

Andrew J. Spano, Westchester County Executive County Board of Legislators

## A Guide for Caregivers:

What You Need to Know

A Guide for Caregivers: What You Need To Know A Need To Know A Guide for Caregivers: What You Ne

What You Need To Know A Guide for Caregivers: \

Caregivers: What You Need To Know A Guide for

A Guide for Caregivers: What You Need To Know

Need To Know A Guide for Caregivers: What You Need To

What You Need To Know A Guide for Caregivers: What Y

Caregivers: What You Need To Know A Guide for Caregi

A Guide for Caregivers: What You Need To Know A G

Need To Know A Guide for Caregivers: What You Need To Know A Guide for Caregivers

What You Need To Know A Guide for Caregivers: What You Need To Know A Guide for

Caregivers: What You Need To Know A Guide for Caregivers: What You Need To Know

A Guide for Caregivers: What You Need To Know A Guide for Caregivers: What You

Need To Know A Guide for Caregivers: What You Need To Know A Guide for Caregivers:

What You Need To Know A Guide for Caregivers: What You Need To Know A Guide for

Caregivers: What You Need To Know A Guide for Caregivers: What You Need To Know

A Guide for Caregivers: What You Need To Know A Guide for Caregivers: What You

Need To Know A Guide for Caregivers: What You Need To Know A Guide for Caregivers:

What You Need To Know A Guide for Caregivers: What You Need To Know A Guide for

Caregivers: What You Need To Know A Guide for Caregivers: What You Need To Know

# A Guide for Caregivers: What You Need to Know

DEPARTMENT OF SENIOR PROGRAMS & SERVICES Mae Carpenter, Commissioner





## A Guide for Caregivers: What You Need to Know

**Mae Carpenter Commissioner** 

Diane Aparisio
Deputy Commissioner

Laura Bolotsky Director of Operations

Published by
The Westchester County Department of Senior Programs and Services
Family Caregiver Support Program
1974 Commerce St., 3<sup>rd</sup> Floor, Room 209
Yorktown Heights, New York 10598
(914) 245-9167



## TABLE OF CONTENTS

Introduction	1
Family Caregiver Support Program	2
Challenges Caregivers Face	4
Taking Care of You	5
Share the Care	7
Balancing Work and Caregiving	8
Depression in Caregivers	9
When Your Loved One Resists Care	10
Age-Related Changes	11
How to Talk to Health-Care Professionals	12
Home-Safety Tips	13
Long-Distance Caregiving	15
Resources	16
Caregiver Web sites	19
Glossary of Terms	22
Important Numbers and Document Finder	25

## INTRODUCTION

The Westchester County Department of Senior Programs and Services provides caregivers with the support, help and information they need to care for their loved ones in a safe and caring environment for as long as possible. This Guide was created to inform caregivers about the services we offer through our Family Caregiver Support Program. We believe that this information will empower caregivers to enhance the quality of life for themselves and their loved one and to let them know they are not alone.

#### WHO IS A CAREGIVER?

If you help your mother remember to take her medications and follow up with her medical appointments, or assist your father by taking him to buy groceries, you are a caregiver. Essentially, caregivers are people who help others with things they are unable to do for themselves.

#### **COMMON CAREGIVING ISSUES**

There are numerous challenges that new caregivers face - from learning about an illness and providing care for a loved one to making plans for their future. The purpose of this guide is to provide new caregivers with an overview of issues that most caregivers share. The following list of steps can make the job of caregiving easier:

- Talk to a health care provider and learn about the disease or condition of your loved one.
- Consider your options in order to meet all of the presenting needs.
- Explore your local community resources.
- Create a plan for immediate care and assistance.
- Allow others to assist in the care of your loved one.
- Organize important information and leave it in strategic locations.
- Make plans for the future such as long-term care.
- Find family, friends and support groups to talk with about your circumstances.
- Create a plan to keep your life together.
- Make a copy of your loved ones important papers, such as their Social Security card, insurance papers, Medicare/Medicaid and power of attorney documents and keep them on hand.





## THE FAMILY CAREGIVER SUPPORT PROGRAM

Taking care of an older relative or friend can be challenging. Whether you prepare meals for your father, drive your mother to the doctor or provide 24-hour care for your spouse, you are making an invaluable contribution to your loved one's life.

Our mission is to help families and friends meet the challenges of caring for an older adult. You are not alone. We are here to support caregivers in their efforts to provide care for older adults with chronic illness or disabilities. This in turn, promotes the ability for these older adults to remain in their homes and communities. You need and deserve the most up-to-date information about community resources and services that can help you.

The Westchester County Department of Senior Programs and Services offers information and referral on a wide variety of helpful services. This, in turn, enables you to provide the best care to your older relative, while also taking care of yourself.

The first step is to call:

The Westchester County Department of Senior Programs and Services Family Caregiver Resource Unit 1974 Commerce St., 3<sup>rd</sup> Floor, Yorktown Heights, N.Y. 10598 (914) 245-9167

#### CAREGIVER COUNSELING

Meeting the challenges of caregiving can sometimes be an overwhelming task. Our staff can meet with you to review your caregiving situation and provide guidance about your options.



#### **PUBLICATIONS**

"Caring", our free quarterly newsletter, is filled with helpful information for caregivers. You'll find articles on community resources, health and safety tips, a "Question and Answer" column and other timely articles. A free guide to caregiver support groups and respite services is available as well.

#### CAREGIVER RESOURCE SERVICE CENTERS

Five full-service Caregiver Resource Centers have been established throughout Westchester to provide advice, information and services to help caregivers in their role of caring for an elderly family member. They are staffed by professionals who care and recognize your special needs and provide direct services and referrals.

Our 12 Library Caregiver Resource Centers provide free pamphlets and a large inventory of books, videos and DVD's on a variety of subjects related to caregiving that can be checked out. All the centers are listed under the "Resources" section starting on Page 16 of this guide.

#### **GRANDPARENTS PROGRAM**

The Grandparents Program offers support groups and workshops to help seniors who are 60-plus years and are raising grandchildren 18 years old and younger. The program's goal is to enable the children to remain in a nurturing family environment rather than be placed in foster care.

#### **EDUCATIONAL WORKSHOPS**

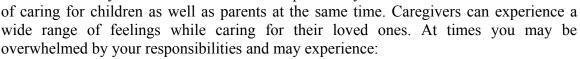
Workshops for caregivers are given at various sites throughout the County. Learn about services available to help caregivers meet the challenges of caring for a loved one. Topics include community resources, stress management, planning ahead for your loved one and other topics to help caregivers.



## CHALLENGES CAREGIVERS FACE

Caregiving is a loving act. However, meeting the challenges of caregiving can sometimes be an overwhelming task. Caregivers wear many hats and are torn in many directions. A caregiver's role may include: personal assistant, housekeeper, accountant, shopper, chauffeur, medical coordinator and nurse.

Historically, women have been the primary caregivers in families. Many women have the added responsibility



**Sadness and grief** - Seeing the decline of your loved one's health can be difficult to watch especially if the person in need of care is suffering and has a short time to live. Many people begin the grieving process while their loved one is still alive, adding more pain and stress to an already painful situation.

**Fear and worry** - Questions such as what will the future hold? Where do I get extra help? Can I afford this? The reality of these questions and others can plague a caregiver with fear and worry while caring for a loved one in declining health.

**Anger** - It is not uncommon for caregivers to be angry with their loved one for putting them in the role of caregiver. They may also feel anger toward doctors or family members who are not assisting as needed. If you are experiencing a lot of anger, now is the time to reach out for help. Call (914) 245-9167 for help in dealing with your anger.

**Guilt** - Occasionally caregivers feel guilty that they are not doing enough to make their loved one happier or to improve their situation. They may also feel guilty for having negative feelings toward their loved one. Many times guilt is also felt for neglecting a spouse and children, and for enjoying time away from the care of your loved one.

**Fatigue** - Because their many responsibilities stretch them in different directions at the same time, caregivers are often stressed and as a result, fatigued. Situations such as caring for two households, looking after an Alzheimer's patient who wanders or is incontinent, can overly burden a caregiver.

**Isolation** - Feelings of isolation are normal, given the significant reduction in the amount of free time a caregiver has available to socialize.



## TAKING CARE OF YOU

Before you can care for another person, you must care for yourself. Being in good shape physically and emotionally will make you happier, more relaxed and a much better caregiver. Here are some steps to lessen stress and take care of yourself.

#### I will:

- Anticipate my/our future needs: plan ahead.
- Allow others to help.
- Take things one day at a time.
- Be sure to rest and eat properly.
- Be good to myself.
- Learn about local resources that are available to help.
- Create a contingency plan B.
- Pay attention to my own health.
- Set aside time for leisure activities.
- Share my thoughts and feelings with friends.

The following are several guidelines to remember in your role as caregiver:

**Set realistic goals-** Recognize that you can not do everything and allow others to help you even if they do things differently.

**Maintain your health-** Do something you enjoy each day even if it is just for a few minutes. Your well-being affects everything you do, so be sure to care for yourself by eating well balanced meals, getting enough sleep and rest, and exercising regularly.

**Try a support group-** Support groups can help caregivers manage stress levels through the exchange of ideas and practical tips on caregiving. Support groups are unique in that they provide an opportunity for caregivers to share feelings and experiences in a supportive environment.

**Avoid caregiver burnout-** Burnout is the result of prolonged stress in the caring for your loved one. Caregivers often work hard to ensure the well-being of their loved one. In many instances caregivers do not pay attention to their own health and suffer from symptoms of burnout.



 ${\bf Questions?} \ {\bf Call \ the \ Family \ Caregiver \ Support \ Program \ (914) \ 245-9167}$ 





Here are some of the early warning signs:

Chronic fatigue - exhaustion, tiredness, a sense of being physically run down Anger directed at your loved one Being overly self-critical Being cynical, negative and irritable Frequent headaches and gastrointestinal disturbances Weight loss or gain Sleeplessness and depression

The best prevention is to become aware of the symptoms and take steps to minimize the risk of burnout. Do you have someone who can be your sounding board when you've reached your limit? Taking time off from caregiving is critical to recharge yourself physically and emotionally. Regular physical activity is an important way to release tension. Remember, it is important to be in the best physical condition for yourself and the person you're caring for.



### SHARE THE CARE

The responsibilities and tasks required to care for an older adult can be very demanding. Recognize that you may need help. Finding ways to get other family members to help can be a saving grace.

Start by inviting relatives to your home for a family meeting. Be sure to include your loved one in this meeting, if possible.



Make a list of all of the tasks you perform for your loved one. Pick out the tasks that you feel only you can do, and then distribute the list of remaining tasks you need help with. State the issues as factually as possible and create a plan that identifies who will be responsible for completing the identified tasks.

#### **Tips for Successful Family Meetings:**

- Be ready with notes regarding the issues you want to address. Have information handy regarding any community resources that you are considering.
- Attempt to respect the wishes of your loved one, and if possible, include them in the meeting.
- Allow for different points of view to be discussed. Listen carefully! A relative may have a great idea.
- Use "I" statements to express feelings, so that they do not sound accusatory.
- Share the responsibilities by giving each person a task so that you, as the primary caregiver, do not become resentful for carrying the bulk of the caregiving burden.
- Plan a meeting to follow up on your plans at least two or three months after the first meeting to evaluate the current plan and make any necessary changes.



## BALANCING WORK AND CAREGIVING



It can be tough for today's caregivers to balance their responsibilities as caregivers with the demands of their

jobs. In order to beat the stress associated with the responsibilities of work and family, learn how to:

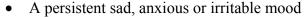
- **Share responsibilities-** Get the family involved in caregiving tasks.
- Take time out for yourself- Indulge yourself in something you enjoy.
- Get help~ Identify the things that you do not do well and ask for help from family and friends.
- Talk to your employer- Separate your office work from your caregiving responsibilities as much as possible. Using your lunch break to locate resources for caregiving is appropriate. You can also inquire about any Employee Assistance Programs that may be offered by your employer in support of caregivers, such as flex-time schedules, job sharing or part-time work.
- The Family and Medical Leave Act (FMLA)- Ask your employer about this program. It was designed to help employees balance their work and family responsibilities by taking reasonable unpaid leave for certain family and medical reasons.
- Use community resources- Call the Family Caregiver Support Program to see what programs are available to caregivers in your area.
- **Hire a home-care worker-** If it is becoming too much, consider hiring a home-care worker to give assistance to your loved one while you are at work.
- **Join a caregiver support group-** Even if you can only go occasionally, a support group helps you to realize you are not alone. A lot of information on caregiving and hints on how to maintain balance in your life is shared between members, which may be helpful.



## DEPRESSION IN CAREGIVERS

Even if you do everything "right" you may still feel depressed. Caregivers are vulnerable to depression because of the nature of what they do. Being socially isolated and over-burdened by too many roles and responsibilities can contribute to putting them at risk.

Depression is a serious but common condition. Here are some of its symptoms:



- Feelings of worthlessness, hopelessness or excessive guilt
- Change in appetite
- Sleep disturbance
- Fatigue or lack of energy
- Feelings of low self-esteem
- Loss of interest or pleasure in activities previously enjoyed
- Difficulty concentrating, remembering or making decisions
- Suicidal thoughts or attempts
- Persistent physical symptoms that don't get better with treatment

Many people experience occasional episodes of sadness. For caregivers however this can be a painfully common problem. Studies show that among caregivers, an estimated 46 percent are clinically depressed.

#### TREATMENT IS AVAILABLE

Fortunately, there are many ways to successfully treat depression and make significant differences in peoples' lives. Depression must be diagnosed clinically, so if you have signs of depression start with a complete medical check up to rule out any physical causes. Medications or an unrecognized disorder, for example, may provoke depression. Next, consult with a psychiatrist or a healthcare professional that specializes in recognizing and treating depression and other mental health concerns.

The treatment for depression is individually designed based upon a person's symptoms, ability to participate in treatment and available resources. Treatment can include some combination of medicine, therapy, psychosocial support and activities. In addition, mental stimulation, increased social support and physical activity may also help alleviate the symptoms.



## WHEN YOUR LOVED ONE RESISTS CARE



When your loved one is experiencing a decline in their mental, emotional or physical health and refuses offers of help - or will not admit to difficulties - it is essential to understand the reasons why.

Once you do, you can better provide the help that is needed. Remember, it may be difficult for seniors to admit they need assistance. They may believe accepting help will mean a loss of independence, of becoming a burden to the family. Perhaps they are worried about the expenses involved in receiving formal assistance.

Involving that person in an honest and respectful discussion about these concerns may help eliminate them. Your discussion can include the options of care and identifying those areas of care you believe are needed the most. It might happen that your loved one may agree to the major needs and will accept help for other needs at a later time.

You may need to involve other family members as well as a doctor, case manager or member of the clergy to overcome the senior's resistance. As the primary caregiver you may need the help of other family members to discuss and take part in the care of the senior. Involving a professional, such as a social worker, may help the senior recognize that their need for care is serious.

One discussion may not be enough. You may need to have a series of talks over time. Compromise and acceptance may be reached, and both the caregiver and the senior will benefit.



## AGE-RELATED CHANGES

Aging is not a disease. Just because people age does not mean they will be sick. But the body does change as part of the normal aging process. Below is a list of some of those age-related changes and the impact they may have on your loved one.



**Vision** - Many seniors accept failing vision as a normal part of the aging process.

However, many of the problems associated with the aging eye can be prevented, minimized or corrected with good eye care and regular eye exams. Vision changes that occur as we age are reduced visual acuity, or clearness of vision, diminished ability to focus on objects, decreased color vision, and the need for increased illumination. Early diagnosis and treatment is the single most important factor in preventing vision loss.

**Hearing** - Hearing becomes less acute as we age. Higher frequencies are especially troublesome and make conversations difficult.

**Balance** - Sudden changes in a body's position may upset a person's sense of balance. Dizziness and a fall may result.

**Sleep** - Changes in sleep patterns are not uncommon as one ages.

**Taste** - The sense of taste can diminish, making food bland. It is not uncommon for a sense of smell to diminish as well. This powerful combination can lead to an increased lack of interest in food and eating.

**Bone Density** - Bones tend to get thinner and joints tend to become stiffer as a person ages. There are changes in cartilage tissue which can lead to more restricted movement, increased risk of fractures and a stooped posture.

**Digestion** - Changes in tissue and muscles can slow digestion which may cause constipation.

**Body temperature** - The body's ability to regulate body temperature can decline. The result of this process can be overheating or the need to wear too many layers of clothing on hot days.

**Skin** - As skin ages it becomes more fragile and the layer of fat under the skin gets thinner. This makes the skin more sensitive to the touch.

**Minor memory loss** - Very minor changes in memory may occur with normal aging. Age, however, does not denote significant mental decline. If symptoms such as confusion, disorientation, or significant memory loss are noted, evaluation by a doctor is needed.



## HOW TO TALK TO HEALTH-CARE PROFESSIONALS

Your father returns from a check up and reports that the doctor didn't say much, so he must be fine. Or, your mother returns from a clinic visit with a referral for tests, but doesn't know what they're for. Or perhaps the relative you're caring for has three new prescriptions for medication – but can't explain why he's suddenly taking them. Sound familiar? These scenarios illustrate



why it's important for older people's families to play a key role on the health-care team.

As caregivers, you can help. Whenever possible, accompany your relative to the doctor's and stay with him or her during discussions. By opening the lines of communication, the doctor and caregiver both gain a better understanding of what the patient is facing and how best to help. There are several things you can do to get the most our of doctor visits:

- Prepare your older relative for each doctor's visit. Help her write down the symptoms that need to be discussed. Make a list of all current medications, including over the counter remedies.
- Don't be afraid to discuss problems with the doctor. The more information shared, the better help the doctor can provide. Using your prepared notes, state the medical problem clearly and concisely. Inform the doctor of any medications the patient is taking and discuss any side effects.
- Ask for an explanation of the diagnosis. Make sure it is explained in layman's terms so that you and your older relative can understand.
- Always encourage the physician to talk directly to the patient. Allow the older relative time to answer questions and talk directly with the physician.
- Ask about tests and treatments and the reasons for them.
- Ask about alternative treatments to the one the doctor prescribes.
- Make sure that you and the patient understand the doctor's explanations and instructions. Consider taking notes or bringing a small tape recorder to ensure that you remember all that was discussed.
- Educate yourself about your loved one's condition. A wealth of information is available on the Internet, bookstores, libraries and voluntary health organizations.

Remember, don't be afraid to take an active role and be an advocate for your family member. Consider your loved one's care a "team effort," where each member brings a special perspective on how to reach the goal of obtaining the optimum quality of life for your loved one.



### **HOME-SAFETY TIPS**

Here are some tips and ideas to keep your loved one safe in the home. They will give you a new way to see your home in order to prevent injury to your loved one.

#### Home furnishings

- Furniture should be positioned in low-traffic areas such as corners and sections of the room, out of the range of mobility.
- Furniture should be stable and without sharp corners, if possible.
- Avoid the use of scatter/throw rugs, as they may cause a person to trip and fall.
- Consider the placement of barriers or gates at the top and/or bottom of stairs or dangerous areas.

#### Bathrooms

- The bathroom is the most likely area of a household where a person may fall. Placing non-skid adhesive strips in the tub or on the floor of the bathroom, is an easy and inexpensive way to prevent falls.
- Tub seats are also extras that may assist an individual with mobility issues. They permit individuals in wheelchairs or those with minimal strength in their arms and legs to maneuver into the tub/shower area.
- Hand-held shower attachments are a good investment for those individuals
  experiencing difficulty with mobility in their arm and wrist joints, such as arthritis
  sufferers.

#### **Bedrooms, Living Rooms**

- Keep extension cords in "out of the way" places (such as behind furniture) to prevent tripping and failing. Do not place extension cords in "high-traffic areas" or under rugs, as they can wear down and cause fires. It may be a good idea to invest in a cord ramp protector to place over the cords.
- Shelves should be strategically placed in bedroom and living room areas to limit reaching. Shelves should be low enough to avoid using a stepstool. All items should be at eye level in order to find them easily.



#### Lighting

- Make sure the house is well lit, especially hallways and dark corners.
- Put nightlights in bedrooms, bathrooms and hallways.
- Make sure lighting can easily be reached and turned on and off.
- It is a good idea to have ample lighting outside, especially on porches and walkways leading to one's home, as well as driveways and garages. Lights and sensor lights (lights that automatically go on when a motion is detected) may be purchased at most hardware stores.

Adapted from: "Home Safety Tips for Seniors," Senior HelpCare, Inc. Copyright- New York State Office for the Aging 2001-2004



## LONG-DISTANCE CAREGIVING

Long distance caregiving has become more common than not and offers very specific challenges. In order to ensure that your loved one is receiving the care that is needed the following tips can help:



- Make regularly scheduled visits. Use your visits to determine the level of assistance your loved one needs.
- Arrange for help when needed. Ask your loved one what they believe their needs are. Also, ask your loved one's friends, neighbors and any other care providers what needs they see.
- Plan regular check in times. Regular phone calls are a great way to check in with your loved one.
- Enlist the support of local friends. Locate a friend or neighbor close to your loved one that can be called if there is an emergency.
- Get local information. Keep an address book with the names, addresses, and phone numbers of your loved one's doctors, landlord and other important contacts. Get a copy of a local phone book from your loved one's home town so that you have access to local resources when they are needed.
- Connect with community resources. Identify any support systems that may be available through the clubs, organizations or religious communities your loved one is involved with.
- **Help your loved one accept care.** Acknowledge and work through any presenting issues or concerns regarding the acceptance of care. Treat your loved one and their wishes respectfully.

Mardi Richmond. Adapted from: Long Distance Caregiving: Caring for an older, ill or disabled adult. Copy written 2003. Journeyworks Publishing.



### RESOURCES

The Family Caregiver Support Program was created to provide advice, information and services to assist caregivers in their role of caring for an elderly family member. The following five Full Service Centers are staffed by professionals who can provide direct services and referrals;

#### Westchester County Department of Senior Programs and Services

9 South First. Ave., 10<sup>th</sup> Floor, Mt. Vernon, N.Y. 10550 (914) 813-6394

**Family Caregiver Support Program** 1974 Commerce St., 3<sup>rd.</sup> Floor, Room 209 Yorktown Heights, N.Y. 10598 (914) 245-9167

#### **Yonkers Office for the Aging**

2 Park Ave. Yonkers, N.Y. 10701 (914) 377-6822

#### **ElderServe**

170 Hamilton Ave. (at the Lighthouse) White Plains, N.Y. 10605 (914) 683-7530

#### **Alzheimer's Association**

2900 Westchester Ave., Suite 306 Purchase, N.Y. 10577 (914) 253-6360



The Westchester County Library Caregiver Resource Centers have brochures, books, videos, CDs and DVDs on all aspects of caregiving and can be found at the following locations;

#### **New Rochelle Library**

One Library Plaza, 3<sup>rd</sup>. Floor New Rochelle, N.Y. 10801 (914) 632-7878

#### **Somers Library**

Route 139, Reis Park Somers, N.Y. 10589 (914) 232-5717

#### Warner Library- Tarrytown

121 N.Broadway Tarrytown, N.Y. 10591 (914) 631-7734

#### **Port Chester Library**

1 Haseco Ave. Port Chester, N.Y. 10571 (914) 939-6710

#### Field Library -Peekskill

4 Nelson Ave. Peekskill, N.Y. 10566 (914) 737-1212

#### **Greenburgh Public Library**

300 Tarrytown Road Greenburgh, N.Y. 10607 (914) 993-1600

#### **Katonah Village Library**

26 Bedford Road Katonah, N.Y. 10536 (914) 232-3508



#### **Ossining Public Library**

53 Croton Avenue Ossining, N.Y. 10562 (914) 941-2416

#### **Rye Free Reading Room**

1061 Boston Post Road Rye, N.Y. 10580 (914) 967-0480

#### **Scarsdale Public Library**

54 Olmstead Road Scarsdale, N.Y. 10583 (914) 722-1300

#### John C. Hart Memorial Library

1130 Main Street Shrub Oak, N.Y. 10588 (914) 245-5262

#### **White Plains Library**

100 Martine Avenue White Plains, N.Y. 10601 (914) 422-1400



## WEBSITES FOR CAREGIVERS

#### www.nfcacares.org.

One of the first caregiver websites. Support for caregivers. Education and advocacy for caregiving.

#### www.caregiver.org

Tips and resources for caregivers. Available in Spanish & Chinese. Fact sheets include legal information.

#### www.alz.org

Website for the Alzheimer's Association. Good for anyone dealing with dementia.

#### www.aarp.org

American Association of Retired Persons website with information for caregivers.

#### www.caps4caregivers.org

Information for children of aging parents.

#### www.caregiver.com

Founded by caregiver and author of "The Fearless Caregiver", Gary Barg. On-line newsletter and print magazine "Today's Caregiver". User friendly.

#### www.eldercare.gov

Provides information on local services for seniors and their caregivers throughout the United States.

#### www.familycaregiving101.org

Good tips on family caregiving. Talks about stages of caregiving.

#### www.careguide.com

Financial resources.
Legal information.
Caregiving tips and resources.
Health information.



#### www.wellspouse.org

This site gives support to husbands, wives and partners of the chronically ill and disabled.

#### www.pbs.org/thoushalthonor

Summary of documentary on caregiving. Excellent links to other services. Forum for caregivers.

#### www.nia.nih.gov

National Institute on Aging Center. Links to a variety of health/illness sites. Links to services and resources for seniors.

#### www.elderweb.com

Sourcebook with links to information related to care of the elderly. Well-organized site.
Can locate services by state.

#### www.Firstgov.com

Can access birth and marriage certificates. Easy steps to learn about eligibility for benefits.

#### www.benefitscheckup.org

Finds free federal and state assistance programs. Easy to use.
Spanish available.

#### www.aoa.gov

Administration on Aging website. Information for elders and their families.

#### www.healthfinder.gov

From the National Institutes of Health. Covers a wide range of health information. Links to other health related sites. Information available in Spanish.

#### www.familydoctor.org

From the American Academy of Family Physicians. User friendly.
Health information for the entire family.
Information available in Spanish.



### www.medicare.gov

Government website for the Medicare program. Information on Medicare Part D, drug program.



### **GLOSSARY OF TERMS**

**Activities of Daily Living (ADL)-** personal hygiene, bathing, dressing, grooming, toileting, feeding and transferring.

**Adult Day Care-** centers that have a supervised environment where seniors can be with others.

**Advance Directive-** a legal document that states a person's health care preferences in writing while that person is competent and able to make such decisions.

**Alzheimer's Disease-** a dementia that causes a serious decline of intellectual functions, including thinking ability, memory and motor skills.

**Assisted Living-** residential housing for seniors offering independence, choice of services, and assistance with Activities of Daily Living, including meals and housekeeping.

Congregate Living- a type of independent living in which the elderly can live in their own apartments but have meals, laundry, transportation, and housekeeping services available.

**Durable Power of Attorney-** a legal document that authorizes another to act as a person's agent. It is "durable" because it remains in effect should the person becomes disabled or mentally incompetent.

**Estate Planning-** a process of planning for the present and future use of a person's assets.

**Guardian**- the one who is designated as having protective care of another person or that person's property.

**Hospice**- a program that allows a dying person to remain at home while receiving professionally supervised care.

**Incontinence**- involuntary discharge of urine or feces.

**Medic-Alert-** bracelet identification system, linked to a 24-hour service that provides full information in the case of an emergency.



**Medicaid-** a public health program through which certain medical and hospital expenses of those having low income or no income are paid from state and Federal funds; benefits vary from state to state.

**Medicare-** a Federal health insurance program for people 65 or older and for certain disabled people under 65.

**Occupational therapy**- therapy that focuses on the Activities of Daily Living such as personal hygiene, bathing, dressing, grooming, toileting and feeding.

**Ombudsman**- a person who helps residents of a retirement facility with such problems as quality of care, food, finances, medical care, residents rights, and other concerns; these services are confidential and free.

**Physical therapy**- the process of relearning abilities, such as how to walk, maintain balance and "transfer" from one position to another – perhaps from a bed to a chair.

**Pressure sore-** a breakdown of the skin caused by prolonged pressure in one spot; a bed sore.

**Prognosis**- a forecast of what is likely to happen when an individual contracts a particular disease or condition.

**Range of Motion (ROM)**- the extent of possible passive (movement by another person) movement in a joint.

**Rehabilitation-** restoration, after a disabling injury or disease, to a person's maximum physical, mental, vocational, social, and spiritual potential.

**Respite care-** short-term care that gives primary caregivers free time away from their responsibilities.

**Speech Therapy-** the treatment of disorders of communication, including expressive language, writing and reading and communication required for Activities of Daily Living.

**Stroke-** sudden loss of function of a part of the brain due to interference in its blood supply, usually by hemorrhage or blood clotting.

**Sundown Syndrome-** a period of severe confusion, agitation, irritability, and occasionally violence that occurs at the end of the day in some seniors.



**Support groups**- groups of people who get together to share common experiences and help one another cope.

**Symptom-** signs of a disease of disorder that help in diagnosis.

**Transfer-** movements from one position to another, e.g., from bed to chair, wheelchair to car, etc.

Will- legal document that states how to dispose of a person's property after death, according to that person's wishes.

Adapted from: The comfort of home: An illustrated step-by step guide for caregivers. By Maria M. Meyer with Paula Derr, RN (1998)



#### **IMPORTANT PHONE NUMBERS**

Primary Doctor
Health Insurance
Specialist
Specialist
Specialist
Pharmacy
Hospital
Other Caregivers
Neighbors
DOCUMENT FINDER, LOCATION OF:
Health Insurance
Health Care Proxy
Living Will
Bank Accounts
Social Security Card
Car Insurance
House Insurance
Life Insurance
XX/211

