

AARP

CONNECTING CAREGIVERS TO COMMUNITY™

CAREGIVERS' HANDBOOK



AARP

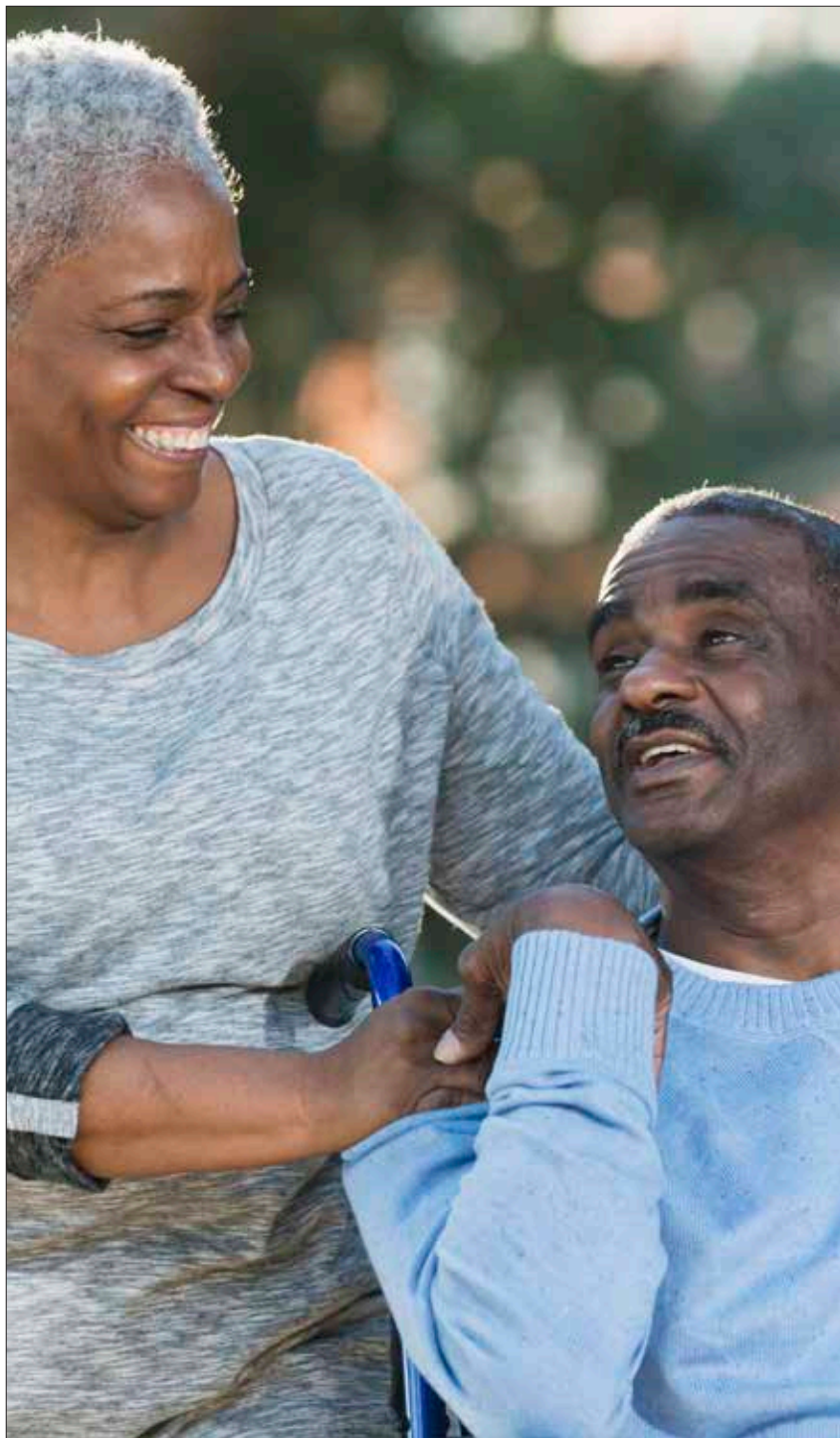
Family Caregiving™

A close-up photograph of two hands clasped together in a supportive grip. The hands are of a dark skin tone. The background is softly blurred, showing a person's shoulder and a grey garment. The overall mood is one of care and connection.

**CONNECTING
CAREGIVERS
TO COMMUNITY**

Caring for an older loved one is a blessing and a challenge. The time, effort and love you give are precious, and in many instances life-sustaining. Please know that your church family is here to support you.

This handbook is for you. You may want to bring it with you to each program activity and have it handy when you connect with your Caregiver Buddy Volunteer. It contains two sections. The first section lists numerous resources—assessment forms, advocacy tips, helpful articles, lists of resource organizations, and much more. Use these resources to reduce your stress, find services to assist you and learn about useful ways to manage caregiving. The second provides a place where you can record what you are learning through the Connecting Caregivers to Community (CC2C) program. Then you can capture how you plan to incorporate the information learned into your everyday life using the 3-2-1 method.



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CAREGIVER SELF-ASSESSMENT TOOL

This self-assessment tool is a resource you can use to get a snapshot of your own personal needs. Simply place a “√” next to the statements that you agree with. Then, share your results with your church, family, friends and the local agency on aging to learn how they might help you.

CAREGIVER SELF-ASSESSMENT TOOL

I agree √	Caregiving Statement	Possible Resource
	<i>I work outside the home.</i>	Employer caregiver support benefits
	<i>I feel lonely sometimes.</i>	Support groups, caregiver peer support
	<i>I need to learn about support services.</i>	Educational workshops and written materials
	<i>I need to plan for my future.</i>	AARP's <i>Prepare to Care</i> booklet and Caregiver Resource Center, www.aarp.org/caregiving
	<i>I wish someone would acknowledge what I do.</i>	Celebrations for caregivers
	<i>I have been missing church too often.</i>	CDs of church services, Internet video of church services, telephone spiritual support
	<i>I could use suggestions to make caregiving easier.</i>	Educational workshops, support groups, AARP's <i>Prepare to Care</i> and Caregiver Resource Center, www.aarp.org/caregiving

CAREGIVER SELF-ASSESSMENT TOOL

I agree √	Caregiving Statement	Possible Resource
	<i>I would like to stay in touch with my church family.</i>	E-mail support, telephone calls and visits from church members
	<i>I need to connect with other caregivers.</i>	Support groups, caregiving online community
	<i>I want more spiritual support.</i>	Telephone or Internet spiritual support
	<i>I don't have anyone to help me.</i>	Practical help in the home, homecare agencies
	<i>I am stressed.</i>	Support groups, respite care, telephone support
	<i>I want to use my computer to receive support.</i>	Caregiver chats, online community and blogs
	<i>I need a break from caregiving.</i>	Respite care
	<i>Other:</i>	



CAREGIVERS SELF-ADVOCACY TIP SHEET

The Caregivers Self-Advocacy Tip Sheet is a handout that contains the Caregivers Rights and tips for working with support agencies and organizations. You can distribute this tip sheet to caregivers at any time. It is particularly useful when discussing the need for self-care. Tip sheets can be made available in the church office, placed on the website or mailed upon request.

CAREGIVER'S BILL OF RIGHTS

I have the right...

- 1.** To take care of myself. This is not an act of selfishness. It will give me the capability to take better care of my relative.
- 2.** To seek help from others even though my relatives may object. I recognize the limits of my own endurance and strength.
- 3.** To maintain facets of my own life that do not include the person I care for, just as I would if he or she were healthy. I know that I do everything that I reasonably can for this person, and I have the right to do some things just for myself.
- 4.** To occasionally get angry, be depressed and express other difficult feelings.
- 5.** To reject any attempts by my relative (either conscious or unconscious) to manipulate me through guilt.
- 6.** To receive consideration, affection, forgiveness and acceptance for what I do from my loved one for as long as I offer these qualities in return.
- 7.** To take pride in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of my relative.
- 8.** To protect my individuality and my right to make a life for myself both now and when my relative no longer needs my full-time help.
- 9.** To expect and demand that as new strides are made in finding resources to aid physically and mentally impaired persons in our country, similar strides will be made towards aiding and supporting caregivers.

This "Bill of Rights" is adapted from *Caregiving: Helping an Aging Loved One* by Jo Horne, AARP Books, 1985



CAREGIVER TIPS: GETTING WHAT YOU NEED FROM AGENCIES

The following are some strategic tips you can use when working with various agencies to obtain information or access support services. In some cases you may be transferred a few times before you get what you need, but don't give up. Use the following information to ensure success.

- Be prepared. Assess your needs and those of your loved one using *Prepare to Care* by AARP, www.aarp.org/caregiving. Purchase a notebook to record your caregiving information.
- Talk with other caregivers first to discuss their experiences with various agencies.
- Contact your local department of aging. Identify it by using the online Eldercare Locator at www.eldercare.gov or calling 1-800-667-1116. Briefly share your caregiving situation and clearly state what you need.
- Ask to speak with a case manager at the local agency of aging if you or your relative has complicated needs.
- Ask for the first and last name and direct telephone number of everyone you speak with. Note who you are being referred to and their department.
- Ask about alternative solutions to meet your needs.
- Ask about the eligibility criteria, how to apply for services, fees, whether there is a waiting list and what types of insurance are accepted.
- Repeat back the information you hear to ensure you understand what is being said.
- Ask for references from other clients.
- Always compliment helpful individuals and inform their supervisors of their good work. Send them a thank-you card. Report rude workers to their supervisors.
- Follow the chain of command when voicing a complaint.
- Put concerns or recommendations in writing. A word put in writing is worth a thousand spoken words.

- If necessary, get help from state and national organizations, particularly regulatory agencies.
- Be sure to keep good notes in your caregiving notebook.
- Develop a contingency plan if the service provider is unavailable at some point.



RESOURCES FOR AFRICAN AMERICAN CAREGIVERS

The following are organizations that offer resources targeting African American caregivers. They provide information to help you care for patients with specific diseases. Contact these groups and ask about resources specifically for African Americans.

AIDS

- Act Against Aids: Centers for Disease Control and Prevention, 1-800-232-4636, www.cdc.gov/ActAgainstAIDS
- Black AIDS Institute: 213-353-3610, www.BlackAIDS.org

Alzheimer's and Related Disorders

- Alzheimer's Association: 1-800-272-3900, www.alz.org
- Ethnic Elders Care Network: 925-372-2105, www.ethnicelderscare.net

Cancer

- African American Breast Cancer Alliance: 612-825-3675, www.aabcainc.org
- Sisters Network: 713-781-0255, www.sistersnetworkinc.org
- Celebrating Life Foundation: 1-800-207-0992, www.celebratinglife.org

Diabetes

- American Diabetes Association: 1-800-DIABETES, (1-800-342-2383), www.diabetes.org

General Health

- Net Wellness: 513-558-8766, www.netwellness.org
- Journey to Wellness: 404-364-1878, www.journeytowellness.com
- National Women’s Health Information Center: 1-800-994-9662, www.womenshealth.gov
- Medline Plus: 1-800-CDC-INFO, (1-800-232-4636), www.nlm.nih.gov/medlineplus/africanamericanhealth.html

High Blood Pressure

- American Heart Association: 1-800-242-8721, www.heart.org
- National Heart Lung and Blood Institute: 301-592-8573, www.nhlbi.nih.gov

Mental Health

- National Alliance on Mental Illness: 1-800-950-NAMI, (1-800-950-6264), www.nami.org

Obesity

- Weight-control Information Network: 1-877-946-4627, www.win.niddk.nih.gov/index.htm

Osteoporosis

- NIH Osteoporosis and Related Bone Diseases National Resource Center: 202-223-0344, www.bones.nih.gov, NIHBoneInfo@mail.nih.gov

Stroke

- Internet Stroke Center: 214-648-3111, www.strokecenter.org
- National Stroke Association: 1-800-787-6537, www.stroke.org

CAREGIVING STRESS BUSTERS

6 Ways to Cope and Remain Strong

by: Candy Sagon | from: *AARP The Magazine* | Dec. 2012/Jan. 2013

Caring for a sick loved one can take a huge toll on your health. Try these 6 simple tips on how to take better care of you.

1. Make the Freezer Your Friend

“Telling caregivers to ‘eat right’ is useless advice,” says Washington, D.C., dietitian Katherine Tallmadge. Caregivers usually know what to eat; they just don’t have time to cook healthier meals. Her answer: batch cooking, which lets you freeze individual portions that you can eat during the week. She tells harried caregivers to make a big pot of a hearty, all-in-one meal like a soup or stew with meat, beans and vegetables.

2. Mix in Meditation

Twelve minutes of daily meditation can dramatically improve the mental health of caregivers, report UCLA researchers. In their study, 65 percent of family caregivers who practiced a chanting yogic meditation called Kirtan Kriya every day for eight weeks saw a 50 percent improvement on a depression-rating scale. Meditation also increased telomerase activity—a sign that cellular aging had slowed, says study author Helen Lavretsky, M.D.

3. Stockpile Healthy Snacks

Nutritious foods you can grab on the run help keep blood sugar levels on an even keel and energy levels from flagging, says Tallmadge. She nixes the typical granola bars—“too high in sugar”—opting instead for what she calls “real food” with hunger-busting protein. That means a handful of whole almonds or a PB&J sandwich. Plus, healthy snacks are a good way to add more fruits, vegetables and fiber to your diet.

4. Slow Down

Whether it's heating up food for dinner or helping someone in the bathroom, the advice is the same: Don't rush. "It sounds obvious, but when you're stressed and distracted, you're more prone to having accidents. What you don't need is to cut or burn yourself, or slip in the tub," says Karen Rowinsky, an Overland Park, Kansas, social worker who specializes in caregiver counseling. A 2006 study found that such accidents can be warning signs that you're at your limit.

5. Volunteer

This may seem counter-intuitive—you're already doing so much to help your family member. But helping out in a different way, in a different setting, can be gratifying and therapeutic, says Barry J. Jacobs, Psy.D., author of *The Emotional Survival Guide for Caregivers*. "One woman told me she volunteers weekly at an animal shelter because the pets are so responsive," he says. Plus, last year a University of Michigan study found that volunteers live longer than non-volunteers.

6. Improve Your Sleep Habits

Disrupted sleep saps your energy for dealing with the demands of caregiving, says Cleveland Clinic geriatrician Ronan Factora, M.D. Brain scans of sleep-deprived patients in the University of California, Berkeley's sleep lab also found that brain measures of anxiety shot up by more than 60 percent in those who were the most fatigued. So adopt good sleep habits—a dark room, fewer distractions in the bedroom—for more restful sleep.

See also: AARP's Caregiving Resource Center at www.aarp.org/caregiving.

HIRING SOMEONE TO HELP WITH HOME CARE

Finding an Agency, Costs and Questions to Ask

Most questions about family caregiving can't be answered with a simple yes or no. But, the question of whether home care agencies are all alike is one of the few that can be answered.

The answer is a definite no.

Here's some information you'll need if you're considering using an agency to help you find in-home help.

Firstly, you should know there are two basic kinds of home-care services that Medicare and other insurers cover: skilled care, which is provided by a health care professional, primarily a nurse, therapist (physical, occupational or speech) or social worker; and, personal care, such as help with bathing, grooming or other such tasks, provided by home health aides, (also called personal care workers or attendants.)

Secondly, you should be aware that Medicare only pays for a home care worker—skilled or personal—for a limited period and under special circumstances, typically following a hospital stay. To qualify a patient for Medicare coverage, a doctor will have to verify that the patient is homebound and needs part-time help. If the patient qualifies for skilled care, the Department of Health & Human Services booklet “Medicare and Home Health Care”—www.medicare.gov—can help you determine whether he or she can also qualify for personal care. Medicare does not cover personal care alone, if this is the only care the patient needs. Medicaid, the benefit for lower-income people, does cover some home care for longer periods of time, but coverage varies from state to state. Private insurance generally follows Medicare guidelines.

These are the various kinds of agencies you may encounter:

Medicare and Medicaid: Certified Home Health Agency (CHHA)

These agencies are certified by Medicare and Medicaid to provide skilled services and are licensed by the state. Medicare will only pay for those services provided through a Medicare-certified agency. These agencies may also provide personal care through their own home health aides or through another agency, usually a licensed agency, with which they have a contract.

Licensed Home Care Agency

This type of agency is licensed by the state and can provide nursing and personal care services. Some provide long-term personal care to patients through contracts with Medicaid. Most services, however, are paid for by the patient or the family.

Non-medical or Companion Agency

These agencies are not licensed, and their services are not covered by insurance. Companion or home helper services include keeping the person company and doing chores like picking up prescriptions from the pharmacy. Workers have varying levels of experience and training. These agencies are frequently small, locally run businesses that are franchises of large, national companies.

Employment or Registry Agency

These agencies provide names of available nurses and aides. You contact and pay the person directly. Your state may also maintain a registry through its Department of Health, or you can ask friends and neighbors for recommendations. Hiring on your own can work well but also carries additional responsibilities of financial management, supervision and arranging backup.

Many family caregivers do not investigate home care agencies until there is a crisis, like a fall or an unexpectedly short hospital stay. Even in these situations, you should ask questions about the agency before you sign an agreement. Medicare and Home Health Care, mentioned above, include a helpful checklist with questions you should ask when you are contacting various agencies. Be especially careful to find out how the agency screens, trains and supervises home care workers. Ask about the agency's rules for what aides can and cannot do.

Bringing someone into your home or your family member's home can help to ease the burden on you. But, in order to choose the right home care agency for your family member's needs, you will need to do adequate research to ensure you have reliable information on your options, including how to manage the type and duration of the services that will be provided, as well as the costs.

Establishing a set of "house rules" that respects your family member's and your own privacy, as well as the home care worker's needs, will help create a good working relationship.

You can find general quality comparisons of Medicare-certified agencies in your area at Medicare's Home Health Compare site — www.medicare.gov/homehealthcompare/search.html.

This site won't tell you about important aspects of care such as workers' reliability and communication skills, but it may help you to narrow down the choices.

For another source of information, visit United Hospital Fund's Next Step in Care — www.nextstepincare.org — particularly its For Family Caregivers page.

See also: AARP's Caregiving Resource Center at www.aarp.org/caregiving.



CREATE YOUR CAREGIVING TEAM

5 Tips on How to Get Others to Lend a Hand

from: AARP | December 19, 2011

When faced with a parent who needs your help, you're suddenly thrust into the role of a caregiver. You're likely to discover that you need help too. Just as it takes a village to raise a child, it takes a village to care for an aging parent. Here are five tips to create a caregiving team that works well for your family.

1. Hold Regular Family Meetings.

Gather your siblings and other key relatives to develop a care plan for your parent—ideally long before you're in a crisis situation. Involve your parent in all discussions. Firstly, figure out the finances—how much is available for your loved one's care, and secondly, what each family member can contribute. Make sure everyone voices his or her concerns. Put the family agreement in writing and reassess the situation every few months.

2. Call on Friends and Family Members for Help.

If a friend or relative asks, "Is there anything I can do?" have a list prepared with a wide range of tasks and activities that need to be done and ask what they might be able to help out with. Are they available to do errands, walk the dog, pick up books from the library or go grocery shopping? Set up a rotating visiting schedule for their help.

3. Use the Internet to Communicate with your Team.

Start a family Facebook page and a blog. Set up a family schedule online. This is the easiest way to communicate with your family and friends about what's going on without getting signals crossed or spinning your wheels. For tips on starting a blog, go to www.carepages.com.

4. Figure Out the Legal Issues.

Does your parent have a will, a living will and powers of attorney for health care and finances? If not, it's essential to prepare them now. Your parent and siblings should agree on who is handling finances, whose name or names will be on bank accounts and who will be the one signing legal documents or checks in an emergency. Know where to find all relevant legal documents, including their house deed and insurance policies. Review how bills are being paid and whether a better system is needed. Make sure your parent files an income tax return every year.

5. Identify Community Resources.

Contact your local government agency or community center with aging offices that may have a staff member available to help you. Contact local synagogues or churches to find out what services they offer older people and their families. Check out www.eldercare.gov, a service from the U.S. Administration on Aging, to pinpoint services in your community. Many community-based services offer free services, including regular telephone calls, help around the house and volunteers to make friendly visits.

See also: AARP's Caregiving Resource Center at www.aarp.org/caregiving.

PUBLIC BENEFITS CAN HELP

Older adults can have a hard time paying for basic necessities such as health care and food. There are a variety of federal and state programs that fill this need. Learn how to help your loved ones apply for benefits.

Identify Benefits Being Used

Find out what public benefits your loved one is already receiving and what other types they may qualify for. Make a list of these benefits and add to it as needed so that there's always an up-to-date record. These can include:

- Social Security
- Veteran's Benefits
- Medicaid

Find Out What's Available

Use AARP's Benefits QuickLINK to determine what programs your loved one qualifies for as well as to learn about other programs unique to your state. Helpful hint: Gather information about your loved one's resources before going online. After completing the Benefits QuickLINK survey, print out fact sheets, applications and websites for public benefits programs in your loved one's home state. If your loved one qualifies for a program, find out if he or she wants to apply and help him or her do so. Visit AARP's Benefits QuickLINK at www.benefitscheckup.org/aarpkeybenefits.

Apply for Appropriate Programs

Gather proof of your loved one's monthly income and other resources. Your State Health Insurance Assistance Program (SHIP) can provide guidance if more in-depth help is needed during the application process. Find the relevant SHIP program by visiting www.shiptalk.org. Note: The program name may be different in your state.

Take Care of the Details

Look over your loved one's documents for important notices about changes in his or her public benefits (these notices can be difficult to understand). Public programs may require recipients to show documentation for each year that they still qualify for the program. Keep these papers organized in an easy-to-find location.

What's Available

Social Security: Social Security is a national program that provides monthly income to people starting at age 62, or those who become disabled and meet strict disability and work eligibility requirements. To receive retirement benefits, you must have paid Social Security retirement taxes for at least 10 years or meet other specific requirements. Your benefit amount depends on your work history or that of your spouse, whichever is higher, and the age at which you start receiving benefits. The program also provides benefits to family members under certain conditions. To apply, visit your parents' local Social Security office, call 1-800-772-1213 or visit www.ssa.gov.

Medicare: For a variety of information on Medicare, check out AARP's Medicare section at www.aarp.org/health/medicare-insurance or go directly to Medicare's website at www.medicare.gov.

Medicare Part D Extra Help Program: This program assists people with Medicare who have limited incomes and assets to pay for most of their Medicare Part D premiums, co-payments and deductibles. It also provides continuous drug coverage throughout the year. If your loved ones are enrolled in Medicaid, Supplemental Security Income (SSI) or a Medicare Savings program, they will automatically get Extra Help with paying for Part D. Otherwise, they will need to first apply for Extra Help and then enroll in a private Medicare-approved prescription drug plan. Certain assets, such as your house and vehicle, do not count against the resource limit. Apply online through AARP’s Benefits QuickLINK tool. You can also apply by using Social Security’s online application at www.ssa.gov/prescriptionhelp.

See also: AARP’s Caregiving Resource Center at www.aarp.org/caregiving.



HOW CAREGIVERS CAN GET PAID

How to Get Financial Help for Taking Care of Mom, Dad

by: Cynthia Ramnarace | from: *AARP Bulletin* |

Updated December 15, 2011

Imagine that you could get compensated for driving Mom to the doctor, helping her get dressed and administering medications.

In some places, and in some cases, you can. Here are ways your commitment to Mom and Dad can result in more money in your pocket—either from direct cash payments or federal income tax breaks.

Compensation may be available for those taking care of their parents.

Federal Cash Benefits

Most states offer programs that use a Medicaid waiver to allow direct federal payments to family caregivers for their services. However, in most cases only care recipients whose income is low enough for Medicaid status qualify.

In New York and California, for example, the care recipient must apply for and be granted admission to a personal assistance program. The number of hours of care covered will be determined by a caseworker. The care recipient is then in charge of recruiting, hiring, training and firing the personal assistant. Payment comes directly from the state.

Eligibility rules and program setup vary by state; for more information on services in your area, contact the National Resource Center for Participant-Directed Services at www.caregiver.org/national-resource-center-participant-directed-services.

These programs, which aim to keep people living independently and address home health aide shortages in rural areas, are far from comprehensive. In addition, they “are in some distress now because of budget cuts in all of the states,” says Howard Gleckman, a resident fellow at the Urban Institute. “But they’re there, so there’s at least a chance you can use some of that money to pay a relative for your care.”

Direct Private Pay

Your parents could pay you directly for hours spent helping them with domestic, personal care and medical-related duties. “This is becoming increasingly commonplace,” says Gleckman. “But if you do this, it’s very important you have a caregiver contract in place.”

A caregiver agreement proves that a parent is paying for a service and not giving a gift. A history of cash gifts can disqualify your parent for future Medicaid enrollment, which pays nursing home fees for those who cannot afford them.

If you do decide to enter a private pay relationship, you must:

- Pay tax on your earnings, and your parents must report the payment on their income tax forms.
- Make your hourly rate in line with the national average pay rate for home health aides, which is about \$10 an hour. “You can’t pay your niece \$200 an hour to take care of you as a way to reduce your assets in order to become eligible for Medicaid,” says Gleckman.

“You might be tempted to just accept payment off the books from your parents, but that is risky,” says Gleckman, because of the Medicaid issue. Cash-strapped states are being very strict in determining eligibility, and they can request five years of bank account and tax records. “If your parent has a regular withdrawal of \$1,000 a month, for instance, they’re going to ask about that,” Gleckman says.

Long-Term Care Insurance

“Check your parents’ long-term care insurance policy. Some plans, although not many, offer a cash benefit that allows the policyholder to spend a certain amount of money each month on in-home assistance,” says Gleckman. “These policies are very expensive, and most carriers won’t even sell them because the possibility for fraud is so high,” says Gleckman. “But there are a few policies out there that do this.”

Dependent Tax Exemptions

If you are caring for a relative but none of the direct pay options fit your situation, consider whether you qualify for claiming your parent as a dependent on your income tax return. “Your parent doesn’t need to live with you,” says Melissa Labant, technical manager of the American Institute of CPAs. “But, you do have to provide more than 50 percent of Mom or Dad’s basic living expenses, including housing, food, clothing and other necessities. So perhaps they have their own apartment, but you pay the rent,” says Labant. “Or they can be living in assisted living, and you help pay for that.”

The exemption is the same as what you’d get for one of your kids: \$3,700 for the 2011 tax year for each care recipient. But here’s the caveat: Your parent’s earnings, excluding Social Security, cannot exceed the deduction amount, in this case \$3,700. So if your mom’s pension or investment income totals more than that amount, you cannot claim your parent.

If you are not married and your parent qualifies as a dependent, you can also save on your taxes by filing as head of household. “It’s a more favorable tax filing status than single and makes people eligible for lower tax rates, more credits and sometimes more tax breaks,” says Labant.

Deductible Medical Expenses

Did you pay to build a wheelchair ramp on your parents' home? Do you use your vehicle to drive them to medical appointments? "These costs are deductible on your return," says Labant, "as long as the cost exceeds 7.5 percent (for 2011) of your gross adjusted income." (That bar rises to 10 percent in 2013.) This is the case even if your parents don't qualify as dependents, as long as you are paying more than 50 percent of their medical fees.

See also: AARP's Caregiving Resource Center at www.aarp.org/caregiving.



PAYING FOR LONG-TERM CARE

Learn the Basics about Who Covers What

by: AARP Education & Outreach | from: AARP |

Updated September 2010

You're not the only one worried about the skyrocketing costs of long-term care or confused by all the rules about insurance coverage. AARP surveys report that many people mistakenly believe Medicare will cover all the care they'll need as they age. Others think they already have coverage through different types of insurance, only to find out, too late, that they don't. As a result, they may watch a lifetime of savings vanish to pay bills.

Most people finance long-term care through a patchwork of options—savings, investments and insurance, as well as government or community services. Here's what you need to know to make your savings last as long as you do:

Medicare pays for a short stay in a nursing home under very strict conditions. In general, you need to be receiving medically related skilled care after being in the hospital for three days or more. Restrictions also apply if you want Medicare to cover services you receive at home. You must need skilled care, such as care provided by a nurse or therapist, and your doctor must order it from a Medicare-certified agency. Medicare does not cover ongoing care or help with personal care, such as bathing or getting dressed.

Private health insurance covers hospital stays, prescription drugs and doctors' visits. Similar to Medicare, it usually pays for short-term rehabilitative services but does not pay for ongoing long-term care you may need down the road.

You'll probably need a patchwork of sources including savings, investments and insurance to be financially secure enough to pay for your long-term care.

Disability insurance can tide you over if you are too sick to work. This is salary replacement, designed to cover expenses such as food and mortgage payments if you or your spouse can't work. However, most policies max out once you hit 65.

If you can't get a policy through your employer, buy one through an outside insurer. Disability insurance will usually not be enough to cover the extra care and services you need while you're disabled.

Medicaid is a federal and state program that provides health and long-term care services for people with low incomes and few assets. To qualify for long-term care, individuals must be unable to manage daily activities such as eating, bathing or dressing.

Exactly who and what is covered varies from state to state, so be sure to check your state's Medicaid program at www.medicaid.gov/about-us/contact-us/contact-state-page.html.

State programs and services can help you stay in your home by providing home-delivered meals, transportation and housekeeping chores. Contact the Eldercare Locator at www.eldercare.gov to find out what's available near you.

Faith-based groups and health-related organizations also offer similar services, as well as support groups and people who drop by for a friendly visit. Call your place of worship and contact the local chapter of organizations such as the American Diabetes Association at www.diabetes.org, or the Alzheimer's Association at www.alz.org. See additional organizations under the section: Resources for Afro American Caregivers

Long-Term care insurance is specifically designed to cover some of the costs—but do your homework because long-term care insurance is not the right option for everyone. People with limited incomes, or people whose incomes will be significantly lower after retirement, might not be able to afford the cost

of insurance premiums over a long period of time. Compare a number of policies from different insurers, read the details and ask your insurance agent a lot of questions. In his column about whether long-term care insurance is right for you, AARP financial expert Jonathan Pond discusses what options to consider before purchasing insurance.

A reverse mortgage lets you tap into your home's equity to pay for long-term care. You do not have to pay back this loan as long as you continue to live in your home. These agreements can also be complicated, so be sure to have your financial adviser review the plan. Go to AARP's reverse mortgage page for additional information and expert advice.

Continuing Care Retirement Community (CCRC) is another option for some people. These communities provide supportive housing, assisted living and nursing care on one campus. Some CCRCs offer a life care agreement: You pay a large entry fee in addition to a regular monthly fee. As your needs increase, you start to receive more care, but your monthly fee stays about the same. Here, too, review the contract carefully with a trusted financial or legal adviser.

See also: AARP's Caregiving Resource Center at www.aarp.org/caregiving.

RESOURCES FOR PERSONS WITH DISABILITIES

The following are resources for caregivers who are care for children and adults with disabilities.

American Association of People with Disabilities

Promotes equality, economic empowerment and independent living for people with disabilities.

www.aapd.com

1-800-840-8844

American Foundation for the Blind

Enables persons who have visual impairment to access freedom and choice in life.

www.afb.org/default.aspx

212-502-7600

The Arc

The largest organization for the welfare of all children and adults with mental retardation.

www.thearc.org

202-653-3700

Best Buddies International

Provides one-to-one friendships and integrated employment for persons with disabilities.

www.bestbuddies.org

305-374-2233

Center for Parent Information and Resources (CPIR)

Your central “Hub” of information and products for the network of Parent Centers serving families of children with disabilities.

www.parentcenterhub.org

973-642-8100

Disability.gov

A federal resource on programs and services in communities nationwide.

www.dol.gov/odep/topics/disability.htm

Easter Seals

Offers child development services, vocational training, employment services and medical services.

www.easterseals.com

312-726-6200

Helen Keller National Center

Helps the deaf and blind live normal lives.

www.helenkeller.org/hknc

404-766-9625

Institute on Independent Living

Works for self-determination and equal opportunities for persons with disabilities.

www.independentliving.org

Mental Health America

Provides education and services for persons with mental health problems.

www.mentalhealthamerica.net

1-800-273-TALK

National Organization on Disability

Promotes the full and equal participation of persons with disabilities in all aspects of life.

www.nod.org

646-505-1191

Paralyzed Veterans of America

Advocates for veterans.

www.pva.org

1-800-424-8200

President's Committee for People with Intellectual Disabilities (PCPID)

Works to expand life opportunities for people with intellectual disabilities.

www.acl.gov/programs/empowering-advocacy/presidents-committee-people

202-690-6590

United Cerebral Palsy Association

Advances the independence and productivity of people with cerebral palsy.

<http://ucp.org>

1-800-872-5827

NOTES 3-2-1

Record in the space below helpful information you are receiving through the Connecting Caregivers to Community (CC2C) activities or through your Caregiver Buddy Volunteer.

Date: ___/___/___

PRESENTER _____ CONTACT _____

3 Tips worth adopting include:

2 People to connect with include:

NAME _____ CONTACT _____

NAME _____ CONTACT _____

1 Thing I am very grateful for today:

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Caregiver Journal Page

This space has been provided for you to capture your thoughts and wishes about caregiving. Many caregivers find keeping a journal very therapeutic as it is an opportunity to process the experience of caregiving, allows a release of tension and can lead to a deeper self-appreciation. Journaling can help you focus, reflect and organize your thinking and emotions. Use the next few pages to record some of your thoughts, plans, and insights about your journey. You may want to read over your entries from time to time to uncover patterns, wisdom, strengths and valuable life lessons.



Caregiver Journal Page



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Caregiver Journal Page

#YOUR LOVE Matters

Caregiver Journal Page



Caregiver Journal Page





Program brought to you through a partnership of
AARP Foundation and AARP Multicultural Leadership.
Written by Angela Heath and Linda Barbarotta.
Illustrations by Alicia Wallace.