborhood clubs, and repair people</i>

## ***The person I'm caring for***

## ***services & where to find help***

needs legal help

services: legal assistance with matters pertaining to law

resources: *private attorney, 60+ legal program, local bar association, Legal Aid*

needs help with grief over the death of a loved one

services: bereavement support

resources: *bereavement support groups, faith community, senior centers, hospice, community hospitals, mental health associations*

needs help getting around, transportation

services: special transportation for older persons

resources: *Call-A-Bus, Call-A-Cab, MetroAccess*

needs help with housekeeping

services: maid and personal services

resources: *Area Agency on Aging, Visiting Nurses Association, faith community, neighbors, Department of Social Services*

needs help with personal care (bathing, dressing, grooming, toileting)

services: home health or personal care aide

resources: *private home health companies, Visiting Nurses Association, private nurses, public health nurses, Area Agency on Aging, Department of Social Services — In-Home Aide Service*

needs regular nutritious meals

services: meal program

resources: *home-delivered meals, Meals-On-Wheels, Senior Nutrition Program*

needs companionship during the day when I'm at work

services: friendly visitors, adult day care center, senior centers

resources: *adult day care, live-in attendant, social service agencies*

needs services for physical disabilities

services: handicapped services

resources: *condition-specific organizations, local office of Individuals With Disabilities*

# housing options



**contacts:** neighbors and friends for recommendations, phone book under "Housing," case manager or social worker, hospital discharge planner, faith community

One of the most **basic decisions** for caregivers is "**where**" the care will take place.

Many options are available, depending on your loved one's needs and resources, as well as the duties and responsibilities you, as caregiver, are willing and able to provide.

Sometimes the best option for the older person is outside the family in a senior home or community. These places meet different needs, depending on the resident. Below is a listing of housing options and their services.

**independent living** - adult or senior communities for people over a certain age. The resident usually owns or rents a home or apartment in a secure or "gated" community. Services may include meals, housekeeping, and landscaping, plus many community activities. This option is best for healthy, active seniors who wish to live with people their own age.

**home sharing** - an option for people who want to stay in their homes, but need help with expenses or household tasks. They can share their home with someone looking for affordable housing in exchange for cleaning or yard work, for example. Elderly people may choose to live together and share expenses and household duties.

**continuing care retirement community (CCRC)** - offers a long-term contract that provides housing, services, and nursing care, often all in one place. Usually, when residents enter a CCRC they are healthy and active. As needs change, the CCRC provides a higher level of care. This could be assisted living or a nursing home. Some advantages include privacy and independence, physical and financial security, easy access to healthcare and community facilities.

**federally funded senior housing** - rental apartments designed for seniors who want to live on their own. The monthly rent depends on the size of the apartment, services, and the monthly income. Government-subsidized housing may be available for those who have low incomes and limited assets.

**assisted living residence** - best for people who need help with activities of daily living, or ADLs, such as eating, dressing, getting around, remembering to take medicine, but otherwise do not need the specialized care of a nursing home. They have single or double

rooms, suites or apartments, designed to meet personal service and other healthcare needs.

**nursing home** - offers the most care options: a full range of nursing and personal help; diet, therapy, social, and recreation services. Meals, laundry, housekeeping, and medical care are also available. Many offer religious services and counseling, rehabilitation services, hospice care, dialysis in select facilities, and Alzheimer's Units.



# senior housing check list

The American Association of Homes and Services for the Aging recommends that you visit several places after you and the person who needs care have decided on the best option. Below is a general check list of things to look for and questions to ask, no matter what type of housing is chosen.

- *What services are provided? Do employees of the facility itself (provide the services) or an outside agency?*
- *What kinds of activities and recreation are offered? How often? Are there activity rooms?*
- *What is the daily or monthly rate? What services are included in this fee? What other services are available for an extra fee?*
- *How much input do the resident and caregiver have in daily life and care? Is the schedule flexible?*
- *What are the choices of living space? Can a resident bring furniture and other personal items from home?*
- *Is the location convenient for friends and relatives to visit?*
- *What happens if additional services are needed later on? Do residents have to move or can they be cared for at the same site?*
- *In checking the building for safety features, are there well-lit stairs and halls, handrails, well-marked exits, a way to call for help if needed? Are all areas wheelchair accessible?*
- *If it applies to your situation, does the facility accept Medicare and Medicaid?*
- *Are the facility and administrator licensed? Ask to see the most recent inspection report.*
- *How are medical emergencies handled?*
- *Are residents well-groomed and ready for a full day of activities?*
- *Are exits clearly marked, and paths to exits open? Complies with fire safety codes?*
- *Is there a lawn or garden area to let residents get fresh air, and a policy that encourages them to go outdoors?*
- *Do bedrooms open onto a corridor and have windows?*
- *Do you smell heavy odors, pleasant or unpleasant?*
- *Does the kitchen staff separate food preparation, garbage, and dish washing areas, and keep perishable foods refrigerated?*
- *Are the dining rooms attractive and do they have tables convenient for wheelchairs and serve appetizing food?*
- *Do toilets accommodate wheelchairs?*

# legal issues



**contacts:** attorney, Maryland Legal Aid, accountant, case manager, social worker, hospital discharge planner

Of course it's always **best** to **prepare** for the **road** ahead.

But end-of-life issues are very tough to talk about, and easy to put off until tomorrow. However, tomorrow your loved one may be unable to make decisions, putting you in charge. If you talk ahead of time, you'll know their wishes, making your decisions easier. Also, encourage them to talk with an attorney. It can put everyone's mind at ease. Here are some legal issues often faced by caregivers.

**advance directives** - advance directive is a healthcare term to help healthcare providers with decisions about care if a person is unable to make decisions for him/herself. It covers both living wills and healthcare power of attorney.

**living wills** - usually become necessary when patients are no longer able to speak for themselves. While your loved one is still healthy and able to make decisions, he can instruct his doctor to withhold or remove life support treatments if he becomes seriously ill or injured, with no hope of recovering. In Maryland, living wills must be in writing or the doctor will follow the family's wishes. Hospitals, nursing homes, your doctor, the Area Agency on Aging, and your lawyer should all have a living will form available for your completion.

**power of attorney** - There are three basic forms of power of attorney.

(1) Healthcare power of attorney allows a patient, while he is still healthy, to choose someone he trusts to make healthcare decisions for him. The person granting healthcare power of attorney (the patient) will always have final say in decisions, as long as he is able to do so. If the patient becomes unable to make decisions, the agent, or person given healthcare power of attorney, can then make the decisions. This gives broader power than a living will, which only covers life-support treatment. The agent can act as an advocate to make sure the loved one's wishes are followed for all treatments when he is unable to do this for himself.

(2) Power of attorney can also help with financial matters. It allows the person to appoint an agent to make financial decisions, such as bill paying. The person chooses which decisions the agent can make.

(3) Durable power of attorney allows a person to choose an agent to make decisions, if the person is unable to make decisions on his own. A doctor or the court system must decide if the person is unable to make decisions. A recent law in Maryland allows a person granted power of attorney to assume durable power of attorney, even if the person granting it (the patient) has not specifically requested it. This must be done through an attorney.

## estate planning

Estate Planning is a term covering all aspects of deciding how a person's estate (property, money, and other assets) will be handled after death. It includes a will, trusts, endowments, charitable contributions, and other final wishes. With good estate planning, you can avoid problems for the family, save on taxes, and know that your loved one's wishes will be followed after death. Estate planning can also include advance directives, power of attorney, and guardianship. Talk with an attorney, or the Senior Legal Aid, if you can't afford an attorney for more information. Senior Legal Aid is listed in the phone book in the state government pages.

**trusts** - most useful for people with a large amount of property or other assets. Property can be held in trust for the benefit of others after a person dies. The property does not go through probate, the legal process to pass property from the estate to the heirs. A person can also put property in trust to himself. Trusts can affect Medicaid benefits for nursing home care, so it is vital to work with an attorney before making this decision.

**guardianship** - when the person you are caring for is no longer able to make decisions, and there has been no advance planning, the caregiver or another responsible person can apply for guardianship

through the courts. The court appoints an attorney for the person cared for to determine if that person actually cannot make decisions for himself. The court further decides whether



the person applying to be a guardian is the best choice. If there is no suitable person to act as guardian, the court appoints an agency or person. Guardians have decision-making power over healthcare, finances, and other care matters.

## sixty-plus legal program

This program for people 60 and older on limited incomes provides low cost legal services. Each client receives a free first visit with a program attorney. If you need further legal assistance, you will be referred to a local attorney who charges a reduced fee. Services include wills, powers of attorney, living wills, small estates, and deed changes. Call 1-800-510-0050 or TDD 410-539-3186 for more information.

# financial issues

**contacts:** accountant, case manager or social worker, Social Security Administration, Area Agency on Aging, Department of Social Services, State Division of Eligibility Services, lawyers who specialize in medical assistance law, banks and credit unions, The Senior Health Insurance Program (SHIP)

Caring for an older person can involve both **long-term** and **acute care**. Long-term care helps people over a long period of time who have chronic illnesses, or illnesses or disabilities that get progressively worse over a long period of time. Acute care lasts only for a short period of time, until the person gets better, and usually takes place in a hospital.

## the costs of long-term care

Whether you are dealing with acute care versus long-term care can affect payment for the care. Medicare, for people 65 and older, pays for acute care or skilled nursing care, but not long-term care such as a nursing home. Medicaid can pay for long-term care when the patient can no longer pay. The patient must meet certain income requirements for Medicaid.

Investigate admissions offices at nursing homes for optional services and payment plans. If you decide to care for your loved one at home, services that provide care in the home are available. In addition to the cost of care, you are adding the cost of food, clothing, medical equipment, and other needs to your household budget.

## the Senior Health Insurance Program (SHIP)

SHIP offers health insurance counseling to older Marylanders and their caregivers. The counselors assist in person and on the telephone with:

Medicare; Medicare supplements (Medigap Plans); HMOs; long-term care insurance; medical assistance programs; pharmacy assistance benefits; denials, appeals, and grievances; billing problems; and healthcare fraud and abuse. In addition, public education presentations are offered. In Prince George's County, call 301-265-8450.

## government programs and entitlements

Medical Assistance (Medicaid); Medicare; Food Stamps; Supplemental Security Income; Social Security; Department of Veterans Affairs; Maryland's Senior Care Program; Medicaid Waiver Program

For the most part, government programs have strict income requirements, but even people who normally don't qualify may be able to get some kind of help. Most programs aim to help people stay in their homes and live the highest quality of life they can. The programs also try to help as many people as they can. So, even if you don't think the person you are caring for qualifies for any programs or entitlements, ask. Call your local Department of Social Services or Area Agency on Aging.

## federal tax credits

Tax laws can work in favor of the elderly or blind. If you are assisting a low-income person who owns her own property, ask an accountant or a member of the Area Agency on Aging about property tax credits that can lower costs.

## homeowner options

Many banks and credit unions offer reverse mortgages, home equity conversions, and sale leasebacks for people who own their own homes. These programs can provide money to help pay for medical costs, long-term care, and in-home care. Talk with your banker for more information.

## long-term care insurance

This is a form of private insurance that covers long-term care. The time to apply is while a person is still healthy. It must be purchased before age 80, and before long-term care services are needed.



# caregiving options



Whether you decide to take **care** of your **relative** at home or in an outside facility, it pays to **know** your **options**.

You want to get the best care for his needs, but you must also consider your needs as a caregiver.

## respite care

### **contacts:**

*Area Agency on Aging  
local nursing homes  
religious groups  
home health agencies*

Caring for the caregiver. With the many pressures of caring for an elderly person, it's easy for you to forget about caring for yourself.

Caregivers face stress, isolation, grief, frustration, guilt, exhaustion, and resentment. These are all normal feelings, but feelings you need to handle for your sake and the person you're caring for.

Respite care provides time off for caregivers. It can be as simple as arranging for someone to stay with your loved one so you can visit friends, or arranging for your loved one's overnight care in a nursing home. Take advantage of offers from friends and relatives to stay with the person you're caring for so you can enjoy time on your own. The point of respite care is to give you a break. You need it.

## adult day care

### **contacts:**

*Area Agency on Aging  
hospitals  
senior centers  
religious, civic service, fraternal,  
or neighborhood groups*

At times, the person you're caring for may need and want to be around people his own age. In addition to offering a chance to socialize, many adult day care centers also offer health services, meals, recreational activities, nursing care, and various therapies. Transportation to and from the center is

often another option. Many also offer care for Alzheimer's patients. They are usually open weekdays during business hours, allowing you, the caregiver, to hold down an outside job. Many adult day care centers are also open seven days a week.

Adult day care centers offer a variety of payment options. Sponsorships or scholarships may be available. Look also to community groups to sponsor those who otherwise cannot afford it.

## home/community- based care

### **contacts:**

*Area Agency on Aging  
social services departments  
religious groups  
Eldercare Locator*



Even people who are seriously ill can be taken care of at home. The goal of the Area Agency on Aging is to offer services to help elderly and disabled people stay in their own homes for as long as possible.

We can link you to skilled medical services that provide in-home care by nurses, therapists, and other healthcare professionals. Home or health aides can help with household chores and personal care. Agencies also provide assistance in obtaining medical equipment such as monitors, hospital beds, toilet seats, and other devices to make caring for someone much easier.

**home health nursing care** - A home health agency nurse visits to evaluate the patient's condition, and to plan the type of nursing care needed to carry out the doctor's medical plan. The nurse will teach the patient and the caregiver some home care techniques such as





giving medicine, changing sterile dressings, and catheter use. The nurse works with the patient's doctor and may visit on a regular basis to check the patient's condition.

**in-home aide** - This person helps with general housekeeping chores; preparing meals; and providing escort service to and from doctor appointments, pharmacies, and shopping.

**home-delivered meals, often called Meals-on-Wheels** - These are nutritious, already-prepared meals delivered five or more days a week to people who can't leave their homes. Some areas also offer home-delivered groceries as an option.

**congregate meals** - The Senior Nutrition Program provides meals to Maryland's older citizens in a group setting where programs and other services are available. Meals are served at senior centers, apartment complexes, places of worship, and other places where seniors may gather together.

**chore and personal care services** - They can include homemaking services, or household repairs and yard work.

**long distance caregiving** - If you are caring for someone who lives more than two hours away, providing your relative's needs may be difficult to find. The Area Agency on Aging and the Eldercare Locator can refer you to resources in the community where your loved one lives. Eldercare Locator: 1-800-677-1116.

**friendly visitor and companion services** - Volunteers make regular visits to elderly homebound or ailing adults. These visitors offer a break from isolation and can read to, talk to, or help write letters for the homebound adult. These services may also be available through a home health agency.

**telephone reassurance** - This daily phone call reassures that an older person is okay. Either the senior calls out to check in at a certain time, or a volunteer calls the senior at home.

**equipment locating** - In addition to medical equipment, there are devices that make it easier for a person to live independently, or that help the caregiver. Some examples are forks and knives that are easy for a person with arthritis to grip, portable toilets, and special lights to help with reading.

## assisted living

### contacts:

*individual assisted living communities and group homes*  
*Eldercare Locator*  
*Area Agency on Aging*  
*Maryland Department of Aging*

In some cases, the best place to care for an elderly person is in an apartment designed for this purpose. Assisted living communities



help people with activities of daily living (ADLs) such as bathing, dressing, eating, and taking medicine. Many allow the residents to bring furnishings from home, and encourage a great deal of independence.

## senior care program

### **contacts:**

*Maryland Department of Aging  
Local Prince George's County Senior Care Program  
301-265-8450*

The State of Maryland provides coordinated, community-based in-home services to seniors with disabilities. Senior Care funds services for seniors who may be at risk of nursing home placement. Clients can access publicly-funded services, or if they're not available, Senior Care will make arrangements with private vendors. These services can include personal care, chores, adult day care, financial help for medications, medical supplies, respite care, home delivered meals, emergency response system, transportation, and others. This program is available to people over 65 who have limited income and assets.

## nursing home care

### **contacts:**

*individual nursing homes  
ElderCare Locator  
Area Agency on Aging  
Maryland Department of Aging*

At times the person you care for may require more than you can give. Sometimes you just need to take a few days rest or a vacation. Nursing homes offer the most care options at times like these. They care for people who need 24-hour attention to their healthcare and personal needs. Patients can be admitted on a long- or short-term basis. They have a full range of healthcare services, to include nursing care, personal assistance, dietary supervision, therapy, social events and recreation. They also provide all meals, laundry, and housekeeping.

## hospice

### **contacts:**

*Hospice organizations  
Area Agency on Aging  
hospitals  
case managers or social workers  
nursing homes*

Hospice is a type of quality, compassionate care for the end of life. It uses a team approach to medical care, pain management, and emotional and spiritual support tailored to the patient's wishes. The emphasis is on making the patient comfortable, and allowing him to



die with dignity and choice. Care is usually in the home or in homelike settings operated by a hospice program. Emotional and spiritual support is also offered to the patient's family and caregiver.

# healthcare matters



Whether you are a **caregiver** to someone who lives in your home or in a facility, **healthcare** is usually your **primary** concern.

In-home caregivers are responsible for carrying out much of the medical plan and see firsthand any changes in the person's condition. If the person you are caring for lives outside your home, you need to make sure that you understand the treatment plan and see that it is being followed.

## who's on your healthcare team?

**primary care physician** - this doctor is also called a family doctor, internist, or family practice physician and is in charge of your relative's overall health plan. Primary care physicians prescribe medication and treatment (including therapy), and refer patients to specialists if needed. They work with the nursing staff (whether the patient is in a facility or taken care of at home) who carry out the treatment plan.

**gerontologist** - this doctor specializes in the care of older adults.

**nurse** - A registered nurse follows the doctor's treatment plan. The nurse discusses the plan with the patient and, if necessary, the family. Home health nurses evaluate the patient's condition and decide what nursing care the patient needs in order to follow the treatment plan. They also teach the patient and caregiver many ways to keep the patient as comfortable and independent as possible in the home.

**physical therapist** - Therapy is often needed if the patient has lost the use of a limb or muscles because of illness or an accident. The therapist reviews the physician's treatment plan, and prepares a therapy

**nutritionist, dietitian** - Meals planned by a trained nutritionist can improve patient health and meet special diet needs for illnesses such as diabetes, heart conditions, and high blood pressure.

**case manager, social worker, hospital discharge planner** - While in the hospital, your relative is assigned to a case manager to plan for care after leaving the hospital. The case manager



routine and schedule. Physical therapy can be done wherever the patient is staying. The therapist works closely with nurses and doctors to discuss progress and any necessary changes in therapy.

**speech language therapist** - If your relative has suffered loss of hearing, or the ability to speak or understand, a speech therapist can help the patient relearn or practice those skills. The speech language therapist works closely with doctors and nurses to discuss progress and adjust therapy accordingly.

**occupational therapist** - This specialist helps patients with an illness or injury that has affected their ability to carry out daily activities such as dressing, walking, and bathing. The therapist helps them to relearn skills or learn different ways to carry out these activities, sometimes using devices that make tasks easier.

locates and helps arrange any necessary nursing care, rehabilitation, or other services the patient needs.

**geriatric care manager** - This is a new field in private care management for the elderly. After an evaluation, the geriatric care manager helps decide the services needed, and then works with the caregiver to set up and locate the services. This is a convenient option for caregivers who live far from the person they are caring for. You can locate geriatric care managers in the Yellow Pages under social services, social workers, aging services, and home health services.

## taking care of someone's health

### **contacts:**

*family doctor, health department*

*social worker, case manager, hospital discharge planner*

*Area Agency on Aging*

As a caregiver, you play a vital part in your loved one's health. You often have charge of her home medical treatments and medication. You are also a very important link between the doctor and patient.

## prepare for emergencies

When an emergency strikes, the last thing you need is to look up numbers. Keep the following by your phone in an obvious place, so you or anyone else caring for your loved one can easily find them.

- 911 (yes, this is obvious, but who knows how you'll think in an emergency)
- name of doctor and phone number
- name and phone number of the hospital, and the doctor the patient prefers
- Poison Center of Maryland: 1-800-492-2414
- 24-hour oxygen number, if necessary
- list of medications and any known allergies to medications
- medical insurance information
- number where you can be reached.

But remember, you are just a link. You do not shoulder total responsibility. The main decision-making responsibility lies between doctor and patient. It's important for the patient to have decision-making control over her treatments, especially when she must rely on others. It is very tempting as a caregiver to make decisions for your loved one. But your most effective role is helping the person you are caring for understand the treatments and take part in her decisions.

To help your loved one make decisions, you must know the situation, so gather as much information as you can at first. This may mean a difficult conversation with the person you are caring for. Some people are very private about their health, or don't want to burden family or friends. But you need accurate information. If necessary try talking with other people in your loved one's life such as neighbors, friends, and other relatives to get these answers.

## healthcare questions you need to ask

- Who is your doctor/primary care physician?  
Dentist?
- What other doctors do you see?
- What illnesses or injuries do you have?  
Do you have any other health problems?
- Which doctor is treating which illness  
or injury?
- What treatments have the doctors ordered  
to help you?
- What medicines are you taking? How often  
do you take them? What are they for? Any  
known allergies to medications?
- What over-the-counter medicines do you  
take? How often? For what reason?
- What health insurance do you have?  
Where are your insurance cards?
- Do you have an advance directive or  
a living will?

As long as the patient allows it, you can go with the person you are caring for on doctor visits. Feel free to ask questions of the doctor, especially about home care. During certain parts of the visit, the doctor may ask you to leave in order to allow some private time with the patient.

With a Release of Medical Information from the patient, you can get his medical records from his doctor. You can take these along to any other doctor or specialist.

## insurance

### **contacts:**

Maryland Senior Health Insurance Program  
Senior Information and Assistance Office  
Maryland Department of Aging

**private insurance** - Additional health insurance and long-term care insurance can be purchased to supplement existing retirement or survivor benefits, and can cover a wide variety of medical situations extending into long-term care. Check all the insurance policies your loved one may have. She may have a policy that she has been paying for on her own, or she may be covered under a spouse's policy. See what services the insurance covers — doctor visits? prescriptions? dental visits? eye exams? long-term care?

**Medicare** - Most Americans who are over the age of 65 or certified as disabled by the Social Security Administration are eligible for Medicare. It's divided into Part A and Part B:

Part A usually requires no premium payment — while the person was working, his wages helped pay the premiums. People who never had a job or have not paid enough into the Social Security Fund while they were working can purchase Part A and pay a monthly premium. Part A covers hospital stays, home healthcare, skilled nursing care, and all hospice care, to include medication and counseling.

Part B is an optional package for which a person pays a monthly premium, and is usually withheld from the patient's Social Security check. Part B pays 80 percent of approved expenses. The patient must pay for the remaining 20 percent, any uncovered expenses, and an annual deductible.

**Medigap** - Medigap is a separate insurance policy that pays deductibles and co-payments. These plans are highly regulated by the Medicare program.

**Medicare HMO's** - This alternative to supplemental health insurance allows beneficiaries to receive care through a Health Maintenance Organization rather than a "fee for service" plan. Members choose a primary care doctor, usually trained in internal medicine, who will coordinate the patient's healthcare.

**Medicaid** - This federal program pays for the medical care of people who cannot afford it. Those eligible for Medicaid (based on low income and assets) receive doctors' services, hospital care, medicine, supplies, and other necessary services, including long-term care. Each state manages its own program and has certain income eligibility rules to follow. The program covers the cost of nursing homes, adult care homes, hospices, and, in some cases, care in the patient's own home.



## spiritual needs

**contacts:** *relative's place of worship*  
*caregiver's place of worship*

While dealing with sometimes overwhelming healthcare needs, it is easy to overlook spiritual needs. The person you are caring for may no longer be able to attend services or social functions of her faith community; yet, and especially in hard times, a person may turn to her faith and rely on the peace it can give. An active member of a faith community can feel especially isolated. Perhaps her place of worship has always been a large part of her life, and her illness takes her out of this community. The subsequent feeling of isolation can affect her physical and mental health.

Most churches, synagogues, and other places of worship offer outreach services such as visits from the clergy or members to give support for spiritual needs, shut-in visiting programs, or even meals, house-cleaning, or repair services. Many communities regularly pray for the sick and their caregivers. Faith communities can be a source for healthcare equipment on loan, and provide educational programs on end-of-life planning and other caregiving issues. They may also offer support for caregivers through support groups and respite care visits, as well as spiritual counseling. All can be found at places of worship.

# transportation options



**contacts:** Washington Metropolitan,  
Area Transit Authority, Prince  
George's County public transportation

If you **ask** most elderly people what they **value** the most, it is usually **independence**.

From making our own decisions and taking care of our own needs, to getting around town, independence is something we all try hard to keep. But for some older people, physical disabilities limit their freedom to travel, or they need special help to get where they want to go. Most also don't want to burden family or friends by asking for rides. And, they may live on a limited income, making cabs too expensive.

## transportation

Here are services that can allow some freedom to the person you are caring for. Many churches and civic organizations offer ride programs. The Washington, DC area and Prince George's County also have several public transportation options.

***Metrobus and Metrorail*** - Both offer discount fares to people 65 and older, and to people with disabilities who have a Metro Senior Citizen ID Card. Metrobus and Metrorail travel over much of the Washington, DC area. Metrobus discount cards are available at public libraries, Giant, and Safeway. You can call 301-699-3500 or TDD 301-699-9133 for the location of the nearest library. For information on Metrorail discount cards, call 202-637-7000 or TDD 202-628-8973.

**The Bus** - This Prince George's County bus service operates weekdays within the county. Seniors and people with disabilities ride at a reduced rate. Call 301-324-BUSS or TDD 1-800-735-2258 for route and other information.

**Call-A-Bus** - Any resident of Prince George's County who is not served by or cannot use existing bus or rail services may call for curb-to-curb bus service. You can make reservations up to 14 days ahead, and the service is available Monday through Friday, except holidays. Disabled persons must provide their own escort, if needed. For reservations, call 301-499-8603.

**Senior Transportation Services (STS)** - Seniors can use the STS which regularly schedules curb-to-curb transportation throughout the county. It provides transportation to a number of senior programs including a free ride to county nutrition sites. For the Nutritional Programs, call 301-265-8450. Seniors can receive transportation for medical purposes, such as dialysis. Call 301-499-8603 for more information on the medical program. General transportation to senior activity centers, shopping trips, and other recreational outings is also available for seniors. Call 301-883-5656 for more information.



**MetroAccess** - The Washington Metropolitan Area Transit Authority (WMATA) provides curb-to-curb service for people with disabilities who cannot use regular public transportation. A person must qualify for and apply for a MetroAccess identification card. As this is a curb-to-curb service, the driver does not assist riders in getting to and from the vehicle. To find out whether the person you care for is eligible, call 301-562-5360 (voice) or TDD 301-588-7535. To make reservations, call 301-562-5360 (voice) or TDD 301-588-7535.

**Call-A-Cab** - Seniors and disabled residents of Prince George's County may receive reduced-cost cab rides through this program. Rides via participating cab companies are available at any time, especially when MetroAccess and Call-A-Bus are not available. To join the Call-A-Cab program, call 301-883-5656.



# self care for the caregiver



When you started **caring** for your **relative** or **friend**, you knew it was going to be **tough**.

But you did it anyway — he needed you, and you really wanted to help him. And, you are doing everything you can to give that help.

But what are you doing for yourself?

Caregivers face huge amounts of stress. This is hard enough to deal with by itself, and it can also lead to more serious

problems if you don't get help. Stress can worsen any medical problems you may have, and create new ones. Who will take care of your loved one if you have to go into the hospital?

Stress and other conditions can also cause psychological problems such as anxiety disorders, depression, phobias, drug and alcohol abuse, insomnia, and even violence. The bottom line: you cannot be a good caregiver if you do not take care of yourself. You need to maintain your health — both physical and mental — and find ways to cope.

## support groups

### **contacts:**

*faith communities*

*Area Agency on Aging*

*online support groups through the internet*

*ElderCare Locator*

*hospice*

*senior centers*

*nursing homes*

All humans have a basic need to be understood. This is especially true for people who are going through, or have already gone through, a stressful situation. Support groups offer you a chance to talk with people who face the same things you do, and they understand like no one else. You can talk about all your fears, frustrations, and even the emotions you feel you shouldn't have, like anger and resentment. Support groups are also a great place to learn how other people have handled the same situations you have, or how they cope with the same problems you face. You can find out about different resources, and most importantly, make friends.

## spiritual needs

Perhaps you're someone who has not stepped into a church in years, or maybe you have always been very active in your faith community. In either case, many find strength and peace in their faith. While facing the stress of caring for a relative, it is important for many to regularly attend services, especially if the services have always been a part of one's life. Many people also find other ways to sustain their faith, such as praying or meditating, that bring some kind of comfort. Faith communities regularly pray for the sick, and the people who care for them. Sometimes just knowing people are praying for you can make a difference.

Look also to churches, synagogues, and other places of worship for spiritual counseling and support groups. Often they have volunteers to help with yard work or housekeeping, or volunteers to stay with your loved one so you can enjoy time away.

## family

One group that caregivers often overlook when seeking help is family. Often the family — either your own, or, if you are caring for a friend, her family — is willing and able to help take care of their relative. We suggest holding regular family meetings to discuss the person's condition and ways everyone can help. More than likely they want to be included in their relative's care. As a caregiver, you may need to release some of the responsibility for the sake of the person you are caring for and for yourself.

Family members can help in different ways. Perhaps they can drive their relative to appoint-



ments, run errands, drop by regularly so you can get an evening out, or do the laundry every week. Look over your day-to-day duties and see what can be handled by someone else. Most importantly, allow them help you.

Unfortunately, there are cases where family will not help. You, the caregiver, are left with total responsibility, and that can lead to a lot of anger and resentment. In these cases, you must look outside the family for help to not only perform the duties, but also to provide a safe place where you can express your feelings.



## stress management

### **contacts:**

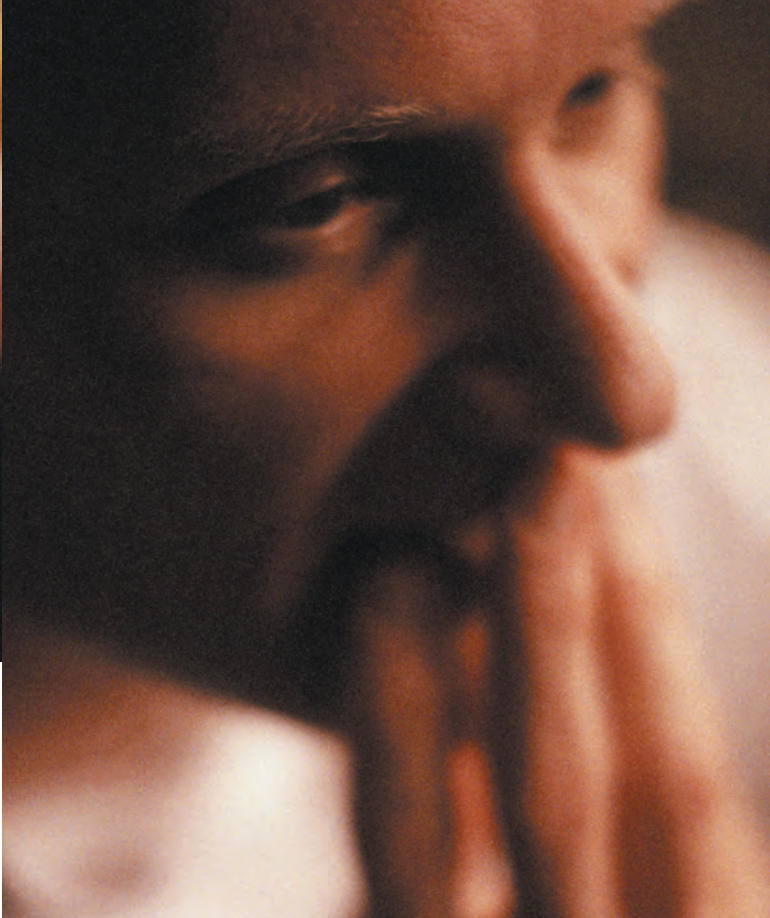
*support groups*

*family doctor*

*friends*

*social worker or case manager*

So how are you doing? How are you handling the stress of caregiving? No time to think about stress? Too many other things to worry



## Family Medical Leave Act (FMLA)

### **contacts:**

*caregiver's employer*

*attorney*

*MD Legal Aid*

Caregiving does not necessarily mean you have to quit your job to take care of a relative. In some cases, you may need time off only for medical emergencies, or to make arrangements or handle problems as they come up.

The FMLA allows you to keep your job and health insurance (if it is already being offered) while you take up to 12 weeks a year off to care for a seriously ill spouse, parent, or child. This time can be scattered throughout the year as needed: a few weeks at a time, or 12 weeks in a row. There are restrictions to this law: companies with less than 50 employees do not need to follow it, and your employer must already be offering you health insurance. Talk with your company's human resources department for more information.

about? You owe it to yourself and the person you are caring for to manage the stress you face. First though, you have to be aware of the stress.

Below are questions you should ask yourself often. They will help you become aware of the stress in your life so you can do something about it.

- Are you getting enough sleep?
- Do you cry often?
- Do you overreact to everyday situations?
- Do you have time for other family members?

- Do you make time for yourself?
- Do you get out often?
- Do you feel guilty or resentful of your situation?
- Do you argue often with the person you are caring for?  
With other family members?
- How is your own health?
- Do you feel you know enough to care for your relative?
- Have you started smoking again? Other nervous habits?
- Are you drinking more alcohol than you used to or using  
other drugs to relieve the stress?
- Are you worried about your money situation?

Unfortunately, there is no magic potion that will get rid of stress. It is always going to be there, and you just have to learn to manage it. Two ways to help deal with stress are to take regular breaks, and to vent your feelings.

As often as possible, find someone to stay with your loved one while you get out of the house. Even an hour away can give you a new outlook. Some caregivers find it helpful to schedule regular breaks, so they are more sure to take them. Whatever works for you, it is worth it.

## some ideas to help relieve the stress are:

- read a book you've always wanted to read
- take a walk around the neighborhood
- play games with your pet or just enjoy its company
- join a support group
- call a friend
- write a letter to an old friend you haven't seen in a long time
- make a regular date with your spouse
- play backgammon with your children or grandchildren
- go to religious services
- join an exercise class (and go!)
- close your eyes and listen to the birds sing
- play your favorite music
- meditate for a couple minutes a day
- treat yourself to a manicure or even a massage

There may also come a time when you need more than stress management. Do you always find yourself angry with the person you're caring for? Have you been yelling or screaming a lot at the person, or holding back on affection or even food? Are you blaming the person for your situation? Have you thought about hitting your loved one? When was the last time you had a good night's sleep? Do you remember the last time you laughed? These signs of burnout indicate that it is time to get help.

Talk with your family doctor or a social worker about getting professional help. You may also decide it is time to give up your role as caregiver. It is too difficult for anyone to be a full time caregiver forever. Everyone has their limits. Before you reach yours, stop. Maybe it is time to make different arrangements for taking care of your loved one, such as a nursing home or assisted living community, or another relative. Whatever new arrangements you make, you're doing the right thing for you and your loved one.



# unraveling caregiving terms



Like any field, caregiving has its own special terms.

Knowledge of these can save you a tremendous amount of time and trouble. Below are selected terms based on definitions from the National Institute of the Aging, National Institutes of Health.

**activities of daily living (ADL)** - activities performed as part of daily living such as bathing, grooming, eating, using the toilet, and dressing.

**aging in place** - concept that allows the person to stay in their home in spite of physical or mental decline that may occur as the person ages.

**assistive devices** - non-medical equipment that makes daily tasks easier to handle for both the patient and the caregiver. Many allow patients to remain as independent as possible.

**geriatric evaluation** - a medical, psychological and social testing of an older person. A doctor, mental health worker, and a neurologist work together to test the patient in different areas. Helps to decide what type of care, if any, the person needs.

**home healthcare** - health services provided in the homes of the elderly, disabled, sick, or recovering people. The services may include nursing care, social services, a home health aide or homemaker services, and rehabilitation therapies such as physical, speech and occupational.

**home-delivered meals** - a program that delivers meals to the homebound. Sometimes called Meals on Wheels.

**home health aide** - helps in the home with personal care, light housekeeping, meals, and shopping.

**hospice** - a program that improves the quality of a dying person's life. Hospice care can take place in the person's home, a special hospice facility, or both.

**long-term care** - the medical and social care given to people who have severe chronic impairments. It may include care in the home by family members, voluntary or employed assistance such as a home care agency, or care in an institution.

**long-term care ombudsman** - helps residents in long-term care facilities such as nursing homes and assisted living communities maintain their legal rights, control over their own lives, and personal dignity. If you have a problem with care at a nursing home or assisted living community, you can call the ombudsman for help.

**Medicaid** - a national medical assistance program managed by each state. It reimburses providers for medical and health-related services administered to persons who have no health coverage. Nursing home care for older persons in need is also covered by Medicaid.

**Medicare** - a national health insurance plan for people over 65 and for some people under 65 who are disabled. It includes two parts: Part A covers hospital costs and some skilled nursing care, and Part B is the supplemental portion (for which the insured pays premiums) that covers a part of the doctor's fee and therapy.

**nutrition site** - as part of Maryland's Senior Nutrition Program, there are senior centers, churches, apartment buildings, and community centers all over the state that offer balanced, nutritious meals for the elderly. The program offers group meals to help seniors eat better, and opportunities to make friends.

**Older Americans Act** - enacted in 1965, its purpose is to give elderly citizens more opportunity to participate in and receive the benefits of modern society — for example, adequate housing, income, employment, nutrition, and healthcare.

**self-help, self-care** - a healthcare concept stressing that individuals can manage many of their own health problems when they have the right training and medication. It teaches how and when to use self-treatment techniques and when to seek professional help.

**senior center** - gathering place that has programs and social activities exclusively for seniors. Many have medical services or a meals program. Services are usually free and include transportation.

**Social Security** - a national insurance program that provides income to workers when they retire or are disabled, and to dependent survivors when a worker dies. Retirement payments are based on workers' earnings during employment.

**social services** - services designed to help individuals with problems that concern housing, transportation, meals, recreation, and family support and relations. These services are provided by professional social workers.

**Supplemental Security Income** - a national program providing supplemental payments to older persons who already receive public assistance. The program's aim is to raise the incomes of these individuals to the poverty threshold.

notes

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# caregiversresources

## **caregiving**

Area Agency on Aging, Prince George's County ..... TTY (301) 985-3894 • (301) 265-8450  
1-866-DFS-4001  
[www.goprincegeorgescounty.com](http://www.goprincegeorgescounty.com)

Agenet.....[www.Agenet.com](http://www.Agenet.com)  
*Online information on products and services that are helpful in elder care*

American Association of Homes and Services for the Aging .....(202) 783-2242  
[www.aahsa.org](http://www.aahsa.org)

American Association of Retired Persons (AARP) .....(202) 434-2277  
[www.aarp.org](http://www.aarp.org)

The Center for Family Caregivers .....[www.familycaregivers.org](http://www.familycaregivers.org)  
*Online information, resources, and products for the elderly and support for their families*

CareGuide .....[www.careguide.net](http://www.careguide.net)  
*Online resources and guidance to elder care solutions*

Eldercare Locator .....(800) 677-1116  
*Resources to find community assistance for seniors*

National Association for Home Care .....(202) 547-7424  
*Provide helpful information for home caregivers*

National Family Caregivers Association .....(800) 896-3650

Prince George's County Department of Social Services .....(301) 209-5000

Senior Information & Assistance Program, Prince George's County .....(301) 265-8450  
1-866-DFS-4001

## **healthcare**

Area Agency on Aging, Prince George's County .....(301) 265-8450  
1-866-DFS-4001  
[www.goprincegeorgescounty.com](http://www.goprincegeorgescounty.com)

Healthcare Financing Administration .....[www.hcfa.gov](http://www.hcfa.gov)  
*Federal agency that administers Medicare, Medicaid, and the State Children's Health Insurance (CHIP)*

Hospice of Prince George's County .....(301) 572-2489  
1-800-869-2136

Hospice of the Chesapeake .....1-866-301-4994

Senior Health Insurance Counseling & Assistance .....(301) 265-8471

Prince George's County Department of Family Services Mental Health Authority Division.....(301) 985-3890

Prince George's County Health Department's Adult Evaluation & Review Service (AERS) .....(301) 324-2980

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**legal**

Legal Aid Bureau	
Senior Citizen Law Project (MD)	(301) 927-6800
Long-Term Care Ombudsman.....	(301) 265-8483
<i>Advocate for nursing home residents</i>	
Maryland Disability Law Center.....	1-800-233-7201
Maryland Volunteer Lawyer Services .....	(800) 510-0050
<i>Low cost legal services for those over 60</i>	TDD (410) 539-3186
State Survey Agency .....	(410) 402-8000
<i>Surveys every Medicare and Medicaid-certified nursing home in Maryland</i>	
Prince George's County Bar Association .....	(301) 952-1442

**general**

Administration on Aging: A subdivision of the U.S. Department of Health and Human Services ....	(202) 619-0724
<i>Helpful information for older persons and their families</i>	<a href="http://www.aoa.gov">www.aoa.gov</a>
Call-A-Bus .....	(301) 499-8603
<i>Demand-response, curb-to-curb bus service to all residents of</i>	TTY 1-800-735-2258
<i>Prince George's County who cannot use existing bus services</i>	
Christmas in April .....	(301) 868-0937
<i>Preserves and revitalizes homes and communities</i>	
Eldercare Locator .....	(800) 677-1116
Maryland Relay .....	7-1-1 (within Maryland)
<i>Offers alternative means of communication for</i>	Customer Service (800) 552-7724
<i>hard-of-hearing, deaf, blind or speech disabled</i>	
Metro Access .....	(301) 562-5360
<i>Public transportation for those unable to use regular public transit system</i>	TDD (301) 588-7535
National Council on Aging .....	(202)-479-1200
<i>Organizations and professionals dedicated to promoting the dignity and well being of older persons</i>	<a href="http://www.noca.org">www.noca.org</a>
National Institute on Aging .....	<a href="http://www.nih.gov/nia">www.nih.gov/nia</a>
<i>Subdivision of NIH, conducts scientific research in an attempt to understand the nature of aging</i>	
Maryland Pharmacy Assistance.....	1-800-226-2142
Senior Training Employment Program (STEP) .....	(301) 265-8450
Prince George's County Department of Housing and Community Development .....	(301) 883-5531
Social Security Administration.....	1-800-772-1213
Veterans Administration .....	1-800-872-1000
Federal Retirees.....	(202) 606-0500
Prince George's County Public Libraries, Hyattsville Branch .....	(301) 985-4690
	TDD (301) 808-2061
Top Banana Groceries On Call.....	(301) 372-3663
<i>Home-delivered groceries</i>	
Medicaid Waiver .....	(301) 265-8450