

Because We Care

A Guide for People Who Care



Administration on Aging

U.S. Department of Health and Human
Services

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Introduction

If the last century is any indication, we are headed for exciting times in the decades ahead. There will be new technologies to make our every day lives easier. We can expect breakthroughs in medical research that will astonish us and give millions more hope for healthy, longer lives. And, if there are as many advances in international and community relations, hopefully we will also see a more inclusive embrace of humankind.

All of these developments will be good news for the nation's millions of family caregivers. Assistive devices are already saving many caregivers from placing their own health and well-being at risk, but there are many day-to-day activities that remain difficult to complete without some kind of assistance. There also are diseases like Alzheimer's, Parkinson's, cardiovascular disease, and diabetes for which cures or preventive measures are desperately needed. Here is where the kindness and love of family, friends, and neighbors have made the difference for so many older persons and their caregivers.

We, at the Administration on Aging, have met and talked with hundreds of family caregivers from across these United States. Their experiences have left an indelible impression in our hearts and minds. What they have shared with us, about the extraordinary gifts of love they are giving older relatives and friends in need of care, inspired us to offer *Because We Care: A Guide for People Who Care*¹.

So many family caregivers have said that they wish they had known more about how to provide care, about the resources that exist, about how to get help for their loved ones and themselves, about what they can do to be sure that their own quality of life is optimal. So many family caregivers have said that future caregivers need to have the opportunity to understand caregiving and its dimensions ahead of time, in order to be prepared for the challenges that may arise. So many persons receiving care have said that they are concerned about the health and well-being of their caregivers.

To each and every one of you who is or may be a member of the community of caregivers, we dedicate this guide. We respect and acknowledge your love and your dedication. The guide is yours to use. We hope that it will be of help . . . because we care.

¹ <http://www.aoa.gov/wecare/contents.html>

Preface

Because We Care: A Guide for People Who Care² is being offered by the U.S. Administration on Aging (AoA) as a resource guide to the growing number of Americans who are caring for an older family member, adult child with disabilities, or older friend. This *Guide* provides information and a range of suggestions to make caregiving easier and more successful--whether you are the caregiver or the person who ensures that your family member or friend receives the best possible care from others.

Because We Care recognizes the wealth of information which can be accessed by caregivers via the World Wide Web. It organizes the information to address particular aspects of caregiving. To access web-based information, just click on the text words or phrases that are highlighted. Where information is not yet available at other web sites, we fill the gap and provide you with information.

We have listed web sites that offer a range of information that caregivers can use. However, references from this AoA web site or from any information services sponsored by the AoA to any non-governmental entity, product, service or information does not constitute an endorsement or recommendation by the Administration on Aging or any of its employees.

The AoA is not responsible for the contents of any of the "off-site" web pages referenced. While the *Because We Care* Guide includes links to sites that may reference other information, the Administration on Aging does not endorse ANY specific products or services mentioned. Full responsibility for any use of these links rests with the user.

Because We Care will continue to expand and evolve. Thus we invite you to revisit this site from time to time. We'd also like to hear from you. Feel free to tell us what you find useful and what additions you'd like to see in future editions of *Because We Care*.

How to Contact the Administration on Aging (Telephone, Fax, Mail, E-Mail):

- E-Mail AoA at: aoainfo@aoa.gov
- Mailing address: Administration on Aging, 330 Independence Avenue, SW, Washington, DC 20201
- To find services for an older person in his or her locality, call the National Eldercare Locator at (800) 677-1116 9:00 A.M. to 8:00 P.M. Monday-Friday, EST

² <http://www.aoa.gov/wecare/contents.html>

- For technical information and public inquiries, telephone the Administration on Aging's National Aging Information Center³ at (202) 619-7501. FAX: (202) 401-7620 (email: naic@aoa.gov)
- For media inquiries, telephone: (202) 401-4541
- To alert AoA to any issues with hyperlinks (broken links etc.) e-mail: webmanager@aoa.gov

³ <http://www.aoa.gov/NAIC/default.htm>

Forward

Because We Care: A Guide for People Who Care⁴ is being offered because fully one-fourth of American families are caring for an older family member, an adult child with disabilities, or a friend. This guide offers you a range of suggestions to make caregiving easier and more successful, whether you are a caregiver or the person who ensures that your loved one receives the best possible care from others.

Caregiving takes time, effort, and work. It can challenge you intellectually and emotionally, teach you flexibility and strengthen your problem solving abilities. Over time some care receivers recover and/or improve. If so, this can be very satisfying, but even when those being cared for are not able to improve, your efforts are enhancing the life of someone you care so much about, someone you love.

We asked members of our Administration on Aging staff to share some of their own caregiving experiences with you. These experiences are testaments—testaments of love, devotion, and, yes, grief. Being a caregiver, as their stories indicate, is far more than a role. It is more often an act of love. These testaments are shared below.

Their Story

In March of 1997 my sister and I drove to Ohio to help our mom and dad in the aftermath of my mom's knee replacement surgery. Our parents lived 360 miles from us, in the same house where we grew up. Little by little we saw that things were not going as smoothly as we'd thought, and our mom and dad would fill in for the other when weaknesses arose. Somewhere along the line our dad had stepped away from taking charge, making hard decisions, and following up with the doctors. Now this role was to be taken up by his children.

Four months later we faced another acute care situation. This one involved my mother's open heart surgery--one that took us through extremes--from hope to despair, from weakness to strength, from anger to faith, but always, always, involving love. We literally dropped everything else in our lives and went home to Ohio for eight weeks.

⁴ <http://www.aoa.gov/wecare/contents.html>

I was surprised to find that I was a much stronger person than I had thought I was. I was decisive, assertive, tenacious, and resourceful-- all qualities in which I quite often feel lacking. I had always felt myself to be compassionate, but I was amazed at how little I felt I was really giving to my mom. Rather I was grateful to have had the chance to continue receiving the love she had shown me every day of my life.

As my mom overcame one crisis after another and there seemed to be hope for a recovery, I had all the worries of her well-being added to by thoughts of "How will we maintain their dignity while doing what we think is best?" Though these haunting, fleeting thoughts added to the stress we already were under, I know my sister and I would have given anything to have had to confront these challenges, had it meant that our mom would have been with us longer.

Now that our mom is gone, my sister and I (and our husbands and children) find ourselves involved in the long-distance caregiving of our dad--one mainly of emotional support. I know that one day the physical aspects of caregiving will present themselves in his case. I only hope that that day is a long way off, because when I lose him, I will lose my mom all over again. Having our dad to worry about has given us something to be responsible for, and by comforting him we suppress our own emotions. When he is gone, all those emotions will flow forward, I'm afraid.

Her Story

I was my father's caregiver from 1988 to 1998 when he died. He lived in our family summer home, a 200-mile round trip from my home.

My caregiving began with an IRS problem. He called me when he received IRS and State documents dunning him for taxes he had not filed since 1971. I reconstructed his documents from drawers and cubby holes, re-filed, and was able to negate the penalties and get him over \$3000 back in senior citizen property tax rebates. From that point on he handed over most of his financial transactions to me. As time went on, he agreed to let me drive him to doctor appointments. Meanwhile, on my monthly visits, I noticed he was not paying his bills on time. I offered to take that over too. In time, I took over his grocery shopping and laundry too. More time went on and I noticed he was not washing or cleaning. I upped my visits to twice a month and then once a week. There were "crashes", and so many crises, followed by periods of stabilization. This went on for 5 years.

The last 5 years of my father's life were exceptionally difficult for me. Little by little, I gave up my life to tend to his needs and still hold on to my job. I fought

with doctors, with other caregivers and with him. My life was almost entirely consumed with trying to hold my job and keeping him afloat.

My two siblings said they cared deeply for our father but lived in other parts of the country. My older sister, a schoolteacher who lives in Florida, helped in the summer and then went back to her own life. My younger brother fled, saying he was unable to deal with his issues with his father. I understand this as my father could be a very difficult man. But why did they abandon me, too?

I have many friends. Oh, they were sympathetic and understanding but it was clear that this was my problem. Now I know that I failed them by not telling them specific things I needed them to do to help me--simple things like mow my lawn, take in my mail, make a few calls. In the end, I realized I gave them nothing to do other than call me.

I get paid for doing a job. Yet, sometimes, I really hoped for more support. It was my dream that one of my co-workers would just volunteer to take over an assignment for me. It did not happen because I DID NOT ASK. Maybe they never really knew how hard and time intensive all of this was. I have always been so very conservative with my leave and it was evaporating in huge chunks. There is one thing I still have anger about. I was so totally engulfed with the sheer mechanics of dealing with the hired home caregivers, the doctors, the paper work, the decisions--I did not have the opportunity to recognize what was going on. I was losing my last parent. My father was leaving this life and I was so concerned that he was always dignified and considered a person that I lost my chance to really understand what this meant to me. Two years later, I still grapple with this.

Getting the information I need was so very frustrating. Here I was in the business of older persons and I struggled to find basic information about alternatives, not financial aid, but alternatives. I can remember calling the Michigan AAA in tears and asking the Director what to do. I told him I couldn't think right anymore. "THIS WAS MY FATHER, please help me." I was so ashamed to fall apart. He gently said, "The same thing happened to me with my mother," and he told me what to do. We want to know the options, but when you are so emotionally involved, sometimes you just want someone to tell you what to do. Making these decisions for your incapacitated parent are FAR WORSE than having to make them for yourself--FAR WORSE. All historical issues dissolve--all you want is for them not to hurt him more, help him, keep him dignified and keep him safe.

The end comes when you don't expect it and then, that's it. The family gathers. It is more than likely that you are the ONE, the caregiver, to make all arrangements for this last goodbye. They stay at your house, eat all your food and fuss over what

is going on. You are WIPED OUT but no one seems to give this a thought, thinking you can still carry the ball. And you do. After you put them on their planes, there you are. You pay the bills. Their lives are hardly unchanged while yours has changed dramatically, which leaves you reeling. You would not have done anything otherwise. Or would you?

It has been just about two years and I feel I am just now coming up for air. Ten years is a long time. I lost all of my 40s to caregiving. I regret none of it. I regret none of the caregiving and the miles on the road and the loss of what we call a personal life. That was my life. It yielded riches my siblings will never know. I walked our Dad out of his life with the most dignity I could muster at the time. But sometimes, I wish I had been kinder, less critical and demanding of everyone involved. Who knew it would end in what seemed to be (even after all those years) so abruptly? I never would let myself think that way. I look at a picture of us taken a month before he died and see how withered he was. I wonder, what was I thinking of? But more than anything, I wish I would have had more time to spend with him those last months. I had to work. I visited him at the Vet's home (60 miles from my house, a TRULY WONDERFUL PLACE) in bits and snatches.

In the end I feel remarkably privileged to have been given the gift of caregiving. I did not welcome it. I resisted it. I often treated it poorly, but I learned far more about life than I ever could have imagined. If I could go back, what would I do differently?

Accepted the responsibility as a special gift and a privilege rather than a trial.
Given friends and family members definite, specific tasks to help me.
Taken more time off from work, including leave without pay.
Who knew it would end so soon? I honestly thought we had at least a couple of years, he was doing so very well at the Vet's home. Now, I am crying too. That's good, I never had the time to cry when I was going through it.

Just Tell Me What You Want Me to Do

As a caregiver, one of the most important lessons that I learned was to be specific about the kind of assistance we needed from family and friends. "Just tell me what you want me to do," was a constant refrain. It was always hard to identify something in response to that question. As a result, I passed up many chances to get help with simple tasks that others could have very easily performed. Often, my lack of specificity led people to come up with their own way of making a contribution--like washing clean dishes, dusting and vacuuming places that did not need it, and watering plants that were already struggling to overcome excessive

care and feeding. But when it came to personal care--like bedpans and diapers--even those who asked to help were no where to be found.

All families have a history, a culture, a way of relating to each other which is uniquely "their way." In our family, there was no question about who was in charge. Mom maneuvered, manipulated and marshaled everyone within her span of control. That was one of the reasons the loss of control over her life was so difficult for her. As caregivers, we had to learn that doing everything for her was not always the "best" for her. Allowing her to recognize her own limitations and choose her own solutions was often a much more rewarding experience for all. My father was the primary caregiver for his wife. Mom's illness had really been hard on him. More stressful then we knew. It was 10:30 one hot July evening when I received a call from my mother. "They have just taken your father by ambulance to the emergency room. He blacked out. He may have had a heart attack."

When we arrived at the hospital, we found that he was not in pain but being admitted to the hospital for observation and tests. We never got a clear understanding of what caused the blackout, but Dad was deemed medically OK to return home after a week. What he really needed was a break. And since he would not take it on his own, his body found another way to get some rest.

The Sandwich Generation

Mom is 74, married and lives in New Jersey. She was forced to retire at 62, got seriously depressed, and then took wonderful care of my Grandmother, who became frail at 98 and died at nearly 100. Soon after, my Mom developed emphysema caused by 50 years of cigarette smoking. Mom returned home with oxygen, a visiting nurse and an attendant.

All of this help was not enough to take care of everything, so I dropped my life and went to New Jersey. I left my job, my husband and three school-aged kids. I worked very hard for 3 weeks to take care of all the arrangements, medical and otherwise, to ease my Mom into self-sufficiency, to prepare the house and refrigerator for the long winter. The psychological issues and the loss due to illness by my Mom and step Dad were very difficult. I, who hate to cook, prepared 3 months worth of frozen meals with some fancy recipes. I shopped till I dropped. On the last day, we invited one couple over and celebrated my Mom's 73rd birthday. She was getting better. I forgot to tell you that I am the only daughter, a 50 year old, very sandwiched.

P.S. There is no happy ending. My Mom is stabilized and although she still smokes, and is still somewhat depressed, she was doing quite fine managing

everything. Unfortunately, my Step Dad got a rare disease that has disabled him. He was 6 months short of 65 and retirement. He is down to 128 pounds at 6 feet tall, depressed, and can't walk, and who do you think is doing everything? My mom is taking care of his dressings, his medication, the paperwork, medical arrangements, specialists, the home and is permanently exhausted. They were supposed to move to Oregon in May 2000 and start their beautiful retirement and here is this situation with prognosis unknown.

In this case, no government program can help. Everything that is in place is fine. I worry night and day. I am still the only backup in case my Mom gets sick again. Believe me, I keep it in the back of my mind as I stare at my annual leave and sick leave.

Mom and Me

I am an only child and an only grandchild who was always showered with love and attention. I don't want to lose that. My mother is the last of my close family. When she goes, I will have lost my family.

My heavy-duty caregiving began abruptly. My mother was in the hospital. I remember that night. She was going home in two days. She looked so good—so young. The following day I went to see her. She was sitting by the window, dressed in a hospital gown. Food was strewn across the floor. I looked at her—this suddenly old, confused woman. I studied her eyes and I knew. I turned to the nurse and said, “This woman has had a stroke. Call a doctor.” My mother's physician was called. They began a course of physical therapy immediately. Day three of the stroke, I offered to take my mother to the bathroom. She could no longer walk. No longer stand. The nightmare had begun in earnest. My mother drifted in and out of consciousness. My stomach tied in knots, my blood pressure soared, my pulse hit 123 and stayed there. I continued to come to work. I don't think that anyone understood. I was facing the loss of my mother—the last of my family. She stabilized. Friends came to visit her in the hospital. They kept me from coming completely unglued. Some cousins came too, but only after I stressed the fact that my mother might die.

My mother improved. She was no longer confused. She could talk. How very thankful I am for that. She was moved to a nursing home for more physical therapy. She made some more improvement. She hated the place, and begged to come home. I began to make plans. I learned how to do transfers. They cautioned me--“Are you sure you know what you are taking on. Your mother is a total care patient.” I assured them that I did. I brought her home where she longed to be.

For the next six months, I slept beside her. Physical therapists came in, home-health aides came in, a friend turned part-time caregiver took over when no one else was there. At night when I got to her house, I made her do exercises. She hit me, pulled my hair, cried out in pain as I straightened fingers that were curled into a clinched fist from contractures. During that time I got about four hours sleep a night. Even if she didn't wake me, I'd wake in the middle of night and sit at the kitchen table—smoking one cigarette after another.

There was no bedroom or shower on the first floor, so we bathed in the powder room using containers of water and she slept in the living room. Finally, the physical therapists said, "We have done all that we can do. She is no longer making any improvement." The Medicare payments stopped.

Now, we were fully on our own. The area agency on aging told me that my mother's income was too high to allow for any help. I hired a full-time live-in aide, using the money that my father had worked so hard to accumulate. She lasted five months. She was the first of many who came and went—some good, some not.

During the first years following the stroke, I suffered a series of illnesses that were, I am sure, brought on, in part, by the emotional stress. I must admit that I would have given anything to have someone reach out to us—to offer to help in any way at all, but this did not happen. I asked friends if they would visit my mother but they never came unless expressly invited for some event. Some of them, I am happy to report, returned the favor and invited us for dinner and even to the beach.

I did this for 8 years. Every night after work I drove to Mom's house, ate dinner with her, talked to the caregiver, took care of the pets, and do little and big things around the house that I was afraid to ask the caregivers to do.

We had parties on every holiday because neither she nor I wanted to sit there with no one to share them with. I tried very hard to make things seem normal when, in fact, they were not. I didn't want others to know that my mother was incontinent. I didn't want them to know that it took an hour and a half of work to get her bathed, dressed, and into the wheel chair in the morning—that she no longer understood how the various parts of her body were supposed to work. Four years ago, at her urging, I bought a larger house with the last of the investment money so that she could have a room of her own. I turned the dining room into a bedroom, put in a wheel chair accessible bathroom, and turned the upstairs bedrooms into three small rental units that produced enough income to cover the mortgage.

Were it not for the caregivers we hired, I don't know what I would have done. They made it possible for me to keep on working and to have some life of my own - to go to my home and husband albeit late at night. I worked very hard to keep my mother from going under financially. This illness cost over \$250,000 out of pocket. I converted her mutual fund investments into rental investments that provided a fairly reliable income and kept pace with inflation. I served as property manager, rental agent, cleaning lady and Ms. Fix-it for the properties. There were times when I felt overwhelmed, yet I wouldn't have had it any other way, because I know that my efforts allowed my mother to remain at home where she wanted to be. My mother has always been there for me with her gentle selfless love. Now this was my time to be there for her, and I am so glad that I was.

Because we are "walking the walk" and because we care, we offer this guide for all caregivers.

I. Where Can We Turn for Help?

Introduction

Caregiving may be one of the most important roles you will undertake in your lifetime. Typically it is not an easy role, nor is it one for which most of us are prepared. Like most people, you may have questions about your care receiver's chronic illness or disability. If you have a job and are juggling several responsibilities or if your family member or friend needs a lot of assistance, you may need help with caregiving, too. Whether you are expecting to become a caregiver⁵ or have been thrust into the role overnight, it is useful to know where you can get information and help.

Individuals Who Can Help You Find Assistance

There are information services with staff who can help you figure out whether and what kinds of assistance you and your care receiver may need.

You can call:

- The National Eldercare Locator⁶, a toll-free service funded by the Administration on Aging⁷ (AoA), at 800-677-1116 for information about assistance that is available in communities across the nation.
- Your State Agency on Aging⁸ (SUA) for information and assistance. Look in your phone book under “aging” or “senior services.”
- Your local Area Agency on Aging (AAA) for information and assistance right in your community. Look in your phone book under “aging” or “senior services.”

Generally, state and area agency on aging services are funded with federal, state, and other monies. These government-funded services are often targeted to those most in need. While there are no income criteria for many services, sometimes, you may have more service options, if you can pay for private help. You can contact your State or Area Agency on Aging for information and assistance⁹.

⁵ <http://www.adrc.wustl.edu/ALZHEIMER/F>

⁶ <http://www.aoa.gov/elderpage/locator.html>

⁷ <http://www.aoa.gov/May2000/FactSheets/AoA.html>

⁸ <http://www.aoa.gov/aoa/pages/state.html>

⁹ <http://www.aoa.gov/factsheets/ia.html>

There are several services that can help you plan for the care that will be needed. They can be accessed through the state or area agency:

- Care management services¹⁰: a care manager¹¹ can assess your relative's needs and resources and draw up a plan to help her remain as healthy and independent as possible.
- Social work services: hospitals and nursing homes usually have social workers and discharge planners.
- Attorneys, who specialize in such areas as wills, trusts, and probate, and financial planners can help with the legal and financial aspects¹² of caregiving

Supportive services for the person needing care can include:

- Transportation
- Meals
- Personal care
- Homemaker

(See the section on "What Services Can Help Us?"¹³ for information on supportive services.)

Other types of resources for caregivers are:

- Caregiver support groups
- Caregiver organizations
- Organizations like the Alzheimers Association
- Chat rooms on caregiving on the Internet
- Family members and friends who have been caregivers

And don't forget, if you are an employee covered under the federal Family and Medical Leave Act¹⁴, you are entitled to take up to 12 weeks of unpaid leave during any one year to care for an older relative.

Additional Resources and Reading Lists

¹⁰ <http://www.aoa.gov/naic/Notes/carecasemanagement.html>

¹¹ <http://www.caremanager.org/gcm/FindManager.htm>

¹² <http://www.aoa.gov/retirement/fpfr.html>

¹³ <http://www.aoa.gov/wecare/what-services.html>

¹⁴ <http://www.elaws.dol.gov/fmla/wren/menufmla.asp>

Federal Government Web Sites

Three web sites provide information on a range of topics related to health and aging as well as links to other health-related sites:

- Healthfinder¹⁵
- Health Information Clearinghouses¹⁶
- Health-Center.Com: Senior Center¹⁷

National Organization Web Sites

The AARP's Helping Older People: Assessing the Situation¹⁸ provides an overview of what you need to ask if you want to do an assessment yourself.

The Family Caregiver Alliance¹⁹ web site offers fact sheets on a variety of topics of interest to caregivers.

Visit the National Alliance for Caregiving²⁰ web site that includes links to a variety of topics related to caregiving.

The National Family Caregivers Association²¹ (NFCA) is a national, charitable membership organization dedicated to making life better for all of America's family caregivers. It offers a variety of information and support to family caregivers.

Children of Aging Parents²², a nonprofit membership organization, can provide information and referral services for a variety of professionals, information about support groups, and educational outreach services.

The Alzheimer's Association²³ and the Alzheimer's Disease Education and Referral Center²⁴ offer extensive information to caregivers of persons with Alzheimer's disease.

Commercial Web Sites

Get Care²⁵ has a listing of various types of services that can be clicked on for a short definition of each and a "click on" printable listing within the article.

¹⁵ <http://www.healthfinder.gov/>

¹⁶ <http://www.health.gov/nhic/>

¹⁷ <http://www2.seniorcareweb.com/default.htm>

¹⁸ <http://www.aarp.org/contacts/caregive/assess.html>

¹⁹ <http://www.caregiver.org/>

²⁰ <http://www.caregiving.org/content/Links.asp>

²¹ <http://www.nfcacares.org/>

²² <http://www.caps4caregivers.org/>

²³ <http://www.alz.org/>

²⁴ <http://www.alzheimers.org/index.html>

²⁵ <http://www.getcare.com/>

Elderhope 911²⁶ offers suggestions on ways to deal with caregiver stress and provides links to numerous organizations and groups designed to help caregivers.

²⁶ <http://www.elderhope.com/911.shtml>

II. What Services Can Help Us?

Introduction

If you are a caregiver and need help, chances are that assistance is available in your community. There are many different government and privately funded services that may be available. Most of the programs and services mentioned in this guide are federally funded through the Older Americans Act. You can get information about these services and programs in communities throughout the nation by calling the Eldercare Locator at 1-800-677-1116. Staff is available from 9:00 A.M. to 8:00 P.M. EST, Monday-Friday.

While some services are free, others are fee-based. In-home and community-based services that you might find helpful include:

- Personal and in-home services
- Home health care
- Transportation
- Meals programs
- Cleaning and yard work services
- Home modification
- Senior centers
- Respite services including adult day care

Personal and In-Home Care Services

Personal and in-home care assistants help with bathing, dressing, preparing meals, house cleaning, laundry, toileting, and other personal “activities of daily living.”

Home Health Care

Home health care includes such care activities as changing wound dressings, checking vital signs, cleaning catheters and providing tube feedings. Home health care staff also may provide some personal care services and light housekeeping.

If the older person for whom you are caring is recuperating from an accident, operation, or illness, he or she may be able to receive home health care assistance through a *Medicare* certified home care agency. If older persons cannot care for themselves because of physical functioning, health problems, or because they no longer are able to mentally process things, they may be eligible for skilled nursing

care or physical, speech, or occupational therapy. In these cases, home health care also may be available. Ask your older relative's doctor if your family member is eligible for these services.

To find out more about home health care, check "Home Health²⁷," a publication by the Centers for Medicare and Medicaid Services (CMS)—formerly the Health Care Financing Administration (HCFA)—the federal agency that administers the Medicare²⁸ program, or talk to the doctor who is caring for your family member. Medicare usually pays for home health care services for two or three hours a day, several days a week, and for the medical care provided by a doctor, nurse, or other health professional. Such care tends to be for a limited time.

If the person for whom you are caring has a limited income and assets, he or she may be able to receive home health care²⁹, personal care³⁰, or hospice services³¹ as well as occupational, physical, or speech therapy³² through Medicaid³³ (a federal-state program, administered by CMS at the federal level). Some older persons with limited assets and income are eligible for help through both the Medicare and the Medicaid programs. If this is the case, your care receiver may be able to obtain personal and/or home health care services on a long-term basis instead of being cared for in an extended care facility. Otherwise, in-home and community-based services may be available through an Area Agency on Aging.

Middle and higher-income persons often pay out-of-pocket for *personal and home health care services*. If you hire staff through a home care agency, ask the agency how they screen their staff and if staff is bonded. Agencies charge you for the costs of doing business; i.e., for management, administration, and recruiting workers. This can be quite expensive, but there are ways to make help more affordable. For example, you can explore the possibility of directly hiring a personal or home health care assistant. If you choose to hire help, be sure to check³⁴ their qualifications and references carefully. Remember, you will then be an employer, and you may need to cover Social Security and other benefits. (See the Section on How Do I Hire a Home Care Employee?³⁵)

Respite Care

²⁷ <http://www.medicare.gov/publications/pubs/pdf/hh.pdf>

²⁸ <http://www.hcfa.gov/medicare/mcarens.htm>

²⁹ <http://www.hcfa.gov/medicaid/ltc9.htm>

³⁰ <http://www.hcfa.gov/medicaid/ltc4.htm>

³¹ <http://www.hcfa.gov/medicaid/ltc2.htm>

³² <http://www.hcfa.gov/medicaid/ltc5.htm>

³³ <http://www.hcfa.gov/medicaid/mover.htm>

³⁴ http://www.caregiver.org/factsheets/care/hiring_help.html

³⁵ <http://www.aoa.gov/wecare/hire.html>

Respite care can be a voluntary or paid service. It can be provided in your relative's home, in an extended care facility, such as a nursing home, or at a senior center or adult day care center. Respite care can extend for a few hours or for several weeks. It provides the caregiver with opportunities to take care of personal affairs, to get some rest, or to take a vacation.

Transportation

Transportation³⁶ services are vitally important to older persons with limited mobility. Transportation enables them to go to their doctors, to the pharmacy, and to attend to day-to-day activities.

Many public mass transit systems³⁷ are fitting buses and other vehicles with hydraulic lifts and other aids to assist older persons and others that have physical disabilities. Sometimes several transit systems operate independently of each other. Transportation options may be available through private companies and private non-profit organizations. These include public fixed-route, demand-response, ride sharing, volunteer drivers, limousines, buses, vans, and regular and special purpose taxis. Some services provide an escort to assist older people.

To arrange transportation for an older person in your community³⁸, contact your local Area Agency on Aging (it is listed under "aging," "elderly," or "senior services" in the government section of your telephone directory). Area Agencies on Aging provide older persons and their caregivers with specific information and assistance in getting transportation and other supportive services in the community.

If you want information about safe driving and older drivers you may want to contact the National Highway Traffic Safety Administration³⁹.

Meals

Good nutrition⁴⁰ can help to improve health and control a range of conditions and diseases. The National Elderly Nutrition Program⁴¹, funded by the Administration on Aging, provides meals to older persons in need and their spouses. Older persons who participate in the group meal program have an opportunity to socialize, receive nutrition education, and take part in other activities, including health screenings.

³⁶ <http://www.aoa.gov/factsheets/Transportation.html>

³⁷ <http://www.dot.gov/accessibility/textonly/index.htm>

³⁸ <http://www.aoa.gov/aoa/eldractn/transp.html>

³⁹ <http://www.nhtsa.dot.gov/>

⁴⁰ <http://www.aoa.gov/May2000/FactSheets/Nutrition.html>

⁴¹ <http://www.aoa.gov/factsheets/enp.html>

Elderly persons who are ill or frail may be able to receive a government-subsidized home-delivered meal. To find out about home-delivered meals programs and other meals programs, please contact the National Eldercare Locator or your State or Area Agency on Aging.

If these meals are not available, see if your grocery store prepares food orders for pick-up or if it provides home-delivery service. A growing number of grocery and meal services are available via the Internet including some that offer organic, ethnic and kosher foods. Many local restaurants deliver meals without additional charge and some even offer senior discounts on meals. A growing number of restaurants offer special low-fat and low-salt meals.

There also are local and national franchised meals delivery services. These are listed in the yellow pages of the telephone directory under “foods--take out”; some can be found on the Internet.

Cleaning and Yard Work Services

An Area Agency on Aging may be able arrange for chore and yard maintenance services or put you in touch with religious, scout or other volunteer groups that provide one-time or occasional services to older persons who need help. Of course, you can hire a cleaning service or yard maintenance firm, but this may be more expensive than hiring someone that works as an independent contractor.

Home Modification, Improvement, and Weatherization Programs

Home modification and repair programs⁴² can make homes safer and more energy efficient. They can result in greater independence for an older person with disabilities. The Home Modification Action Project at the University of Southern California’s Andrus Gerontology Center has online consumer⁴³ oriented information and publications on accommodations and modifications⁴⁴ and how to pay for these. There is information on how to make dwelling units safe for persons with Alzheimer’s Disease⁴⁵. There also is information for builders, a library⁴⁶ of useful publications on housing adaptation, and links⁴⁷ to other useful web sites⁴⁸.

⁴² <http://www.aoa.gov/aoa/elldractn/homemodf.html>

⁴³ <http://www.homemods.org/front.htm>

⁴⁴ <http://www.usc.edu/dept/gero/nrcshhm/>

⁴⁵ <http://www.homemods.org/library/hthelp/access.html>

⁴⁶ <http://www.usc.edu/dept/gero/nrcshhm/library/>

⁴⁷ <http://www.usc.edu/dept/gero/nrcshhm/resources/>

⁴⁸ <http://www.homemods.org/>

Senior Centers

Seniors Centers⁴⁹ offer older people a safe environment where they can take part in a range of activities led by trained personnel that promote healthy lifestyles and where they can develop a network of friends.

Meal and nutrition programs, information and assistance, health and wellness programs, recreational and arts programs, transportation services, volunteer opportunities, educational opportunities, employee assistance, intergenerational programs, social and community action opportunities and other special services are often available through a senior center.

Adult Day Care Services

For older persons with serious limitations in their mobility, those who are frail, and those who have medical and cognitive problems, adult day care centers⁵⁰ can provide care in a safe, structured environment. Adult day care can provide relief to working caregivers and respite for full-time caregivers. Adult day care services⁵¹ include personal and nursing care, congregate meals, therapeutic exercises, and social and recreational activities.

Most adult day care centers, like senior centers, are supported through public and non-profit organizations. Fees may range from a few dollars a day to close to \$200, depending on the services needed. The National Council on the Aging maintains a directory⁵² of adult day care centers and links⁵³ to other related sites.

Additional Resources and Reading Lists

The Administration on Aging-operated National Aging Information Center Internet Notes home design⁵⁴ web page is full of web sites that provide useful information on home modifications, home design, and home safety for the elderly.

To find out about eligibility requirements for benefits under both the Medicare and Medicaid programs, go to the Health Care Financing Administration's dual eligible⁵⁵ web site.

⁴⁹ <http://www.aoa.gov/factsheets/seniorcenters.html>

⁵⁰ http://www.ncoa.org/nadsa/guide_2_ADS.htm

⁵¹ http://www.ncoa.org/nadsa/ADS_factsheet.htm

⁵² <http://www.nadsa.org/>

⁵³ http://www.ncoa.org/nadsa/nadsa_links.htm

⁵⁴ <http://www.aoa.gov/naic/Notes/designliving.html>

⁵⁵ <http://www.hcfa.gov/medicaid/dualelig/default.htm>

III. How Can I Care for Both of Us?

Introduction

Sometimes we are so deeply concerned about the well-being of the person for whom we are caring, that we forget our own needs⁵⁶. We “burn the candle at both ends” and become exhausted, emotionally stressed⁵⁷ or ill, compromising our own quality of life and our ability to care for our family member.

Some Caregiver Do’s and Don’ts

We owe it to ourselves and to our families to also maintain our own physical and emotional health by:

Getting sufficient sleep⁵⁸

1. Eating a healthy diet⁵⁹.
2. Exercising⁶⁰ and staying physically fit⁶¹
3. Choosing appropriate health care⁶² professionals and having periodic health checkups
4. Not abusing alcohol and drugs⁶³
5. Spending social time with family and friends
6. Pursuing our own interests
7. Seeking support⁶⁴ from family, friends, professionals, or your religious advisor or joining peer support groups
8. Using appropriate in-home and community-based services.

Keep in mind that it is normal to feel angry, frustrated, or depressed from time to time. Caregiving can be a difficult as well as a rewarding undertaking. If you are feeling stressed, angry, or depressed:

- Remove yourself from the situation by walking away, even if it’s just around the house

⁵⁶ <http://www.nfcacares.org/tentipsf.html>

⁵⁷ <http://www.mayoclinic.com/hlp/hlpstep.cfm?objectid=D5BAB8F0-C5C7-437B-8CA737AAF6715A51&>

⁵⁸ http://www.fda.gov/fdac/features/1998/498_sleep.html

⁵⁹ <http://www.ars.usda.gov/dgac/2kdiet.pdf>

⁶⁰ <http://www.aoa.gov/aoa/pages/agepages/exercise.html>

⁶¹ <http://www.aoa.gov/aoa/eldractn/fitfact.html>

⁶² <http://www.ama-assn.org/aps/amahg.htm>

⁶³ <http://www.well.com/user/woa/>

⁶⁴ <http://www.caregiving.org/content/Links.asp>

- Talk to someone with whom you feel close
- Call a hot line
- Talk with your doctor or other health professional
- Write down your feelings in a journal

If you find that you frequently are angry or depressed or that your emotions are getting out of control, you may benefit from counseling, and/or get relief in the form of respite, caregiver support groups, and supportive in-home services.

Additional Resources and Reading Lists

Visit the National Family Caregivers Association⁶⁵ web site for information on family caregiving.

⁶⁵ <http://www.nfcacares.org/>

IV. How Can I Improve Our Quality of Life?

Introduction

Older Americans and their caregivers sometimes fall victim to myths that become self-fulfilling prophecies. One is that being old means being sick. The other is that old age and dementia go hand in hand. The truth, however, is far more positive.

Truth # 1. Old age and sickness are not synonymous. The majority of older people are healthy, and, if they are not, many chronic conditions and illnesses⁶⁶ can be controlled or corrected.

Truth # 2. While the incidence of dementia⁶⁷ does increase as people age, the majority of older people score well on tests of mental functioning. Those who do not often have underlying medical problems that account for decreases in mental functioning.

Maximizing Your Care Receiver's Independence and Health

- Keeping or restoring health in the later years often requires more effort and determination than when we are younger. It includes:
- A healthy diet. If your relative or friend has medical problems, you can ask the physician if changes in diet should be made and whether you should consult a registered dietician for additional information.
- Supplements of certain vitamins and minerals, if advised by the physician or dietician. Always remember that more is not always better, that nothing takes the place of a healthy diet, and that some vitamins and herbs can be dangerous, if taken in excess or in the presence of certain medical conditions.
- Exercise. If your older relative or friend is reasonably healthy, he or she can begin a regular program of exercise⁶⁸ including stretching, weight training, and low impact aerobics, after discussing it with his or her physician.

⁶⁶ <http://www.health.gov/nhic/>

⁶⁷ <http://www.neurologychannel.com/dementia/>

⁶⁸ <http://www.aoa.gov/aoa/pages/agepages/exercise.html>

Exercise can help to avoid accidents, improve strength and mobility, lower blood pressure, and help to prevent or control some diseases. If your care receiver is frail or ill, you can ask the physician about what exercises may be appropriate. Your older relative or friend may want to begin such an exercise program under a physical therapist's supervision. The physical therapist can show you how to do range of motion, stretching, and strengthening exercises. Over time, these exercises can help to increase strength and mobility.

- Monitoring, in consultation with your relative's primary care physician and pharmacist, both over the counter drugs⁶⁹ and prescription medications⁷⁰ to ensure that there are no adverse drug reactions⁷¹ or bad reactions between several drugs. Make sure that all medications are appropriate for your care receiver's individual needs⁷² and that the rules for safely taking drugs⁷³ are being followed.
- Staying involved with family and friends.
- Taking part in community activities, such as going to senior center activities.
- Keeping an active mind with activities ranging from reading to card and board games as well as using a computer.
- Learning about assistive⁷⁴ devices that can enhance your older relative or friend's independence and safety.
- Ensuring home safety with such modifications as ramps and low thresholds, better lighting, and nonskid rugs to enhance your care receiver's safety and independence⁷⁵.

Choosing Health Care Providers

It is important for your older relative or friend to have a primary care physician⁷⁶, usually an internist, family medicine practitioner or geriatrician, as well as, specialists if needed. When choosing physicians, check their qualifications. What

⁶⁹ <http://www.aoa.gov/elderpage/walotcdrugs.html>

⁷⁰ http://www.fda.gov/womens/taketimetocare/Meds_Eng.html

⁷¹ <http://www.aoa.gov/aoa/pages/agepages/medicine.html>

⁷² <http://www.ahcpr.gov/consumer/ncpiebro.htm>

⁷³ <http://www.cfinfo.org/educationResources/educationIndex.html>

⁷⁴ <http://www.abledata.com/>

⁷⁵ <http://www.elderweb.com/default.php?PageID=920>

⁷⁶ <http://www.ama-assn.org/aps/amahg.htm>

is their academic background and experience? Are they board certified⁷⁷ in their practice area? You may want to accompany your older relative or friend to the appointment and take notes. This helps to insure that you both understand what medical course of action is recommended and gives you the opportunity to observe the interaction between the doctor and your relative.

The health care provider's attitude toward older persons is important. Is he or she interested in caring for older persons, and willing to take the extra time to conduct a thorough examination, to ask questions, and let you and your relative ask questions?

One note of caution—if your relative is not in managed care, try to choose health care providers that are either preferred or participating providers, if your insurance requires it to make standard payments. Otherwise, you may be responsible for a large percentage of the bill. This is also true for hospitals and all of their subcontractors, such as anesthesiologists.

If your care receiver is limited in his or her physical abilities, ask the physician about the possibility of having physical, speech, or occupational therapy. You also should ask about assistive devices that are available.

Additional Resources and Reading Lists

Federal Web Sites

FirstGov.Gov for Seniors⁷⁸ (Seniors.Gov) has information on a variety of topics including diet, exercise, and consumer protection. It is a federal "portal" site and has links to all federal government web sites with information for seniors.

The Administration on Aging National Aging Information Center (NAIC) Internet Information Note on Exercise and Fitness⁷⁹ lists a host of web sites that feature information about exercises and how to do them as well as organizations in the field.

Go to the NAIC Internet Information Note on Nutrition and Food Safety and view the Consumer Sites⁸⁰ for guides to healthy food choices.

⁷⁷ <http://www.abms.org/login.asp>

⁷⁸ <http://www.seniors.gov/health.html>

⁷⁹ <http://www.aoa.gov/naic/Notes/exerciseandfitness.html>

⁸⁰ <http://www.aoa.gov/naic/Notes/nutrition.html>

The NAIC Internet Notes on Prescription Drug⁸¹ web sites has sections on Geriatric Pharmacy and Drug Use and Name and Generic Prescription Drugs.

Commercial Web Sites

The SeniorCareWeb⁸² Pages can direct you to a range of topics that will help you and your older friend or relative.

Neurology Channel⁸³ has a wealth of information regarding health and medical conditions.

⁸¹ http://www.aoa.gov/prof/notes/notes_prescription_drugs.asp

⁸² <http://www2.seniorcareweb.com/default.htm>

⁸³ <http://www.neurologychannel.com/>

V. What Housing Options Are Available?

Introduction

There are many times when it is not possible for a caregiver and care receiver to live together.

The level of care that your spouse, relative or friend needs may require highly skilled health care personnel on a regular basis. In this case, an extended care facility, such as assisted living or a nursing home, may be a better care alternative.

Your relative or friend may live in another town and does not want to move. There may not be room in your home, or family members, including your relative, may not want to live together.

Whatever the reasons, living in different housing does not mean that you cannot be a good caregiver. You and your relative will, however, need to make arrangements for additional help and/or services as needed--either in his or her present home or in a new housing arrangement.

Points to Consider When Choosing Housing and Living Arrangements

When providing services to older persons who have limitations in their mobility and multiple needs, the type of housing and living arrangements you choose become critical keys in assuring that they get the care they need. Housing and care in this instance go hand in hand. There are many types of housing arrangements available for older persons, and they often overlap in the types of care and services they provide.

Before making a housing choice, you and your older relative should assess present needs and envision, as best as possible, how these needs may change in the future.

- What options will be open to you if the need for more supportive housing and living arrangements arises?
- Will your family member need to move to another care arrangement?
- Are these facilities available in the community, and how much will they cost?
- How are you going to pay for housing and services now and in the future?

- If you enter into housing that requires a substantial deposit at the time of admission, will some of the money be returned if your relative decides to leave?
- What guarantees do you have that the facility is financially secure?

You and your older relative will want to ask these questions before making a decision about moving into a new housing arrangement. If this arrangement involves a large entrance fee or deposit or the signing of a contract, you also will want to consult a lawyer before making the commitment.

Guidelines for Choosing Housing Options

Regardless of what the facility is called, check it out thoroughly before making a decision. The types of facilities listed below range from informal home-share arrangements to commercial enterprises, government-sponsored facilities, and housing options administered by nonprofit organizations. Some are licensed or accredited, others are not.

- Accreditation is an evaluation of a facility's operation against a set of standards. The Continuing Care Accreditation Commission⁸⁴--a membership organization of continuing care communities--is one such organization.
- Licensing⁸⁵ is an evaluation of a facility's operation in accordance with government regulations. About half of the states currently regulate assisted living facilities.
- Many skilled and intermediate care nursing facilities⁸⁶ are accredited to accept patients under the Medicare and/or Medicaid⁸⁷ programs, which means that they must meet certain standards and provide certain services.

Regardless of these considerations, you are responsible, in large part, for ensuring that the facility is the right one for your spouse, relative or friend.

Even if you are not thinking about housing options in the foreseeable future, it is wise to have several in mind in case an emergency arises and you need temporarily care for your relative. Home care agencies often do not have staff available to fill in on short notice, and you may need the services of a long-term care facility.

⁸⁴ <http://www.ccaonline.org/aflist.htm>

⁸⁵ <http://www.ncal.org/about/statsum.htm>

⁸⁶ <http://www.aarp.org/confacts/health/choosingnh.html>

⁸⁷ <http://www.hcfa.gov/medicaid/scindex.htm>

You can:

- Start your preliminary search by phone.
- Visit those facilities that have the services your care receiver wants and needs.
- Take your older relative to see the facility. Better yet, visit several and let your relative make the final choice, if at all possible.

If your relative is able to make sound decisions, and does not like any of the housing options or does not want to move into a facility after visiting several, keep looking or further explore the possibility of home care in her home or yours. Use a check list⁸⁸ (this check list can be used as a general guide for all types of housing) to ensure that the housing arrangement is the right one for your relative.

Types of Housing and Living Arrangements

Listed below are types of housing⁸⁹ and living arrangements, what they generally offer, and for whom they are intended. Added to these considerations are those of costs. While some housing options are modestly priced, others, especially those that are for-profit, tend to be expensive. You can go to the section entitled “How Can We Afford Long Term Care?” for information about government assistance programs for housing and care.

- **Retirement communities** are planned towns with a range of housing, services, and care options.
- **Continuing care**⁹⁰ communities offer varying levels of care in the same building or on the same campus. When Selecting a Continuing Care Retirement Community⁹¹ or retirement community, remember they may encompass everything from housing for independent living to assisted living and skilled nursing home care. Therefore it may be difficult to identify what is offered simply because a facility has a certain name. These communities are usually designed for older persons with substantial financial resources.
- **ECHO Housing**⁹² is a self-contained housing unit temporarily placed on a relative’s lot that is suitable for older persons who are largely self-sufficient.

⁸⁸ http://www.pueblo.gsa.gov/cic_text/health/nursehme/nurs-home.htm

⁸⁹ <http://www.seniorresource.com/house.htm>

⁹⁰ <http://www.aarp.org/confacts/housing/ccrc.html>

⁹¹ <http://www.aahsa.org/public/ccrc.htm>

⁹² <http://www.aoa.gov/housing/accunits.html>

- **Accessory Apartments**⁹³ are self-contained apartments⁹⁴ in the care receiver's home, your home or the home of another caregiver. Designed for older persons who may be largely self-sufficient or need help with housekeeping, cooking, and personal care—commonly referred to as activities of daily living (ADL's).
- **Shared Housing**⁹⁵ can be in the home of the older person or in some else's home. Common areas, such as kitchens and dining rooms, are shared. This type of housing offers the older homeowner added income or the older renter an inexpensive place to live. It may offer companionship, and the possibility of having someone else around, at least part of the time, to help out with chores or in case of emergencies, but this depends on the persons sharing the house. This type of arrangement can work well for those elderly who are independent, but who would welcome a little extra income and/or help. It is important, however, to check the person's references carefully before making a decision.
- **Congregate Senior Housing**⁹⁶ usually offers small apartments. Some offer group meals and social activities. They are designed for persons who are largely independent and do not need personal care or help with activities of daily living.
- **Adult Foster Care**⁹⁷ is usually provided in private homes--often by the owner of the residence. The home usually provides meals, housekeeping and sometimes personal care and assistance with ADL's.
- **Senior Group Homes** are located in residential neighborhoods and offer meals, housekeeping, and usually some personal care and assistance with Activities of Daily Living (ADL's). Usually a caregiver is on site, with medical personnel making periodic visits.

Both adult foster care and group homes may be referred to as Board and Care Homes or Residential Care Facilities⁹⁸.

⁹³ <http://www.aarp.org/contacts/housing/accessapt.html>

⁹⁴ <http://www.aoa.gov/Housing/Accessory.html>

⁹⁵ <http://www.aoa.gov/housing/SharedHousing.html>

⁹⁶ <http://www.lovingcare.net/housing-shared-congregate.htm>

⁹⁷ <http://www.lovingcare.net/long-term-care-adult-foster-care.htm>

⁹⁸ http://www.caregiver.org/factsheets/assisted_living.html

Assisted Living⁹⁹ may provide everything, including skilled nursing care. Others provide only personal care, assistance with ADLs and/or social activities. These may also be called Retirement Homes or Residential Care facilities to name a few.

Nursing Homes provide an array of services¹⁰⁰ including 24-hour skilled medical care for total care patients; custodial care; therapy for patients convalescing from hospitalizations; and personal care and help with activities of daily living for persons with dementia, chronic health, and/or mobility problems.

Additional Resources and Reading Lists

Federal Web Sites

The Administration on Aging's National Aging Information Center lists web sites including sites related to housing sites and directories¹⁰¹, assisted living¹⁰², and nursing homes¹⁰³. The nursing home page includes information on how to choose a nursing home, patients' rights, and payment benefit programs.

- Visit this site for information on the U.S. Department of Housing and Urban Development (HUD)¹⁰⁴ housing programs for seniors.

National Organization Web Sites

The National Resource and Policy Center on Housing and Long-Term Care web site offers information on home modification¹⁰⁵, and government-supported housing programs for older persons as well as links to other useful sites.

This web site, produced by the Family Caregiver Alliance, includes a reading list and articles in the Fact Sheet section that discuss Out of Home Care Options¹⁰⁶ and Assisted Living¹⁰⁷, as well as many other topics of interest to caregivers.

For additional information on various types of housing options¹⁰⁸ go to the Senior Resource Senior Resource¹⁰⁹ web site.

⁹⁹ <http://www.alfa.org/public/articles/index.cfm?cat=6>

¹⁰⁰ <http://www.aahsa.org/public/sh.htm>

¹⁰¹ <http://www.aoa.gov/NAIC/Notes/seniorhousing.html>

¹⁰² <http://www.aoa.gov/NAIC/Notes/assistedliving.html>

¹⁰³ <http://www.aoa.gov/NAIC/Notes/nursinghomes.html>

¹⁰⁴ <http://www.hud.gov/groups/seniors.cfm>

¹⁰⁵ <http://www.usc.edu/dept/gero/nrcshhm/library/>

¹⁰⁶ http://www.caregiver.org/factsheets/assisted_living.html

¹⁰⁷ http://www.caregiver.org/factsheets/assisted_living.html

¹⁰⁸ <http://www.seniorresource.com/house.htm>

¹⁰⁹ <http://www.seniorresource.com/hbc.htm>

The American Association of Homes and Services for the Aging (AAHSA)¹¹⁰ web site describes the types of residences available, what to look for, and offers a search device for member facilities by community. The AAHSA sponsors the Continuing Care Accreditation Commission, which accredits qualified continuing care retirement communities.

The Assisted Living Federation of America (ALFA)¹¹¹ is a national nonprofit trade association dedicated to enhancing the quality of life in assisted living residences and representing the interests of the assisted living industry.

The American Health Care Association (AHCA)¹¹² is a professional organization that represents the interests of licensed nursing homes, assisted living, and sub-acute care facilities. This web site offers information on the types of facilities and how to choose one.

AARP¹¹³ is the largest membership organization of older persons in the U.S. This web page is the gateway to several pages on housing¹¹⁴.

The National Hospice and Palliative Care Organization (NHO)¹¹⁵ promotes quality care for terminally ill patients and provides information about hospice services. Hospices provide medical care for dying patients, as well as counseling and supportive services for the patient and family members. The NHO web site provides information about hospices and performs a search for services in your area. Some hospices help families care for patients at home, some offer services in a hospice center, others are located in a hospital or skilled nursing facility. Many offer a combination of services within a single program.

¹¹⁰ <http://www.aahsa.org/public/find.htm>

¹¹¹ <http://www.alfa.org>

¹¹² <http://www.ahca.org/info/index.html>

¹¹³ <http://www.aarp.org/>

¹¹⁴ [http://search.aarp.org/cgi-](http://search.aarp.org/cgi-bin/htsearch?config=htdig_www_aarp_org&restrict=&exclude=research.aarp.org+www.andrus.org&words=housin)

[bin/htsearch?config=htdig_www_aarp_org&restrict=&exclude=research.aarp.org+www.andrus.org&words=housin](http://search.aarp.org/cgi-bin/htsearch?config=htdig_www_aarp_org&restrict=&exclude=research.aarp.org+www.andrus.org&words=housing)

[g+](http://search.aarp.org/cgi-bin/htsearch?config=htdig_www_aarp_org&restrict=&exclude=research.aarp.org+www.andrus.org&words=housing)

¹¹⁵ <http://www.nhpco.org/>

VI. When Your Care Receiver Lives With You

Introduction

American society is often a muddle of contradictions, and this is certainly true when it comes to families. On the one hand, we cherish the concept of the extended family and laud the ideal of multiple generation households¹¹⁶. On the other we cherish our privacy and fiercely defend our independence. It is thus important for you, your relative or friend, and other family members to weigh the pro's and con's of living together. This is especially true if you are working¹¹⁷ or have other family responsibilities. You will need to consider these before you enter into an arrangement that may or may not be the best option for you and your care receiver.

Pro's and Con's

It is probably best for everyone involved to discuss what you imagine the pro's and con's of living together to be. Every family's situation is unique. Listed below are some of the benefits and drawbacks that may result. It is important for your relative or friend to take part in the decision, and to be a valued and contributing member of the family¹¹⁸ with meaningful roles, whenever possible.

On the plus side:

1. If your care receiver needs considerable care, you will save the expense of a long-term care facility or, at least, some in-home services.
2. You know that your care receiver is getting the best possible care because you are either providing it yourself or directly overseeing the care.
3. You will be able to make major decisions that can give you a sense of empowerment.
4. You will have more time to spend with your family member or friend.
5. Your children will have an opportunity to spend more time with their grandparent(s) or other older relative, have an important lesson in compassion and responsibility, learn about their roots, and develop a sense of family continuity.
6. If your care receiver is fairly healthy, he or she may help with household tasks, and/or with the children.

¹¹⁶ <http://fcs.tamu.edu/aging/siblings.htm>

¹¹⁷ <http://www.elderweb.com/default.php?PageID=777>

¹¹⁸ <http://www.gu.org/>

On the other side:

1. You may have less time for yourself and/or other family members and if you work¹¹⁹ you may find conflicts between your job and caregiving¹²⁰ responsibilities. Some employment versus care giving responsibilities¹²¹ may be relieved, especially in light of the technology revolution that is taking place, where telecommuting¹²² may now be an option.
2. Depending on your lifelong relationship¹²³, you may find that you and/or your relative resent changes in your relationship that may take place.
3. You will lose at least some of your privacy.
4. Other family members may resent the new arrangement.
5. There may be less space for everyone in the family.
6. You may find that hands-on caregiving is too physically and/or emotionally demanding.

If you decide that you do want to live together, you might want to try it on a trial basis, if possible. You might consider renting or subletting your care receiver's home on a short-term basis so that he or she has the option of returning home if the new arrangement does not work out to everyone's satisfaction.

You will want to consider what, if any, physical changes¹²⁴ need to be made to your residence¹²⁵ and how much they will cost.

Will Intergenerational Living Work in Your Home?

As a guide, you may want to ask the following questions:

1. Is your home large enough so that everyone can have privacy when they want it?
2. Is there a separate bedroom and bath for your family member, or can you create an accessory apartment?
3. Are these rooms on the first floor? If not, can your relative climb stairs safely?
4. Can you add to or remodel your home to provide a first-floor bedroom and bath?
5. Do you need to add safety features¹²⁶ such as ramps and better lighting?

¹¹⁹ <http://www.montana.edu/wwwpb/pubs/mt9506.html>

¹²⁰ <http://ohioline.osu.edu/ss-fact/0119.html>

¹²¹ <http://www.workoptions.com/approval.htm>

¹²² <http://www.gilgordon.com/>

¹²³ http://fcs.tamu.edu/aging/building_positive_relationships.htm

¹²⁴ <http://www.elderweb.com/default.php?PageID=920>

¹²⁵ http://www.design.ncsu.edu/cud/built_env/housing/home_mod.htm

¹²⁶ <http://www.cpsc.gov/cpsc/pub/pubs/701.html>

6. Does the bathroom have a shower, is it large enough to accommodate a wheelchair, if needed, and can safety features, such as grab bars, be installed to prevent falls?
7. Are door openings wide enough for a wheel chair?

You also may want to set some ground rules for privacy.

Sharing Time Together

Obviously, if you want your care receiver to live with you, you will want to share times together.

1. Set aside times to talk.
2. Involve your care receiver, if possible, in family outings and social events.
3. Invite other family and friends to your home, and let them know that you are available to come to their house as well. All of them will not respond, but some will.
4. Even errands, such as shopping, can be something of a social event, and give your relative a chance to participate in decision-making.

At the same time, you want to ensure that other family members do not feel that they have been “displaced” and that they are as important to you as ever.

VII. Living Day to Day

Introduction

As caregivers, we sometimes become so involved in the day-to-day efforts to keep things going that we tend to forget that each day can be an opportunity to try new approaches and activities that will make a positive difference in our life and the life of those we care for.

Some things that can bring about positive changes for the better include:

- Standing back and taking a look at your situation--what is working well and what isn't--and finding ways to make changes for the better
- Establishing routines that effectively meet your care receiver's needs
- Improving your physical surroundings
- Physical, speech and occupational therapy and/or exercise
- Assistive devices, which range from special eating utensils to specially equipped telephones, that increase independence and safety
- Improved nutrition
- Carefully monitoring medications and their interactions
- Intellectual stimulation
- Social interaction
- Spiritual renewal
- Employing home and/or health care personnel who demonstrate that they really do care and who will work to foster independence
- Finding ways to economize on your work load
- Filling each day with activities to which you can both look forward

Hands-On Caregiving

If your older relative or friend needs considerable help, a well-planned routine can make the more demanding parts of your caregiving day go more smoothly, take less time and help to ensure that your care receiver does not develop problems which could be prevented.

- Make a list of all the things you need for morning and bedtime routines, buy several of these items, and have them close at hand, such as bathing items,

medications, and clothing. This saves time and keeps you from having to search or leave the room for them when you are helping your older family member. If you use items in several different places, have duplicate items stored in these rooms, such as the bathroom and bedroom.

- If possible, have someone help you with the morning and bedtime routines, if your older relative needs a lot of assistance, since getting up and going to bed often are the most challenging times of the day.
- Practice good oral hygiene¹²⁷ that includes tooth-brushing, denture cleaning, and cleaning around the gums, preferably after every meal. Good oral hygiene helps to prevent tooth decay, tooth loss and gum diseases, as well as secondary infections that can result from poor dental care. Persons with disabilities or medical problems may need special care¹²⁸ in addition to daily hygiene routines.
- If your older family member is disabled, has poor eyesight or cognitive impairments, you may need to remind them about personal hygiene and/or assist them. If your care receiver is incontinent¹²⁹, it is especially important to ensure that he or she is clean at all times, to use protective (barrier) creams, and to change incontinence aids and clothing as often as needed. Poor hygiene can result in diaper rash and blistering of the skin. Poor hygiene also can contribute to the development of decubitus ulcers (pressure sores) and other problems that cause pain, discomfort and serious, even life-threatening infections. In older women, tight fitting clothing and diapers can lead to yeast infections¹³⁰.

There are new commercial products*¹³¹ that make incontinence much less of a problem than it once was because they keep clothes and bed linens clean and dry. You also can discuss ways in which your care receiver's incontinence may be corrected with your health care provider, including exercises and surgical procedures.

For those web links that have an asterisk, click on the highlighted search word which will take you to the **Abledata** web site; then type in the same search word(s) on the **Abledata** key word search site to gain access to the information you want.*

¹²⁷ <http://www.aoa.gov/aoa/pages/agepages/teethmou.html>

¹²⁸ <http://www.nohic.nidcr.nih.gov/>

¹²⁹ <http://www.nafc.org/site/index.html>

¹³⁰ <http://www.niaid.nih.gov/factsheets/stdvag.htm>

¹³¹ <http://www.abledata.com/text2/keyword.htm>

Older persons with limited movement should be turned in bed on a regular basis to prevent pressure sores¹³². Correct bedding, such as sheepskin or egg carton bed coverings and/or an air mattress, helps to prevent pressure sores¹³³. It is important to move older persons with disabilities at least once an hour, even if it just to reposition them, to do range of motion exercises, and to have them sit in various chairs that offer sufficient support.

Make lists¹³⁴ of:

- Morning and bed time routines
- Medical personnel with their area of expertise, addresses and telephone numbers
- Home health agencies
- Other people who can help or fill in, if you need additional help
- Lawyers and financial advisors
- Where needed items are kept, such as thermometers and blood pressure monitors
- Medications, when they are to be taken, and where they are stored
- Exercise schedules and directions
- Emergency contacts in addition to 911

These lists and other needed information can be put into a clearly marked notebook and kept where others can easily find them in your older relative's room. This book should be complete enough so that someone filling in for you will know exactly what is needed and what to do.

Tips on Safety

Quick, easy, and readily available ways to communicate with others that can help in an emergency are a must for you and your older family member or friend. You can get:

- A cordless speaker phone with memory so that you can simply hit one button in an emergency and get help without compromising the safety of your care receiver.
- A cellular phone, if you and your care receiver travel.
- A signal system* which will summon help with the push of a button, if you leave your care receiver alone, at times.

¹³² <http://www.aoa.gov/Factsheets/pressuresores.html>

¹³³ <http://www.nursingassistanteducation.com/site/courses/eng/nae-ppu-eng.php>

¹³⁴ <http://www2.seniorcareweb.com/senior/worksheets/default.htm>

- A specially equipped telephone* with speed dialing, a large digital display for easy reading, and ring and voice enhancer, if your care receiver has hearing problems.
- An intercom, * that will alert you if your care receiver is having problems when you are in another room.
- Smoke detectors on each floor, which should be periodically checked to ensure that they are operating properly.

If your family member is disabled, you will want to ensure that he or she:

- Has a clear path through each room, that there are no rugs or raised room dividers to trip over, and no slippery floors. You can carpet the bathroom with all weather carpeting to help prevent falls. This can be pulled up in sections, if it is wet.
- Uses a cane or walker, if needed.
- Is secure in his or her wheel chair. If your older relative is weak a tray that attaches to the wheel chair can prevent falls and gives your care receiver a place for drinks, magazines, etc. It is important to ensure that the wheels are securely locked when doing transfers, or if the older person's chair is on an incline.
- Cannot fall out of bed. If the bed does not have guardrails, you can place the wheel chair or other guards next to the bed, and position your older relative in the middle of the bed so that she or he can turn over without fear of falling.

Meals

- As people age, they sometimes experience problems with chewing and swallowing, but there are ways to minimize these problems¹³⁵. The need for certain nutrients¹³⁶ in older person's diets may also change.
- Avoid foods that are high in:
 - Saturated fats
 - Salts, chemical preservatives and additives
 - Sugar and calories that do not enhance nutrition, but may add to excessive weight gain

There are numerous ways to obtain pre-prepared and easy to prepare meals that are nutritious time savers.

¹³⁵ <http://www.fda.gov/opacom/lowlit/eatage.html>

¹³⁶ http://cpmcnet.columbia.edu/dept/dental/Dental_Educational_Software/Gerontology_and_Geriatric_Dentistry/nutrition/Nutrition-Nut_Require.html

For older people who are homebound, meal times can be pleasant social events, when you can be together and talk. If your relative or friend is confined to bed, you can sit and talk while he or she eats and bring a tray in for yourself. There are a host of eating utensils * and accessories that make eating easier for persons with disabilities.

Caring for Your Home

- Use an attractive plastic tablecloth or place mats that are easy to clean and an attractive towel, apron or other covering for your care receiver's clothes, if there is a tendency to spill food. Be sure that it is large and long enough to cover their laps and fold it inward before taking it off to avoid spillage on the floor. Consider having a vase of flowers (even if they are artificial) on the table or next to the bed, if your older relative is confined to bed, and open the curtains and let the sun shine in.
- Use lightweight, plastic easy-grip glasses, or cups with handles. If there is a lot of spillage, try a drink holder with a lid and plastic straw insert.
- If clothes are wrinkled, you can put them in the dryer with a wet towel or sponge on a warm setting. This often saves a lot of time ironing.
- If your care receiver is incontinent, you can:
 - o Use washable or disposable pads on the bed above the sheet
 - o Rubberized sheets underneath the bed sheet.
 - o A stain and water resistant mattress pad.
- If the mattress does become soiled, it will need to be thoroughly cleaned and aired after being sprayed with a safe (always read the label) antibacterial cleaning agent. You can ask your doctor or pharmacist for recommendations.
- You can use water-resistant pads or heavy towels on the wheelchair or furniture that your care receiver uses. If you travel, keep pads in the car for use on the car seat and when visiting other places.

- When buying towel sets, you may want to purchase extra wash cloths since these are used more frequently and wear out faster. Thermal blankets also are useful because they are warm, lightweight, and easy to wash.

Exercise

In consultation with your care receiver's physician and physical therapist, you can plan a routine¹³⁷ of exercises. Exercises even for bed and wheelchair-bound older persons help to improve:

- Circulation
- Lung and heart function
- Posture
- Mental alertness
- Help to prevent:
 - o Diabetes
 - o Pressure sores
 - o Osteoporosis
 - o Heart disease
 - o Stroke

If appropriate, encourage your relative¹³⁸ to do a little more physical activity each week. Vary the exercises¹³⁹ and challenge them to do better. Exercise with them. If they are confined to a bed or wheelchair¹⁴⁰, try to get them to exercise at least five minutes every hour, and again, regularly change their position to prevent pressure sores.

Clothing

Regardless of our age or physical condition, we want to look and feel our best. Today's clothing* options make that a much easier goal to reach. When buying clothing, consider the following:

- Clothing that is washable and wrinkle-free saves on dry cleaning bills and ironing time.
- Slacks and skirts that have elasticized waistbands or tie waistbands are easier to get on and off and are more comfortable.
- Clothing with snaps or zippers and some that button down the front are easier to manipulate.
- Shoes that will not slip off easily, and have a non-skid tread.
- Interchangeable and color-coordinated clothing. e.g. slacks and tops that can go with several others.

Entertainment, Entertaining and Travel

¹³⁷ http://www.cpa.sa.gov.au/benefits_exercise/exercise.html

¹³⁸ <http://www.fitness.gov/activelife/pepup/pepup.html>

¹³⁹ <http://www.indiana.edu/~preschal/resource/digests/march/march99/digestmarch991.html>

¹⁴⁰ <http://www.acs.ohio-state.edu/units/osuhosp/patedu/homedocs.pdf/exer-reh.pdf/physical/wheelstretch.pdf>

Boredom can sap our intellect and spirit, but you can change this by creating activities that you and your care receiver look forward to and by sharing these with others. There are many activities that frail and disabled older people can enjoy. You can:

- Check the TV listings and choose your favorite programs to watch each day rather than having the TV going nonstop.
- Get large print and talking books from the library and read together.
- Play card and board games--they stimulate mental activity.
- Check for special events that are low-cost or free. Invite a friend or family member to join you, preferably one who can drive or help you if your care receiver has a physical disability.
- Go out to lunch or the early-bird specials at restaurants.
- Visit an art-hobby store and see what is available in the way of arts or crafts projects that you and your care receiver can enjoy.
- Invite family or friends over for dinner or lunch. If you have limited funds to entertain or do not have time to prepare food have them over for dessert or snacks, ask each of them to bring something, or to chip in on a carryout meal.
- Plan day trips to local places of interest. Again invite a friend or family member to join you.
- If you can afford to do so, go on a vacation. You can share the adventure and expense with other family members or friends. Many places offer senior discounts. Make sure that they can accommodate your needs, especially if your care receiver is disabled. Large hotel and motel chains now go out of their way to help, if you make your needs known to them. In addition, there are companies and organizations that plan trips¹⁴¹ for persons with limitations in their mobility. Many travel books have special sections on accommodations, travel, and activities for those with limited mobility.
- If you have the room, invite friends or family members to come and stay with you for a while in your home.
- Check colleges, religious organizations, and community centers for free courses and other activities.
- Visit museums, galleries, botanical and zoological parks or a petting zoo.
- If appropriate, get a pet. Your local shelter or humane society has many nice pets available for adoption.

¹⁴¹<http://www.overture.com/d/search/p/netscape/?Keywords=Travel%2Bfor%2Bthe%2BDisabled&Partner=netscape>

- Get a computer with Internet access so that you can e-mail friends, join in chat rooms, learn about things that are of interest to you, and enjoy computer games.
- Ask your local Area Agency on Aging about friendly visitor, volunteer, and telephone reassurance programs.
- Many fraternal, religious, and social organizations have activities specifically for older people. This can be a great way to extend your circle of friends and supportive network.

Additional Resources and Reading Lists

The National Association for Continence¹⁴² offers information on ways to effectively deal with incontinence and provides consumer product information.

This NAIC Internet Notes site on Exercise and Fitness¹⁴³ lists a host of web sites that feature information about exercise and how to do them as well as organizations in the field.

Go to the NAIC Internet Notes on Nutrition and Food Safety and view the Consumer Sites¹⁴⁴ for guides to healthy food choices.

The NAIC Internet Notes on Prescription Drug¹⁴⁵ web sites has sections on Geriatric Pharmacy and Drug Use and Name and Prescription Drugs. AgeNet's Home Safety Checklist¹⁴⁶ can help to ensure your care receiver's safety.

¹⁴² <http://www.nafc.org/site/index.html>

¹⁴³ <http://www.aoa.gov/naic/Notes/exerciseandfitness.html>

¹⁴⁴ <http://www.aoa.gov/naic/Notes/nutrition.html>

¹⁴⁵ <http://www.aoa.gov/naic/Notes/prescriptiondrugs.html>

¹⁴⁶ <http://agenet.agenet.com/?Url=link.asp?DOC/341>

VIII. How Can We Afford Long-Term Care?

Introduction

Some older persons have very limited incomes and assets and are eligible to participate in a number of benefit and assistance programs. Others have adequate assets to cover their regular living expenses, but cannot pay for long-term care for a long time.

Programs for Older Persons with Limited Incomes and Assets:

Meals and In-home Services

If the person for whom you are caring has limited income and resources, there are programs that can help. You may want to find out about the Food Stamp¹⁴⁷ program that provides coupons for purchasing food. Your older relative or friend may be able to participate in a group or home-delivered meals program and receive supportive in-home services through an Area Agency on Aging. These options are discussed in the section on What Services Can Help Us?¹⁴⁸

Benefit Programs

In addition to the Old Age and Survivors Benefit program, commonly called Social Security¹⁴⁹, the Supplemental Security Income¹⁵⁰ program provides benefits to persons with limited incomes and assets who are blind, disabled, or 65 or older. To find out about these programs, contact your Area Agency on Aging or the Department of Social Services where your older relative lives. If your older relative served in the armed forces during wartime or has a service-connected disability, you should inquire about Veterans benefits¹⁵¹ and services.

Housing Programs

There are housing programs¹⁵² for older persons with limited incomes who do not own their own homes. These programs include public housing¹⁵³ and Section 8¹⁵⁴

¹⁴⁷ <http://www.fns.usda.gov/fsp/menu/ABOUT/ABOUT.HTM>

¹⁴⁸ <http://www.aoa.gov/wecare/what-services.html>

¹⁴⁹ <http://www.ssa.gov/retirement.html>

¹⁵⁰ <http://www.ssa.gov/pubs/11000.html>

¹⁵¹ <http://www.va.gov/index.htm>

¹⁵² <http://www.aoa.gov/housing/gahousing.html>

¹⁵³ <http://www.hud.gov/renting/phprog.cfm>

¹⁵⁴ <http://www.hud.gov/progdesc/voucher.cfm>

rental certificates that are available to low-income persons regardless of age and Section 202¹⁵⁵ housing for older persons. These are programs of the Federal Department of Housing and Urban Development, but you can contact your local housing authority for information about these rental-housing options in your older relative's community.

There also are a number of U.S. Department of Agriculture Rural Housing Service programs for persons living in rural areas¹⁵⁶. These range from loans to buy homes to home-improvement and rent subsidy programs.

Health Benefits

Finally, you may want to check out the federal Centers for Medicare and Medicaid Services programs, such as the Qualified Medicare Beneficiary¹⁵⁷ program, that assist low-income Medicare beneficiaries. These programs help low-income seniors pay all or part of the premiums for Medicare. For additional information about Medicare and Medigap policies click on Medicare and You: 2002¹⁵⁸. The Medicaid¹⁵⁹ program covers many of the medical expenses¹⁶⁰ not covered by Medicare, such as prescription medications, and, in some cases, long-term home health and in-home personal care. Each state sets its own income and asset eligibility requirements for Medicaid benefits.

Most states now have programs that pay family caregivers to provide homemaker, chore, and personal care services. Most use state funds to compensate families, while other states use Medicaid waiver funds. Contact your Area Agency on Aging or your department of social services for more information.

You also may want to explore the possibility of purchasing medigap¹⁶¹ and/or long-term care insurance. Medigap insurance is private insurance that usually covers the cost of health care not covered by Medicare as well as Medicare deductibles. Long-term care insurance¹⁶² generally pays a set amount or a percentage of costs for long-term care both at home and in long-term care facilities. However, long-term care insurance may:

- Be quite expensive for persons aged 70 or older.
- Unavailable to persons of advanced ages.

¹⁵⁵ <http://www.hud.gov/progdsc/2eldr114.cfm>

¹⁵⁶ http://www.rurdev.usda.gov/rhs/Individual/ind_splash.htm

¹⁵⁷ <http://www.state.de.us/dhss/dss/qmb.html>

¹⁵⁸ <http://www.medicare.gov/Publications/Search/View/ViewPubList.asp?Language=English>

¹⁵⁹ <http://www.hcfa.gov/medicaid/mover.htm>

¹⁶⁰ http://www2.seniorcareweb.com/senior/financial/health_insuran/medicaid.htm

¹⁶¹ <http://www.medicare.gov/publications/pubs/pdf/finalmed.pdf>

¹⁶² <http://www.aarp.org/confacts/health/privlvc.html>

- Not pay in the case of preexisting conditions.

Most experts recommend buying long-term care insurance when you are in your fifties and in reasonably good health.

Tax Deductions and Credits

Some out-of-pocket expenses associated with long-term care, including transportation to medical appointments, long-term care insurance premiums, prescription drugs, privately hired in-home health care employees, and changes to a dwelling or car for medical reasons, are tax deductible¹⁶³ as medical expenses. The expenses must be for the care of a chronically ill individual who needs help with at least two activities of daily living or requires “substantial supervision to protect against threats to health and safety due to severe cognitive impairment.” Tax credits generally benefit low-income taxpayers. Tax credits usually require the caregiver to live with the care recipient and to be employed outside the home.

Covering Long-Term Care Costs

Many caregivers and care receivers cannot qualify for public-funded assistance because they have substantial income and assets but do not have the financial resources to pay for needed services for extended periods of time without impoverishing themselves. In caregiving, many families deplete the resources they accumulated over a lifetime. If this happens, caregivers may try to provide all of the needed care. This can be difficult for spouses who are frail or have medical problems, as well as for family members especially those who work and/or have children. In these instances, you and your older relative should consider asking other family members to contribute to the cost of care and/or to provide some of the care on a regular basis.

If formal part-time care and informal help from families is insufficient, the older person can enter a skilled nursing or other long-term care facility that is certified to accept Medicaid patients. In some communities, however, facilities have waiting lists of persons who want to enter as Medicaid patients.

Ways to Maximize Your Assets

Most caregivers need to budget wisely and maximize their relative’s assets. There are several ways to do this:

- If your older relative wants to remain at home, she could live on one floor and rent out rooms in the rest of the house through a house-sharing

¹⁶³ <http://www.fsa.usda.gov/dafp/psd/default.htm>

arrangement. This arrangement can bring in a substantial amount of income where housing is relatively expensive or in short supply.

- Another option is to rent out her residence, and have her move to a smaller home, an apartment, your residence, or other housing option. Renting out a residence and house sharing both provide income that will usually keep pace with inflation and offer tax advantages. Improvements, repairs, and all or part of the house can be depreciated. If your older relative lives in the house, she also can claim some of the utilities as a tax exemption.
- If the house is in an unsafe area, or in a neighborhood or community that is declining in value, it may be best to sell. A federal tax exemption of up to \$250,000 is available for a person 55 or older who sells his or her home, or \$500,000 for a couple.
- Another possibility is to provide room and board to someone in exchange for caregiving and/or other needed services. There are several drawbacks to this arrangement, however. It may be difficult to:
 - o Prove to the IRS that your older family member has received home health services in exchange for room and board.
 - o Depreciate the room for tax purposes.
 - o Ensure that the home care employee honors his or her part of the arrangement—providing services in exchange for room and board.

The better arrangement is to rent out the room(s) and pay a home care worker. Some home care workers work as independent contractors (check to see if they have a federal tax ID number to work as an independent contractor). While this arrangement frees you from dealing with social security¹⁶⁴, workers compensation¹⁶⁵, unemployment taxes¹⁶⁶, and other withholding taxes¹⁶⁷—all of which can be complex and time-consuming, there are Internal Revenue Service definitions¹⁶⁸ that govern whether a person is considered to be a contractor¹⁶⁹ or an employee¹⁷⁰ (Go to the articles under payroll taxes). Thus, be sure to consult an income tax preparer, lawyer, or financial planner before considering this

¹⁶⁴ <http://www.ssa.gov/pubs/10021.html>

¹⁶⁵ <http://www.nolo.com/lawcenter/faqs/detail.cfm/objectid/858B36BB-80C1-457B-9965650A58176C14?a=goto00000040400>

¹⁶⁶ http://www.law.cornell.edu/topics/unemployment_compensation.html

¹⁶⁷ <http://business.lycos.com/>

¹⁶⁸ <http://www.irs.gov/pub/irs-pdf/p15a.pdf>

¹⁶⁹ <http://www.irs.gov/faqs/display/0,,i1%3D54%26genericId%3D15856,00.html>

¹⁷⁰ <http://business.lycos.com/taxes/taxarticles.asp>

arrangement. If the home care worker is truly an independent contractor¹⁷¹ then he or she is responsible for paying social security¹⁷² and other taxes.

Contact your insurance company to be sure you are covered against possible liability should property be stolen, damaged, or destroyed, or if a renter or home care employee suffers injury. If you pay the home care worker as an employee, there are companies, listed in the yellow pages under payroll preparation services, which issue salary checks and arrange for withholdings for a fairly nominal fee.

Reverse Equity Mortgages¹⁷³ are another option if an older person wants to remain at home and receive monthly payments from a lending institution. The upfront costs for negotiating this type of loan can be considerable, however. Before making a decision, talk to your lawyer and, if possible, a home equity conversion counselor.

Sale-lease back arrangements allow older people to sell their homes and remain as lifetime tenants. However, this arrangement is legally complex, can impact on an older person's eligibility for Medicaid and similar benefits, and precludes benefiting from any future gains in the value of the property.

Other ways to save money include:

- Checking to see if there is property tax relief for older home owners and what the eligibility requirements are.
- Joining clubs or organizations that offer group supplemental health and car insurance plans and discounts on other items and services.
- Buying at discount and thrift stores, during sales and with coupons.
- Checking with mass transit and taxi companies about senior discounts, non-peak hour ride discounts, and free ride services for persons with low-incomes.
- Asking plumbers, trash pick-up services, restaurants etc. if they offer discounts to older customers—many do, but sometimes only if you ask.

You may be able to save 10 to 75 percent on some items and services, if you follow these suggestions.

Lastly and probably most importantly, be sure your relative's assets and your assets are carefully reviewed, if you are helping with expenses. Are you getting the best return on your investments without risking your principle? Are you aware

¹⁷¹ <http://www.topechelon.com/recruiters/contracting/definiti.htm>

¹⁷² <http://www.ssa.gov/employer/>

¹⁷³ <http://www.aoa.gov/elderpage/walrevmortgage.html>

of all of your older relatives' bank accounts, stocks, bonds or other assets? What about pension plans? Some older persons are not getting the money to which they are entitled from pension plans¹⁷⁴. Having reviewed your assets, what changes can you make to bring in more income? Read good investment books, talk to your bank, your lawyer, and/or find a qualified investment planner¹⁷⁵ or advisor for some ideas.

Additional Resources and Reading Lists

Go to the Social Security Administration¹⁷⁶ web site for information on how to compute benefits, and how to apply.

For information on SSI and other benefit programs visit the Supplemental Security Income Program web site¹⁷⁷.

Go to the Administration on Aging Retirement and Financial Planning¹⁷⁸ site for web resources dealing with financial planning for retirement and general retirement planning.

For information on long-term care insurance go this site dealing with women and long-term care insurance¹⁷⁹. Regardless of the title, this site is equally good for men in making this decision.

This NAIC Internet Information Note lists web sites on reverse equity mortgages¹⁸⁰.

For information on Web sites on HMOs, go to the NAIC Internet Information Note on Health Maintenance Organizations¹⁸¹.

For a brief summary of benefit programs, types of insurance and long-term care insurance go to Who Pays for Health Care Services?¹⁸², a section of the National Association for Home Care's How to Choose a Home Care Provider,

¹⁷⁴ <http://www.aoa.gov/factsheets/pension.html>

¹⁷⁵ <http://www.aoa.gov/elderpage/walfinplan.html>

¹⁷⁶ <http://www.ssa.gov/retirement.html>

¹⁷⁷ <http://www.ssa.gov/pubs/SSI>

¹⁷⁸ <http://www.aoa.gov/retirement/default.htm>

¹⁷⁹ <http://www.aoa.gov/elderpage/walltc.html>

¹⁸⁰ <http://www.aoa.gov/naic/Notes/reversemortgages.html>

¹⁸¹ <http://www.aoa.gov/naic/Notes/HMO.html>

¹⁸² <http://www.nahc.org/Consumer/wpfhcs.html>

IX. How Do I Hire a Home Care Employee?

Introduction

Today, one in four American families¹⁸³ cares for an older relative, friend, or neighbor. An estimated 25 to 40 percent of women care for both their older relatives and their children. Half of all caregivers also work outside the home. It is no wonder then that caregivers often need help. Depending on your work, living, and family arrangements, there are a number of things you can do to make caregiving easier.

Ways to Make Caregiving Easier

Work Options and On-the-Job Training Programs. If you are a working caregiver, it is important to discuss your needs with your employer. Telecommuting, flextime, job sharing or rearranging your schedule can help to minimize stress. Increasingly, companies are offering resource materials, counseling, and training programs to help caregivers.

Involving Older Children. Older children living at home may be able to assist you and/or your older family member. Such responsibility, provided it is not overly burdensome, can help young people become more empathic, responsible, and self-confident and give you needed support.

Asking Other Family Members to Help. You can and should ask other family members to share in caregiving. A family conference can help sort out everyone's tasks and schedules. Friends and neighbors also may be willing to provide transportation, respite care, and help with shopping, household chores or repairs.

Sources of Information

If you need additional information and assistance in caring for your older relative or friend, you can contact:

- The National Eldercare Locator, funded by the Administration on Aging. Eldercare Locator advisors can direct you to agencies and organizations that can assist you. When calling the Eldercare Locator at 1-800-677-1116, please provide the older person's address and ZIP code.

¹⁸³ http://www.careguide.com/Careguide/index.jsp?r_url=null

- The Area Agency on Aging serving your older relative or friend's community can provide information about in-home and community services. Information also is available about benefit and assistance programs for older persons with limited incomes. These include:
 - o Subsidized housing
 - o Food stamps
 - o Supplemental Security Income
 - o Medicaid
 - o The Qualified Medicare Beneficiary program, which covers the cost of the Part A and B insurance premiums, deductibles, and coinsurance for low-income older persons.

In addition, the AAA can direct you to senior center and adult day programs. These programs are particularly helpful to working caregivers who want a safe environment with planned activities for their older relative.

- Senior centers serve active older persons and those who have minor problems with mobility and activities of daily living.
- Adult day programs serve older persons with serious mobility limitations, dementia, or medical conditions that require daily attention.
- Many AAA's have a registry of home care workers from which you can recruit directly as well as information on home care agencies and volunteer groups that provide help.
- Hospital or Nursing Home Discharge Planners also can refer you to home care agencies and home care workers.

Determining the Type of Care You Need

If you decide to hire a home care employee, you need to determine how much and what type of help your older relative needs. Following are descriptions of some of the types of home care personnel:

- **Housekeepers or Chore Workers** may be supervised by the person hiring them and perform basic household tasks and light cleaning. Chore Workers often do heavier types of cleaning such as washing windows and other heavy cleaning.

- A **Homemaker** may be supervised by an agency or you and provides meal preparation, household management, personal care, and medication reminders.
- **Home Health Aides, Certified Nurse Assistants, or Nurses Aides**, often referred to as home health care workers, are supervised by a home care agency's registered nurse and provides personal care, help with bathing, transfers, walking, and exercise; household services that are essential to health care; and assistance with medications. They report changes in the patient's condition to the RN or therapist, and complete appropriate records.

Sometimes, home care employees take on several of the roles described above.

General Eligibility Requirements for Home Care Benefits

Medicare may pay for home health care services through a certified home health care agency¹⁸⁴, if a physician orders these services. Home health care agencies focus on the medical aspects of care and provide trained health care personnel, including nurses and physical therapists. For a patient to be eligible for services paid for under Medicare, she must need skilled nursing assistance, or physical, speech, and/or occupational therapy. Home health care workers are a supplement to this care and usually help the older person for three hours a day, several days a week.

If your older family member or friend needs additional hours of care or requires custodial care, she may be eligible for services under Medicaid. The state where she resides determines if her income and assets qualify her for Medicaid covered services. Otherwise, you or your older relative must cover the cost of having a home care worker.

Home care agencies, which can be nonprofit or for-profit, recruit, train, and pay the worker. You pay the agency. Social Service agencies, in addition to home care services, may provide an assessment of the client's needs by a nurse or social worker, and help with the coordination of the care plan. If services are being covered under Medicare, your doctor, care manager, or discharge planner will probably make arrangements for a home health care agency.

Selecting an Agency

¹⁸⁴ <http://www.mayoclinic.com/invoke.cfm?id=HO00084>

If you select an agency, ask the following questions. Those questions starred with an asterisk should also be asked, if you are hiring the home care employee.

- What type of employee screening is done?
- Who supervises the employee?
- What types of general and specialized training have the employees received?*
- Who do you call if the employee does not come?
- What are the fees and what do they cover?*
- Is there a sliding fee scale?
- What are the minimum and maximum hours of service?*
- Are there limitations in terms of tasks performed or times of the day when services are furnished?*

Unless your older friend or relative needs care for a limited number of hours each day, the rates charged by home care agencies for homemaker, home health aide services and van services for transportation are often beyond the means of middle income families. If this is the case, you may want to explore the option of hiring a home care employee directly.

Hiring a Home Care Employee

- Avenues for hiring home care aides include:
- Asking other caregivers for referrals
- Going to senior or other employment services
- Contacting agencies that assist displaced homemakers and others entering the job market
- Advertising in the newspapers
- Screen home care employees carefully to ensure that they have the necessary qualifications, training, and temperament.

Interviewing Applicants

Your interview with a prospective home care employee should include a full discussion of the client's needs and limitations, with a written copy of the job description; the home care worker's experience in caregiving and his or her expectations.

Special Points to Consider

- If the older person needs to be transferred from a wheelchair, make sure that the aide knows how to do this safely. If the aide does not know how to bathe a person in bed or transfer, but is otherwise qualified, it may be possible to provide the necessary training, but make sure she can do it before hiring her.
- Do not try to hire someone on a 7-day-a-week basis. No employee can remain a good employee for long, if she does not have time for her personal needs and interests. Additionally, aides who live in or sleep over cannot be expected to be on call 24 hours a day. If your older relative needs frequent help or supervision during the night, you should hire a second home care aide, or have a family member fill in.
- If your older relative needs a considerable amount of help, live-in help may be available, which can be less expensive than hourly or per day employees. However, keep in mind that you will be providing food and lodging and that it may be more difficult to dismiss live-in aides, especially if they do not have alternative housing available. It also is important to ensure that the aide has her own living quarters, and that she has some free time during the day, sufficient time to sleep, and days off.

References

Have applicants fill out an employment form that includes their:

- Full name
- Address
- Phone number
- Date of birth
- Social security number
- Educational background
- Work history
- References

Ask to see applicants' licenses and certificates, if applicable, and personal identification including their social security card, driver's license, or photo ID. Thoroughly check their references. Ask for the names, addresses, phone numbers, and dates of employment for previous employers, and be certain to contact them. If there are substantial time gaps in their employer references, it could indicate that they have worked for people who were not satisfied with their performance. Talk directly to former employers rather than accepting letters of recommendation.

With the applicant's permission, it is also possible to conduct a criminal background check.

Job Expectations

When hiring a home care aide, it is important to list the job tasks and to ask applicants¹⁸⁵ to check those they are willing to perform. You should also discuss:

- Vacations
- Holidays
- Absences
- Lateness
- Benefits and wages
- The amount of notification time each of you should give if the employment is terminated or if she resigns.

If you work and are heavily dependent on the home care assistant, emphasize the importance of being informed as soon as possible if she is going to be late or absent so that you can make alternative arrangements. It is helpful to keep a list of home care agencies, other home care workers, neighbors, or family members who can provide respite care, if needed.

Be clear about:

- The employee's salary.
- When he or she will be paid.
- Reimbursement for money the aide may spend out of pocket.

Needed Information

When hiring a home care assistant, if at all possible spend a day or two with him or her, so that you can go through the daily routine together. If this is not possible, have another home care aide, a relative, or friend remain with the new employee at least during the first day. Also, you will need to inform the home care worker, both verbally and in writing, about the older person's:

- Likes and dislikes.
- Special diets and restrictions.
- Problems with mobility.
- Illnesses and signs of an emergency.
- Possible behavior problems and how best to deal with them.
- Therapeutic exercises.

¹⁸⁵ <http://www.nahc.org/Consumer/hdistrhcp.html>

- Medications--where they are located, when and how they are taken, and how to reorder them.
- Dentures, eyeglasses, and any prosthesis.

Also provide information, verbally and in writing, about:

- How you can be contacted.
- Contacts in case of an emergency.
- Security precautions and keys.
- Clothing.
- Medical supplies, where they are kept, and how they are used.
- Food, cooking utensils, and serving items.
- Washing and cleaning supplies and how they are used.
- Light bulbs, flashlights and the location of the fuse box.
- The location and use of household appliances.

Transportation

If free or low-cost transportation is not available, try to hire someone who drives since this saves you substantial amounts of money in taxi or commercial van ride fares. If the home care employee is going to drive your family car, you must inform your insurance company, and provide a copy of the aide's driver's license to your insurance agent. Your insurance company will check to see if the license has been revoked, suspended, or if the aide has an unsatisfactory driving history. If the home care assistant has a car, discuss use of her car on the job and insurance coverage.

Insurance and Payroll

Check with your insurance company about coverage for a home care employee, and contact the appropriate state and federal agencies concerning social security taxes, state and federal withholding taxes, unemployment insurance, and workman's compensation.

If you do not want to deal with these somewhat complicated withholdings from the employee's salary, payroll preparation services can issue the employee's check with the necessary withholdings for a fee.

Some home care aides work as contractors. Even in these cases, you must report their earnings to the Internal Revenue Service. Before employing an aide on a contract basis, consult your financial advisor or tax preparer to make certain that you are following the IRS rules that govern contract workers, since there can be a

fine line between who is considered to be an employee versus a contractor. (For additional information about contractors and employees go to the section on “How Can We Afford Long-Term Care?”)

Ensuring Security

Regardless of who cares for your elderly relative, protect your private papers and valuables by putting them in a locked file cabinet, safe deposit box, or safe.

Make arrangements to have someone you trust pick up the mail, or have it sent to a post box where you can pick it up.

Check the phone bill for unauthorized calls, and, if necessary, have a block placed on 900 numbers, collect calls, three way calls, and long-distance calls. You can always use a prepaid calling card for long distance calls or arrange for a pin number for your personal use from your telephone company.

Protect checkbooks and credit cards. Never make them available to anyone you do not thoroughly trust.

Review bank, credit card statements, and other bills at least once a month, and periodically request credit reports from a credit report company. Your bank can provide you with the names and addresses of these companies.

If you do leave valuable possessions in the house, it is best to put locks on cabinets and closets and to have an inventory with photographs.

Protecting Against, Identifying, and Handling Abuse

Although abusive situations¹⁸⁶ are not common, you must be alert to the possibility. They are one of the primary reasons why it is so important to carefully check the references of a prospective home care aide. You can help to prevent abuse situations by:

- Ensuring that the home care assistant thoroughly understands what the position entails, your care receiver’s medical problems and limitations, as well as behavior that could lead to stressful situations.
- Ensuring that the home care aide is not overburdened.
- Keeping the lines of communication fully open so that you can deal with potential problems.

Following are possible signs of abuse¹⁸⁷ or neglect:

¹⁸⁶ <http://www.aoa.gov/abuse/default.htm>

¹⁸⁷ <http://www.elderabusecenter.org/basic/index.html>

- Personality changes in your older relative or friend.
- Whimpering, crying, or refusing to talk.
- Unexplained or repeated bruises, fractures, burns, or pressure sores.
- Weight loss.
- An unkempt appearance.
- Poor personal hygiene.
- Dirty or disorganized living quarters.
- Confusion, excessive sleeping, or other signs of inappropriate sedation.

If you suspect that an abusive situation exists, don't wait for it to be tragically confirmed. Find a way to check either by talking to the older person in a safe situation or, if necessary, by installing monitoring devices. If you witness, or are told by a reliable source, about neglect; physical abuse; emotional abuse, including yelling, threatening, or overly controlling, possessive behavior, which often involves isolating the older person from others; seek help, if necessary, and replace the home care aide as quickly as possible. If the situation appears serious, remove your care receiver from the premises and place him or her with another family member or in a facility that offers respite care. Always ensure that your relative is safe before confronting or dismissing the worker, especially if you are concerned about possible retaliation.

Once you have ensured your relative's safety, report the aide to Adult Protective Services so they can take appropriate actions to prevent the aide from gaining employment with other vulnerable elders. If the abuse¹⁸⁸ is of a serious nature including, serious neglect, physical injury, sexual abuse, or the misuse of the funds of the older person, you should also contact the police.

Supervising a Home Care Worker

Once you have hired a home care worker, make sure that the lines of communication are fully open and that both you and the worker have a clear understanding of the job responsibilities to the older person and to each other.

Explain what you want done and how you would like it done, keeping in mind that the home care employee is there to care for the older person and not the rest of the family.

If the home care worker lives in, try to ensure that he or she has living quarters that provide you, the older person and the assistant the maximum amount of privacy possible.

¹⁸⁸ <http://www.elder-abuse.com/howtodetectelderabuse.htm>

Once the home care aide is on the job, periodic and/or ad hoc meetings can be held to discuss any problems the home care assistant or the older person may have with the arrangement and to find ways to resolve them. It is important to be positive and open in your approach to resolving difficulties. In most cases, they can be corrected.

However, if, after repeated attempts, you find that major problems are not resolved satisfactorily it may be best to terminate the relationship, and seek another home care employee. During this time, it may be necessary for your older relative to reside temporarily in a long-term care facility or for you to hire an aide through an agency. It is best to have reserve funds on hand should such an emergency arise.

While home care may not be less expensive than nursing home care or assisted living, it offers older people the opportunity to remain at home. What is more, it affords a degree of flexibility and choice for the at-risk elderly that few other living arrangements can provide.

Additional Resources and Reading Lists

The National Association for Home Care's How to Choose a Home Care Provider is an excellent resource that covers a range of topics relating to hiring home care employees through an agency. The information is also useful to those who choose to hire a home care employee independently.

The National Center on Elder Abuse¹⁸⁹ is a major resource on elder abuse issues. The NCEA web site includes fact sheets on major issues, caregiver resources, and contact points in each state to report elder abuse.

¹⁸⁹ <http://www.elderabusecenter.org/>

X. Living With Alzheimer's Disease

Introduction

Caring¹⁹⁰ for someone with Alzheimer's¹⁹¹ disease or other forms¹⁹² of dementia can be very difficult. Alzheimer's disease¹⁹³ is a progressive, degenerative disease of the brain. It is the most common form of dementia. Profound changes in personality and mental functioning are not unusual. Often, our relationships are changed significantly by this.

Signs of Dementia

Signs of dementia can vary from one person to another. Frequently they include:

- Increasing levels of forgetfulness
- An inability to carry out simple tasks
- Difficulty in remembering words or in forming coherent sentences
- Confusion, hallucinations, or paranoia

If dementia is suspected, consult a physician familiar with Alzheimer's disease as soon as possible. Sometimes medications, underlying illness such as strokes, depression, or other conditions, mimic dementia. When this is the case, problems can be corrected, improved, or controlled.

Dealing with Alzheimer's Disease

Alzheimer's disease¹⁹⁴ is not reversible. However, early diagnosis is important because the progression of the disease can often be slowed with the help of medications and the symptoms also can be managed. Early detection means time for everyone to plan ahead.

Most caregivers want to know what to expect, how to deal with changes that result from Alzheimer's¹⁹⁵, help that might be needed, and how to find it. Persons with Alzheimer's disease¹⁹⁶ and their caregivers¹⁹⁷ can find help through the

¹⁹⁰ <http://www.caregiving.com/>

¹⁹¹ <http://www.aoa.gov/factsheets/alz.html>

¹⁹² <http://www.alzheimers.org.uk/about/causes.html>

¹⁹³ <http://www.aoa.gov/alz/index.asp>

¹⁹⁴ <http://www.alzheimers.org/pubs/adfact.html>

¹⁹⁵ http://www.ninds.nih.gov/health_and_medical/disorders/alzheimersdisease_doc.htm

¹⁹⁶ <http://www.docguide.com/news/content.nsf/PatientResAllCateg/Alzheimer's%20Disease?OpenDocument>

¹⁹⁷ <http://www.vh.org/Patients/IHB/GeriatricEducation/AlzheimersTOC.html>

Alzheimer's Association¹⁹⁸ and the Alzheimer's Disease Education and Referral Center¹⁹⁹. These organizations provide excellent information to caregivers of persons with Alzheimer's disease.

Selected Readings and Resources

- Listing of Alzheimer's Disease research centers²⁰⁰
- Local Alzheimer's groups²⁰¹.
- The Alzheimer's Research Organization²⁰² site lists books, national and international organizations and research links.
- Go to the Northwestern University's Alzheimer's Disease Core Center²⁰³ for information about Alzheimer's disease and care options.

¹⁹⁸ <http://www.alz.org/>

¹⁹⁹ <http://www.alzheimers.org/>

²⁰⁰ <http://www.usc.edu/dept/gero/ADRC/otherlinks.htm>

²⁰¹ <http://home.sprintmail.com/~alznet/page8.html>

²⁰² <http://www.alzheimers-research.org/links.html>

²⁰³ <http://www.brain.nwu.edu/core/index.htm>

XI. How Can I Make My Special Needs Child's Future Secure?

A Personal Definition

Independent Living is a philosophy and a movement of people with disabilities who work for self-determination, equal opportunities and self-respect. Independent Living does not mean that we want to do everything by ourselves and do not need anybody or that we want to live in isolation. Independent Living means that we demand the same choices and control in our every-day lives that our non-disabled brothers and sisters, neighbors and friends take for granted. We want to grow up in our families, go to the neighborhood school, use the same bus as our neighbors, work in jobs that are in line with our education and abilities, start families of our own. Just as everybody else, we need to be in charge of our lives, think and speak for ourselves. To this end we need to support and learn from each other, organize ourselves and work for political changes that lead to the legal protection of our human and civil rights.

Adolf Ratzka

Introduction

One of the most challenging aspects of parenting can be the realization that your child will need assistance throughout his lifetime because of developmental disabilities, a mental or physical condition or an illness or disability that resulted later in life. Advances in medical care now enable many people who face challenges because of their physical or mental condition to live into adulthood and old age. In most instances, there are options that allow persons with disabilities to live independently in the community with appropriate supports. However, if you are a caregiver to your adult child, you will want to plan for the possibility that you may not always be able to meet his needs or ensure his welfare.

With special education, employment²⁰⁴ opportunities, housing²⁰⁵ options, medical care, supportive services and financial support and legal arrangements in place, your child may have the tools to be as independent as possible. Membership

²⁰⁴ <http://janweb.icdi.wvu.edu/>

²⁰⁵ <http://www.hud.gov/groups/disabilities.cfm>

organizations²⁰⁶ that work to improve conditions for persons with disabilities might also be able to help.

It's the Law

The Americans With Disabilities Act (ADA)

The Americans With Disabilities Act (ADA)²⁰⁷ is probably the most important law dealing with the rights of persons with disabilities. The ADA prohibits discrimination on the basis of disability in employment, in programs and services provided by state and local governments, in the provision of goods and services provided by private companies, and in commercial facilities.

Signed into law on July 26, 1990, the ADA contains requirements for new construction, alterations or renovations to buildings and facilities, for mass transportation facilities, and for improving access to existing facilities of private companies that offer goods or services to the public. It also assures public access to State and local programs. The ADA also covers effective communication with people with disabilities, eligibility criteria that may restrict or prevent access, and requires reasonable modifications to discriminatory policies and practices.

The Disability Rights Education and Defense Fund, Inc. (DREDF)²⁰⁸ works to ensure the civil rights of persons with disabilities.

The Protection and Advocacy Program (P&A) in each State provides legal representation, advocacy, and information and referral to persons with developmental disabilities. The P&A offers consumers and families information on resources in their State. To find out how to locate your P&A contact the Administration on Developmental Disabilities²⁰⁹ in the U.S.

Department of Health and Human Services:

Below are questions for caregivers and adult children to consider:

Housing and Living Arrangements

Can you live independently? Personal assistance services (PAS) or personal care services (PCS) can promote economic self-sufficiency, independent living, and inclusion of people of all ages and virtually all disabilities into society. Many consumers and families want the option to select, hire, and train their own caregivers and select among services they need for independent living in their

²⁰⁶ <http://www.adanet.org/>

²⁰⁷ <http://www.usdoj.gov/crt/ada/anchor1149130>

²⁰⁸ <http://www.dredf.org/>

²⁰⁹ <http://www.acf.dhhs.gov/programs/add/>

homes and communities. The availability of more consumer-directed PAS is making this increasingly possible.

Medicaid offices can provide information on the availability of funding for these services. There are different types of programs and funding that may be available in each state including Home Health Benefits, Personal Care Benefits and Home and Community Based Services Waivers. Consumers can inquire about their options under each program. The Medicare Program also provides for home health aide services. Consumers and families can get information on PAS, the different programs and funding sources for these types of services from the Protection and Advocacy Programs discussed in the “It’s the Law” section above.

Independent Living Centers (ILCs)²¹⁰ are advocacy organizations that are generally managed by individuals with disabilities. To locate an ILC, consumers and families can click on ILC Links for a list of States with ILCs.

If your child lives with you, can he or she continue to live in your home, if you are not there? Will this require:

- Changes in the physical layout of the house or special assistive²¹¹ (type in the word or phrase that describes the product(s) you want on this site)
- A companion and/or supportive services?
- If so, how will you arrange for payment related to the house and the supportive services?
- Is shared housing, living with other family members, or a group home a better option?
- Another option is housing²¹² designed for persons with disabilities who are between the ages of 18 and 62.
- Mobility and Transportation
- Does your child have the best form of mobility or are there new devices that can help to improve his or her access?
- Have you modified your home for greater access, with ramps or motorized stair climbers?
- Can your child drive and, if not, can she or he learn?
- Can a van or car be modified for his or her use? (Check with your tax adviser to see if this may be tax deductible.)
- If not, are there special transportation services in your community that he or she can use? To find out, contact your State Protection and Advocacy Agency.

²¹⁰ <http://www.bcm.tmc.edu/ilru/index.htm>

²¹¹ <http://www.abledata.com/text2/keyword.htm>

²¹² <http://www.hud.gov/groups/disabilities.cfm>

Keeping Up With New Medical Advances

In today's fast changing world of medical and biotechnology it is more important than ever for you and your child to stay abreast²¹³ of the latest findings and developments relating to your child's condition. These can include the areas of nutrition and assistive devices as well as new drugs and medical technologies that offer improvements and even cures for diseases and conditions that were, only recently, considered to be largely incurable or untreatable. Perhaps one of the best ways to do this is to browse several key²¹⁴ Internet sites from time to time as well as special sites and to join organizations that are working to improve conditions for persons who have specific conditions and disabilities.

The Department of Veterans Affairs²¹⁵, which provides benefits and services to veterans who have service-connected disabilities and conditions. This site offers entrance into a large number of useful web sites that provide information on benefits for Veterans.

Education and Training

The Office of Special Education and Rehabilitative Services (OSERS)²¹⁶ administers programs that assist in educating children with special needs, provides for the rehabilitation of youth and adults with disabilities, and supports research to improve the lives of individuals with disabilities.

Under OSERS, the Rehabilitation Services Administration (RSA) oversees programs that help individuals with physical or mental disabilities to obtain employment through the provision of such supports as counseling, medical and psychological services, job training, and other individualized services. RSA's major formula grant program provides funds to state vocational rehabilitation agencies to provide employment-related services for individuals with disabilities, giving priority to those who are severely disabled.

Individuals with disabilities and families are empowered and are advocating for equal rights, full inclusion in society, independent living, self-determination and employment. The movement toward Person Centered Planning has resulted in

²¹³ <http://www.healthfinder.gov/default.asp>

²¹⁴ <http://www.naric.com/>

²¹⁵ <http://www.va.gov/>

²¹⁶ <http://www.ed.gov/offices/OSERS/>

employment and other choices based on the specific interests, preferences and goals of individuals with disabilities.

University Affiliated Programs (UAP) across the country have been training individuals, families and professionals on issues such as Person Centered Planning and Self-determination. UAPs in each state can be located by contacting the Administration on Developmental Disabilities.

- If your child is older do you feel that every educational²¹⁷ opportunity has been explored and taken advantage of?
- Can new assistive devices open opportunities for learning that were not available when your child was younger?

Today there are more special educational²¹⁸ opportunities²¹⁹ that could further enhance employment opportunities.

Making Financial and Legal Arrangements

If your child or relative does have disabilities that prevent him or her from being financially independent and secure or make personal decision-making difficult, you can investigate legal and financial arrangements which are discussed in the sections on Where Can I Turn for Help?²²⁰; How Do I Hire a Home Care Employee?²²¹; and Who Will Care if I Am Not There?²²²

Selected References and Readings

Federal Web Sites

The President's Committee on Mental Retardation has an excellent listing of federal web sites²²³ relating to the range of agencies that assist Americans with disabilities as well as national organizations²²⁴ that serve Americans with mental retardation and developmental disabilities.

²¹⁷ <http://www.aucd.org/>

²¹⁸ <http://www.fcsn.org/>

²¹⁹ <http://www.fcsn.org/fdrlsped.htm>

²²⁰ <http://www.aoa.gov/wecare/where-to-turn.html>

²²¹ <http://www.aoa.gov/wecare/hire.html>

²²² <http://www.aoa.gov/wecare/who-will-care.html>

²²³ <http://www.acf.dhhs.gov/programs/pcmr/national.htm>

²²⁴ <http://www.acf.dhhs.gov/programs/pcmr/states.htm>

Go to the Federal Communications Commission Disabilities²²⁵ Rights Office for information about the communications technology revolution and the efforts being made to ensure that Americans with disabilities have equal access.

For information on assistive transportation technology projects, contact the U.S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research (NIDRR), State Technology Assistance Projects. For information on accessible transportation, consumers and families can contact their State Protection and Advocacy Agencies.

National Organization Web Sites

The National Institute for Children and Youth with Disabilities²²⁶ has an excellent web site. Click on State Resource Sheets for information in each state. There is information on how to access resources and advocate for appropriate educational supports and services.

Family Voices²²⁷ is an advocacy organization with a web site that covers a wide range of issues.

Visit the National Association of Developmental Disabilities Councils²²⁸ web site. Another good web site is the World Institute on Disability²²⁹. The National Institute on Disability and Rehabilitation Research's information dissemination center²³⁰ provides information about advances in various disability research areas.

This Rehabilitation Engineering and Assistive Technology Society of America site offers some consumer oriented materials relating to assistive technology²³¹.
Commercial Web Sites

This site maintained by the American Association of People with Disabilities offers a listing²³² of web sites -- many of them commercial -- that may be helpful—from magazines to trips for persons with disabilities.

There are numerous companies on the Internet that sell new and used specially equipped vans and other modified vehicles for persons with disabilities.

²²⁵ <http://www.fcc.gov/cgb/>

²²⁶ <http://www.nichcy.org/index.html>

²²⁷ <http://www.familyvoices.org/>

²²⁸ <http://www.naddc.org/>

²²⁹ <http://www.wid.org/>

²³⁰ <http://www.ncddr.org/>

²³¹ <http://www.resna.org/resna/pubsbro.htm>

²³² <http://www.aapd.com/>

This Disabilities Search²³³ site includes organizations, university sites and some schools that serve the developmentally disabled. There is also a directory of conditions that are broadly termed developmentally disabled on this same web page.

²³³ <http://search.lycos.com/default.asp?src=netscape&query=disabilities+search+site>

XII. Who Will Care if I Am Not There?

Introduction

As caregivers, we cannot assume that we always will be able to provide care. Even if we are able to be active caregivers, it is important to establish both emergency and long-term alternative care plans for our older relative or friend, and to make sure that the necessary legal documents are in place.

Legal Documents and Care Plans That Should Be in Place

Every adult should have at least a power of attorney, a living will or medical directive²³⁴ and a will or trust in place so that his or her wishes can be followed. If your older family member does not have these legal directives²³⁵, you both should consult an attorney and have the appropriate documents drawn up.

When making alternative long-term care arrangements, you will want to discuss the matter with your care receiver(s), if at all possible, and follow their wishes about the person(s) or facility that would care for them, if you were unable to do so. If your care receiver(s) want to live with another family member or friend, you will, of course, want to discuss this arrangement with the proposed caregiver to ensure that it is agreeable.

If your relative can make informed choices about an alternate caregiver, living arrangement, and other matters, it will be easier to make long-term plans, if you have a power of attorney²³⁶. If your older relative or friend cannot make informed choices it may be necessary to seek appointment as a conservator and/or guardian. This requires an appointment from the court to act on your care receiver's behalf regarding matters of care and financial dealings. Whenever possible, discuss your plans for alternative living arrangements or caregiver choice with your older family member or friend and with other close family members as well as the designated caregiver. This will help to avoid opposition in the future that could lead to serious problems.

If you are the only possible informal caregiver, you and/or your relative can appoint a trusted friend or perhaps a committee composed of several friends to

²³⁴ <http://www.ama-assn.org/public/booklets/livgwill.htm>

²³⁵ <http://mel.lib.mi.us/social/SOC-wills.html>

²³⁶ <http://www.24thdiscourt.org/legal.htm>

oversee your relative's care, or you may decide that it is best to have a lawyer act as your care receiver's representative. These arrangements also should be legally established.

Once you have decided on an alternate caregiver(s), it will be necessary to ensure that they, too, have the legal power needed to make decisions, should your care receiver be unable to do so. This may involve a durable power of attorney, a special medical power of attorney²³⁷, and, in some states, a special power of attorney, if property is to be bought or sold, or a guardianship and/or conservatorship. As stated before, you should ensure that both you and your care receiver have medical directives, living wills and estate wills and/or trusts established, if there are financial resources available for your care receiver.

In choosing a long-term care housing arrangement it is a good idea to select one that can provide varying levels of care so that your care receiver will not be forced to move, if his or her medical condition changes.

Short-term emergencies don't require the same amount of legal planning, but they must be considered. If you are unable to look after your care receiver, you will need to make arrangements with:

- a relative or friend
- a facility that provides short-term respite care (many nursing homes and assisted living facilities offer such care)
- a home care agency
- a geriatric care manager.

Remember that home care agencies often cannot provide services on short notice, and that you may need to have more than one family member or friend as a backup person. For information on sources of assistance in choosing care alternatives see the section on *Where Can We Turn for Help?*²³⁸ For information on housing alternatives and living arrangements see the section on *What Housing Options Are Available?*²³⁹

Additional Resources and Readings

The National Aging Information Center's Internet Information Note on Legal Services²⁴⁰ for Older Adults and Elder Law has a host of web sites dealing with

²³⁷ <http://www.texmed.org/pmt/lel/legalmedurable.asp>

²³⁸ <http://www.aoa.gov/wecare/where-to-turn.html>

²³⁹ <http://www.aoa.gov/wecare/housing-options.html>

²⁴⁰ <http://www.aoa.gov/naic/Notes/elderlaw.html>

every aspect of legal documents that you and your care receiver might want to consider in planning for the future.

Maine Legal Services for the Elderly²⁴¹ maintains a list of links to legal services in various states which can be helpful.

NAIC's Internet Information notes entitled hospice and palliative care²⁴², for information on this as well as medical directives and the end stages of life.

²⁴¹ <http://www.mainelse.org/states.htm>

²⁴² <http://www.aoa.gov/naic/Notes/Hospice.html>