

Cherish the Circle of Life

Loving Conversations



**A Step-by-Step Guide for
Families Facing Issues of Aging**



Caring for an aging parent is one of the most important—and potentially rewarding—challenges you will ever face.

It's the circle of life.

Your mom and dad used to take care of you.

Now—or at some point in the future—they may need you to take care of them.

If you have a spouse, children and a job, you may feel overwhelmed by trying to care for so many people. If you're single, the challenge can seem all the more daunting.

Yes, the role of caregiver can be a complicated one. It can be painful to watch a loved one grow older. You may feel you can never do enough.

As with many other issues in our lives, achieving success means having the best information. This booklet presents information about issues you might have to address.

While you and your parent may face difficult decisions, the good news is that there are many options available. The key is to choose the option that makes the most sense for your parent and family based on a number of factors, including:

- Your parent's health and mental state
- Both your financial status as well as that of your parent
- Your parent's preferences
- How much time you—and other family members—have to devote
- How extensive is your social support network and that of your parent—friends, church?
- Distance: where does your parent live?

Bear in mind that your family situation and the needs of your parent will probably unfold over time. That's why you should find a place in your home for this booklet. It's a resource you may wish to refer to from time to time.

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The information in this booklet is as accurate as possible, but you and your parent should consult with a doctor, accountant, lawyer, clergy or other advisor before implementing any medical, financial or legal steps. You should also visit and thoroughly investigate any living or care facility you may be considering. Easter Seals is not responsible or liable for any actions taken based on the information in this booklet.



Remember, you're not alone— in three important ways.

Sometimes when we face tough challenges, we feel like we're alone and the whole world is on our shoulders. But you're not alone, and here's why:

1. **You're one of millions.** Estimates show that one of every four households cares for a sick or disabled loved one aged 50 or older. And the population of seniors is expected to double by the year 2030. More and more people will be caring for aging parents in the years to come.
2. **You can make caregiving a family affair.** While you may be the primary caregiver, don't be afraid to ask other family members—or even friends—for help. If possible, assign specific responsibilities to each team member, including their children if they can assist. For example, if your parent lives nearby—and other relatives do as well—one person can bring lunch two days a week, two others can make one dinner each week, one can bring mom and dad to the doctor, and so on.
3. **There are numerous support services** (see references throughout this booklet). These resources exist for a reason: to provide information to you to help your parent in ways you may not be able to help, and to give you more time for yourself. And today, support groups can be both online and in person.

To be effective, it may be wise to expand your circle of support to include friends, neighbors, volunteers, clergy and other professionals. You should not feel guilty because you cannot do everything. Be willing to delegate tasks and take advantage of community programs and professional resources for help.

Encourage everyone in the family—and anyone else who wants to help—to talk freely with your parent about what he/she feels is best, especially before an acute medical situation crops up. When everyone is talking and exchanging ideas, it's usually easier to make life-changing decisions—if and when necessary. And, most of all, remember to keep your parent involved in all decision-making processes.

Great discussions lead to smart decisions.

The purpose of this booklet is to present topics you might have to discuss with your parent—and siblings—ranging from financial matters and living arrangements to health insurance and medications.

While no booklet could possibly cover every topic in full detail, we also indicate sources that provide a comprehensive explanation of each topic. But no amount of information is as valuable as meaningful dialog. Whenever possible, involve every family member in your “Loving Conversations.” Also, try to make sure that your parent either makes—or is comfortable with—every important decision.

Here are some helpful hints:

1. **Don't procrastinate.** It's easy to put off conversations when you anticipate that they could be awkward. But heart-to-heart discussions can bring a parent and child closer together.
2. **True dialog** will depend in part on your parent's mental, emotional and physical condition, which will largely determine the extent to which he or she is able to make—or contribute—to sound decisions. But regardless of his or her condition, try your best to help your parent retain some measure of control over decision-making whenever possible. And try to honor his or her wishes when feasible.
3. **Honesty is the best policy.** It's important that you encourage your parent to express his or her feelings and preferences. It's equally important to express your own needs and limitations, conveying what you can and cannot do.
4. **Reassure** your parent that you are there, ready and willing to help in every way possible.
5. **Educate yourself** so you can bring helpful information and insights to your conversations. Everyone feels better about well-informed decisions because they're based on weighing all the factors and options.
6. **Involve the whole family.** There are even excellent resources available for children between the ages of 5 and 18 to learn about the needs of older adults.

7. **Reach out to your circle of support.** While, your parent and his/her wishes are always central, it is important to learn about and reach out to your existing circle of support. (see Figure 1).

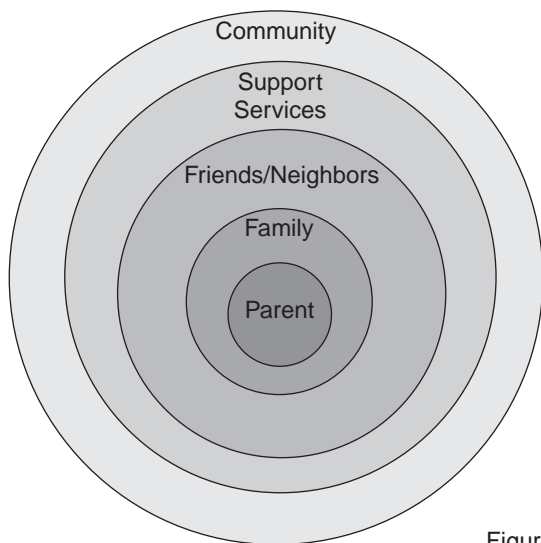


Figure 1

Let's start with Health Insurance and Other Benefits

Your first concern should be decisions about health care—especially insurance coverage. It's a good idea to look at what kind of insurance coverage your parent has, to understand what is available and to discuss whether any changes would be prudent.

Facts about Medicare

The good news is that most people aged 65 and over are entitled to Medicare benefits, and Medicare covers most medical needs. In fact, anyone who has worked for at least 10 years under Medicare-covered

employment is automatically enrolled in Medicare Part A when they reach age 65.

- Medicare Part A (Hospital Insurance) covers hospital services and some home health care and time spent in skilled nursing facilities.
- Medicare provides coverage for limited outpatient and long-term care, based on medical necessity. It does not cover alternative living arrangements such as adult day programs or assisted living.
- Medicare services often result in out-of-pocket costs.
- Medicare covers most admissions to skilled nursing facilities for patients recovering after a hospital stay.
- Medicare also pays for admissions to hospice care for people who have been diagnosed with terminal illnesses. However, when hospice care is chosen, coverage for other Medicare benefits stops.
- Medicare Parts A and B have limited deductibles. Medicare Part B (Supplemental Medical Insurance) covers physician care as well as outpatient hospital and independent lab services. However, you must pay a monthly premium to participate in Part B, and there is a 20% co-pay.
- Part D is the new outpatient prescription drug benefit added to Medicare in 2003 that is now available to all Medicare enrollees. Part D coverage is provided through private plans that contract with Medicare. In addition, additional assistance with plan premiums and cost-sharing amounts is available for low-income beneficiaries. Enrollees in Medicare drug plans pay a monthly premium that averages \$25 across plans in 2006.
- For more information about the Medicare program, visit www.Medicare.gov

Facts about Medicaid

Medicaid—called “Medical Assistance” in many states—is a joint federal and state program designed to help defray medical costs for people of limited financial means.

- Medicaid coverage varies state to state. Medicaid services may be more limited than those covered by Medicare. Most Medicaid generally has limited outpatient therapy coverage, for example.

- To qualify, income and financial assets must be below a specified amount. This can be particularly problematic if only one spouse requires nursing home care. It used to be that the spouse “at home” would have to fundamentally reduce income and assets to poverty levels before becoming eligible. Fortunately, changes in the Medicaid rules now allow the spouse to keep a monthly income and some assets, including the primary residence. But the amounts allowed are always changing, so it’s important to check on the latest details.
- Most states also have applied to the Federal government for permission to provide additional home and community-based services such as adult day care, ongoing in-home care and others. These are known as Medicaid waivers and vary considerably from state to state.
- For more information about the Medicaid program, visit www.Medicaid.com

What is Medigap insurance?

Because Medicare doesn’t cover all outpatient prescription drugs or long-term care, many older people buy a Medigap supplemental health insurance policy:

- Medigap provides access to a broader choice of health care facilities without dipping into additional financial resources.
- Medigap supplemental insurance policy covers deductibles and co-pays. However, Medigap does not cover long-term care. Be sure to examine any Medigap policy to ensure that it doesn’t duplicate other health insurance, such as coverage provided by a previous employer.

What is long-term care insurance?

Long-term care insurance is a private insurance that is usually either an indemnity policy or part of an individual life insurance policy. If it’s an indemnity policy, it’s a type of health insurance in which the insurer pays for certain services after care has been given; there are maximum amounts specified in the policy that will be paid for covered services.

Here’s what you need to know:

- Policies are priced based on the policyholder’s age, the deductible periods chosen and indemnity value or duration of benefits.

- Long-term care services are directed at two different levels of care (determine your parent's needs and make sure the policy will pay for services that will meet those needs):
 1. Activities of Daily Living (ADLs) such as eating, bathing, dressing, getting out of bed and walking.
 2. Instrumental Activities of Daily Living (IADLs) include assistance such as help with managing money, shopping, meal preparation, transportation and heavy housework.
- Policies are available from many sources, including insurance companies and non-profit organizations. You may want to consider long-term care insurance for yourself.

Is your parent covered by a previous employer?

Approximately 37 percent of Americans who retire before age 65 have health insurance coverage from their previous employer, and 27 percent of those older than 65 have similar coverage. However:

- Most retirees have no such coverage. But, if your parent was a member of a union or a veteran, some benefits may be available.
- Typically only the largest companies provide health insurance to retirees. In addition, coverage has generally eroded, and many with this type of health coverage are now expected to pick up a greater share of the cost.
- Fortunately, seniors can get individual health insurance through a variety of sources. In fact, when an individual reaches age 65, they can expect to be solicited by many health insurers.

How to Find Information about other Benefits and Eligibility Requirements

Many older adults are eligible for a variety of federal and state benefits. Depending on a variety of factors, you or a loved one might be eligible for help with:

- Nutrition (including Food Stamps)
- Energy assistance
- Financial Issues

- Legal Issues
- Social Security
- Housing
- In-home services
- Tax relief
- Transportation
- Educational assistance
- Employment
- Volunteer services

To find out more about what programs you or a loved one might be eligible for, visit www.benefitscheckup.org

Where's the best place to live?

Some Questions

The ideal place for your parent to live could change over time. When talking to your parent about living arrangements, you might want to ponder these questions:

1. **Can they maintain their current home?** If your parent is no longer able to do such chores as yard work and housekeeping, can he or she afford to pay someone to do these things? Or are there volunteer groups or church groups that can help out?
2. **Is the home suitable for some of the limitations that might come with growing older?** For example, is there a bedroom and bath on the first floor? Do they have to climb stairs?
3. **Does your parent need help** with grocery shopping and making meals?

Some Options

Option #1: Stay at home

This is by far the most common living arrangement. Some older adults remain in homes they've owned for many years, others move into communities specifically designed for seniors, move to be near other family, or retire far away from their roots.

If aging parents are in good shape physically and mentally and they can still look after their home and themselves, remaining at home is often the best—and simplest—option. Of course, it may be appropriate to make a change in living arrangements should his or her situation change or health concerns arise.

Here are some tips you may wish to share with your parent:

- Whether an older person needs frequent nursing care, assistance with bathing and dressing or meal preparation, he/she can remain at home and arrange for **in-home nursing care and house-keeping services**. There are private pay arrangements and government funded programs to support these options.
- The cost of maintaining one's home while paying for additional services and supports can often be overwhelming. One possible option to consider might be a **reverse mortgage**. Reverse mortgages allow homeowners aged 62 and over to convert home equity into cash while living at home. Visit www.ncoa.org
- For those concerned about leaving their parent home alone all day, there are many **adult day centers** where frail or elderly people can spend a large part of their day. Activities include exercise programs, singing, guest lectures and community outings.
- See whether there is an **Easter Seals Adult Day Center** near where your parent lives (www.easterseals.com). Easter Seals adult day services help alleviate the tremendous responsibilities placed on primary caregivers, allowing them to continue working or just take a brief respite, managing their family life and maintaining their personal health while caring for an aging parent. Easter Seals Adult Day services:
 - focuses on prevention and health promotion through regular monitoring
 - provides a warm and homelike environment

- are staffed by caring, compassionate personnel who receive extensive training and support
 - are housed in a safe and secure setting
 - help to reduce emergency room visits and hospitalization
 - meet the need for extensive, continued care and supervision
 - help prevent social isolation through vital and lively activities
- Older individuals have a variety of **meal choices** to help them retain some independence. Group meals at the senior center or home-delivered meal programs help ensure an adequate diet. Meals-On-Wheels programs are available in most communities. Many supermarkets and restaurants now offer home delivery as well.

STAYING AT HOME?

If the answer to any of the following questions is yes, you should consider whether it may no longer be appropriate or safe for your parent to be alone.

- | | |
|---|--|
| <input type="checkbox"/> Could your parent become so disoriented that he or she might wander off away from the home? | <input type="checkbox"/> Can he or she find and take the right medication when needed? |
| <input type="checkbox"/> Can your parent recognize signs of danger—such as smoke or a fire alarm—and make a quick exit in an emergency? | <input type="checkbox"/> Can your parent discriminate between people he or she should and shouldn't allow inside the home? |
| <input type="checkbox"/> Would your parent know to dial 911 in an emergency? And would he or she be able to communicate clearly? | <input type="checkbox"/> Could your parent be in danger by forgetting to turn off the stove or accidentally starting a fire? |
| <input type="checkbox"/> Is your parent susceptible to life-threatening medical emergencies? | <input type="checkbox"/> Can your parent take care of personal hygiene? If not, have you arranged for help? |
| | <input type="checkbox"/> Is your parent afraid to be alone? |

- **Respite care** brings a trained person into the home to give the full-time caregiver time off to do things like: get a haircut, visit the dentist or take a vacation. Respite care expenses are paid in a variety of ways, primarily private pay but other state/local programs may exist.
- **Geriatric Care Managers (GCM)** are health and human service specialists who help families care for older relatives while encouraging independence. The GCM acts as a guide and advocate—to identify problems and offer solutions including residential and service delivery options.
- For those concerned about falls and other situations while they are alone, **portable emergency call systems** are available in most communities in the U.S. Many such services also offer check-in calls and medication reminders.
- Studies have shown both **health & wellness, activities and rehabilitation** to enhance ones' quality of life and independence as they grow older. Services such as occupational, physical and speech therapy may be available on both an outpatient and in-home basis. Exercise and fitness programs are offered through senior centers and health clubs.

Remember that caregiving is a dynamic challenge. It's important to continually monitor your aging parent—especially his or her physical condition and abilities—so you can discuss periodic adjustments that may be appropriate. This could mean getting additional help while your parent continues living at home. Or it could mean that it might be best for your parent to live in a place where he or she can get the care needed.

Option #2: Move in with family

When children and adults share a household with an aging loved one, the experience can enrich everyone. Conversely, though, such an arrangement presents potential for conflict. Be proactive in discussing possible problems that might arise. Be sure to consider these issues and try to avoid proceeding with this option if you think it might cause more problems than it solves:

- Will it affect children's social lives and relationship with grandparents?
- Will everyone pitch in and make caring for an aging parent a positive

and rewarding experience?

- Will you be pulled in too many directions or can you delegate responsibilities?
- Will your spouse and children get the attention they need?
- Will you have enough time for yourself, including exercise?

WARNING SIGNS

If you spot any of these warning signs, your parent is at risk and you should consider taking action:

- | | |
|---|--|
| <input type="checkbox"/> Sudden weight loss could be a result of a medical issue or may indicate that your parent is not eating. | physical weakness or general inability to handle a vehicle. |
| <input type="checkbox"/> Failure to take medication or taking improper doses may indicate confusion, forgetfulness or a misunderstanding of the doctor's instructions. | <input type="checkbox"/> Increased forgetfulness such as not paying bills, missing appointments, or skipping meals may be a sign of early stage memory impairment, depression or drug interaction. |
| <input type="checkbox"/> Burns, bruises or other injuries may indicate physical problems involving general weakness, forgetfulness or loss of balance. | <input type="checkbox"/> Dozing off while smoking, forgetting to turn off the stove or appliances, or carelessness with candles are fire safety concerns. |
| <input type="checkbox"/> Deterioration of personal habits such as infrequent bathing and shampooing, not shaving, or not wearing dentures could indicate the onset of memory loss or physical problems. | <input type="checkbox"/> Unusual behavior such as hoarding, suspiciousness or wearing clothing not appropriate for weather conditions all can be indications of memory impairment, dementia or mental health concerns. |
| <input type="checkbox"/> Increased car accidents, scrapes or dents can indicate slowed reflexes, poor vision, | <input type="checkbox"/> Disorientation or getting lost in a familiar location should be taken seriously. |

Option #3: Independent Living

Apartments, condominiums and entire communities have been designed with the specific needs of older adults in mind. Some considerations with independent living options include:

- Availability of services such as transportation and meals
- Array of social/recreational options
- Should your parents health take a turn for the worse, could increased assistance be provided or would another move be necessitated?

Option #4: Assisted living

Assisted living facilities vary state-by-state in services, size, philosophy and cost. Some have only a few residents; some have hundreds. Medicare does not pay for assisted living, and Medicaid payments vary considerably from state to state. What most assisted living facilities have in common are a range of support services for individuals who are limited in their ability to care for themselves. One of the key considerations in selecting an assisted living facility is how they handle increases in frailty or confusion. The best possible option is often one that provides a continuum of care that would afford residents the option of “aging in place.”

That's where you can be instrumental. Take your time and look at the many options available. The ultimate choice you and your parent make will have a profound impact on your parent's sense of dignity and well-being. Assisted living facilities typically offer:

- private rooms or small apartments
- common areas for socializing and recreation
- planned activities
- 24-hour staffing and controlled access
- personalized care and support services, including meals that are served in a common dining area or brought to a resident's room
- shuttles for errands and appointments
- housekeeping

- help with medication management and emergency call monitoring
- resident supervision

Option #5: Continuing Care Retirement Community (CCRC)

Many of these communities are located on campus-style settings that provide an attractive environment for retired people. They typically provide a comprehensive menu of care including independent living in private apartments, assisted living and nursing home care. One advantage of a CCRC is that the elderly parent or couple doesn't have to move to another type of facility just because his or her health care needs change over time.

A CCRC usually provides a written agreement or long-term contract between the resident and the community. This agreement often covers the individual's lifetime.

Do bear in mind that CCRCs are expensive and they often charge an entrance fee as well as monthly rent.

Option #6: Skilled nursing facility

Nursing homes can be large or small, rural, suburban or urban. They vary widely in the plans, activities and services they offer. Also known as skilled nursing or extended /long-term care facilities, they provide care for people whose medical needs require licensed nurses and/or therapists, but not the more intensive care of a hospital.

A short-term or long-term stay in a nursing facility can make sense for other reasons:

- Hospitals are discharging patients more rapidly than ever. Yet the patient may still need recovery and rehabilitation before resuming normal activity.
- Healthcare is more complicated than ever, involving various tests, medications and therapies. Skilled nursing facilities may be able to address these complex needs.

Nursing facilities options:

- short-term skilled nursing, restorative and rehabilitative care after hospitalization
- extended care for the frail and chronically ill, and those with Alzheimer's or other forms of dementia

Here are some important and interesting facts you and your aging parent should know:

- At any given point in time, only a small percentage of the elderly population lives in nursing homes.
- Admission requires a doctor's order.
- Nurse's aides provide day-to-day care.
- Nursing facilities take an interdisciplinary approach with social workers, dietitians, physical, occupational and speech therapists, recreational therapists and others on staff to support physical and emotional well-being.
- Many admissions to nursing homes follow hospitalization, especially for Medicare patients. These are typically short-term stays for rehabilitation until a patient is able to be sent home to complete recovery.
- The nursing home selection process will be affected, in part, by whether your loved one is in need of short-term recovery care or long-term care.

Option #7: Alzheimer's/dementia facilities

Over 5 million individuals have Alzheimer's disease or dementia in the U.S., according to the Alzheimer's Association. This translates to 1 in 8 persons over 65.

When looking for a facility or program, be very attuned to the staff's attitude and philosophy about the care they provide. Pay close attention to nursing care plans, meal preparation and planned activities. And look for staff capabilities and facility features designed specifically to make life easier for individuals with memory impairment, such as:

- professional staff trained in helping people with memory impairments
- varied activity programs designed to meet the specialized needs of those with memory impairment
- visual cues such as color-coded hallways, toilet and kitchen locator signs incorporating graphics
- memory boxes—containers that display photos and mementos to help the individual identify his/her room
- secure outdoor space providing opportunities for gardening and walking

In addition to providing specialized care for persons with Alzheimer's or dementia, these programs often offer education and support to family caregivers.

IMPORTANT ISSUES TO CONSIDER WHEN CHOOSING A NURSING HOME OR OTHER FACILITY

- | | |
|--|---|
| <input type="checkbox"/> Are rooms comfortable and do they have adequate light and ventilation? | <input type="checkbox"/> Do recent inspection results reveal any major problems? |
| <input type="checkbox"/> Are activities interesting and varied? | <input type="checkbox"/> Do they accept Medicare and Medicaid, if needed? |
| <input type="checkbox"/> Are meals appetizing and served in a pleasant setting? | <input type="checkbox"/> If your parent is covered by an HMO, is the facility approved for reimbursement? |
| <input type="checkbox"/> What is the facility's reputation for caring about patients' quality of life? | <input type="checkbox"/> Do services and capabilities match parent's needs? |
| <input type="checkbox"/> Is staff friendly, knowledgeable and dedicated? | <input type="checkbox"/> Are rates competitive? |
| <input type="checkbox"/> Are the building and grounds well maintained? | <input type="checkbox"/> Do facility policies and practices support privacy and dignity? |
| <input type="checkbox"/> Does staff encourage family visits and involvement? | <input type="checkbox"/> Is the facility in a convenient location for visits from family and friends? |

Money matters really do matter

When it comes to aging parents' finances, the caregiver may end up handling or arranging for someone else to pay bills, make deposits, manage insurance and benefit claims and countless other financial matters.

Managing financial matters for an aging parent can be challenging, especially if the caregiver lives far away or lacks needed skills. Hence, if someone other than the caregiver is better suited, the caregiver may wish to delegate responsibility or seek outside counsel. After all, poor investment decisions can reduce the parent's assets and lifestyle. Lack of clarity in financial matters can lead to disputes with family members or others, often resulting conflict and even lawsuits.

Here are some topics for family discussion:

1. **What's the current situation?** It's very important to have a reasonably accurate assessment of your parent's finances. Many caregivers have been surprised to find that their parent has far less or more money than they thought.

Try to develop an inventory of all assets, including insurance policies and retirement plans. Is property held jointly with others? Who are the beneficiaries on the policies? Do they have a safety deposit box or documents stored in other places?

Closely review your parent's insurance coverage and government benefits. For example, a disability insurance policy might cover physical therapy or other services in addition to providing monthly disability payments to your parent. A life insurance policy usually has cash value and may even include an option to receive an advance payment of a portion of the death benefit. You or someone you trust should examine your parent's rights and benefits under Social Security, Medicare, Medicaid, private insurance, Veterans Administration and employee benefits.

2. **Consider using outside help, especially if you live far away.** There are professionals who pay bills, balance checkbooks, monitor insurance claims and handle other daily financial responsibilities for other people. Geriatric care managers may also be able to fulfill this role.

3. **Are you accessing all of the benefits you are entitled to?**

There are many free or discount assistance programs available, and many lawyers, financial advisors and other professionals offer free initial consultations. But for ongoing assistance at little or no cost, consider the services available from private organizations and government agencies in your city or state. For example:

- Start with your agency on aging and by visiting www.benefitscheckup.org
- Does your or your spouse's employer offer financial counseling services that are available to workers and their families?
- Social service agencies sponsored by state or county government agencies and private organizations, including those affiliated with certain religious groups but available to people of any faith.
- The local or national offices of disease-specific organizations, including the American Cancer Society or the Alzheimer's Association, as well as other membership groups (such as AARP).

4. **Help your parent think carefully about borrowing money.**

Your parent might need extra cash for medical or other expenses. Sometimes it might make sense to use a credit card or get a loan. If your parent still owns his or her home, he or she might want to borrow against the equity by refinancing the mortgage, taking out a separate home equity loan or getting a reverse mortgage.

National Council on Aging's Use Your Home to Stay at Home™ initiative is a public/private partnership that encourages the appropriate use of home equity to help older people live at home visit www.ncoa.org for 3 publications for seniors on reverse mortgages. Some banks also have loan programs just for people with disabilities so they can buy specially equipped vans or to make homes and businesses more accessible. Before agreeing to any loan, make sure the debt is manageable.

5. **Your own financial contributions to caregiving.** A recent survey by the National Alliance for Caregiving and AARP revealed that families caring for an elderly relative spend an average of \$171 of their own money each month. You will likely contribute some of your own resources as part of the caregiving journey.

There are many programs emerging across the country that provide

emotional, educational and even financial support to family caregivers. See resource section for a list of caregiver related web sites to learn more information on availability or eligibility.

6. **Be aware of your potential liability.** If you become joint owner of a checking or savings account, a legal representative (through a power of attorney) or a parent's trustee or guardian, you may be assuming risks and liabilities. Before signing any document (such as a power of attorney) that is prepared by or for your parent, be sure to get your lawyer's input.
7. **Above all, respect your parents' opinions about their finances.** Remember, while finances, like all other issues affecting your parent, can be discussed by family members involved in the caregiving process, your parent should always be given as much control and involvement in financial decisions as possible. And, if it becomes necessary to assume full responsibility for a parent's finances, be sure to continue sharing information with other family members and keeping your parents informed.

Are you a legal eagle?

Unless you have a lawyer in the family who's conversant with wills, estate plans and other legal issues and documents your parent might need, you'll probably want to seek the services of an attorney. Here are some items and steps to consider:

1. **Take legal inventory.** Check to see whether certain documents have been prepared and will be available when needed: general power of attorney, advance directives for health care and a will.
2. **Discuss their importance.** If any document is missing, discuss with your parent why it may be essential or at least highly desirable.

For example, estate planning may be needed to make sure your parents' assets are distributed as he or she intends and to minimize taxes at death. Part of the process is to make and periodically update a will. Your parent might also wish to consider various trusts or gifts that can preserve assets for heirs. In general, trusts should be set up with the help of an attorney experienced in estate planning and tax issues.

3. **Do your parents have a living will?** This isn't the same as a conventional will. Instead, it contains your parents' instructions regarding medical matters. It specifies what medical care your parent wants—or doesn't want—if he or she should become chronically or terminally ill and is unable to communicate his or her wishes.

Many experts also recommend a “health care power of attorney” or “health care proxy” designating a family member to make decisions about medical treatment. Key point: living wills and health care proxies can prevent unwanted, unnecessary and costly medical procedures.

4. **Consider a durable power of attorney.** This is a legal document that gives one or more individuals the authority to handle finances, property or other personal matters should the elderly person granting the authority become mentally or physically incompetent. The durable power of attorney is considered better for caregivers than a basic power of attorney because it remains in effect even if the person granting the power becomes incompetent.

It's very inexpensive to have the document prepared and the cost is a fraction of what you'll pay to have a guardian appointed by a court, which you'll need if you don't have a durable power of attorney. Moreover, in the absence of this document, many health care providers and institutions may make critical decisions for the patient that may not be what your parent intended.

5. **Think about using reasonably priced specialists.** Consider working with lawyers and financial advisors who specialize in helping the ill or elderly. For example, so called “elder law attorneys” have specific expertise in estate planning, Medicare and Medicaid issues, insurance disputes, fraud cases and other legal affairs affecting the elderly.

Additional tips:

- The reason why you want a lawyer to draw up a durable power of attorney and/or health care power of attorney is to ensure that the documents reflect your parent's desires and are acceptable in your state. This is especially important in any state which does not have a statutory form.
- The Society for the Right to Die provides free information on your state's current laws on both living wills and powers of attorney for health care.

- The National Academy of Elder Law Attorneys has information on how to choose an attorney specializing in elder law. Other referral sources include the local Office on Aging or the local Alzheimer's Association.

Doctors and medications

Because the relationship between doctor and patient is particularly important for elderly people, caregivers should explore whether your parent and his or her physician communicate effectively. There is often a role here for a geriatrician (a physician who specializes in the care of older adults) who will conduct a geriatric evaluation. Encourage and facilitate good communications so that your parent receives the care that he/she needs and deserves. Make sure that:

- The doctor isn't too busy to spend a little time with your parent on every visit.
- Your parent feels comfortable discussing problems, concerns and desires.
- You and your parent make a list of questions before the visit.
- The doctor and your parent decide together on treatments and approaches.
- You and your parent get to know nurses and others who work in the doctor's office.

Medications

To ensure proper use and monitoring of prescription, over the counter, and alternative medication, there are several important issues to stay on top of. Discuss these questions and precautions with your parent and, if necessary, his/her doctor:

- Work with your local pharmacist to keep a record of all current medicines, including their names, purposes and regimens (dose, time and other instructions such as avoiding certain foods, dietary supplements, alcohol, other medicines and activities). "Current medicines" should include over-the-counter and alternative medicines, such as vitamins or homeopathic alternatives.
- Are there instructions and information given with the medicine?

(If not, ask the doctor or pharmacist to write out directions and any other pertinent information).

Additional medication-related tips:

- Make sure your parent doesn't stop taking medicine just because symptoms disappear.
- Encourage your parent to purchase all of his/her RX medications from the same pharmacy.
- Carefully read over-the-counter medicine labels for ingredients, proper uses, directions, warnings, precautions and expiration dates. Many medicines contain the same ingredients. Be sure your parent isn't taking the same drug in more than one form.
- Toss out outdated/expired medicine.
- Store all medicines in their original containers with label and directions.
- Keep medicines away from heat, light and moisture.
- Never store medicine near a dangerous substance, which could be taken by mistake.
- Be sure that your parent never takes someone else's medicine.

Also ask the doctor or pharmacist:

- Are there side effects, and what do you and your parent do if they occur?
- What should be done if your parent misses a dose?
- Can you or your parent crush or split tablets? (Some should only be swallowed whole.)
- What if new or unexpected symptoms or other problems arise?
- About taking a new over-the-counter medicine or alternative the first time, especially if your parent uses other medicine.
- To periodically reevaluate long-term medications and treatments.

Helpful resources to download

"Talking with Your Doctor: A Guide for Older People" from the National Institute on Aging/National Institutes of Health Web site's

Age Pages: www.healthandage.net

“How to Talk to Your Doctor” and “Caregiving: Communicating with Health Professionals” on AARP’s Web site: www.aarp.org

Also visit The American Academy of Family Physicians Web site for relevant articles: www.familydoctor.org

“Communicating Effectively” curriculum on the National Family Caregivers web site: www.nfcacares.org under caregiving resources.

LOOK FOR HELPFUL INNOVATIONS SUCH AS:

- ☐ A medicine container with an alarm or voice reminder
- ☐ A computerized drug organizer-dispenser
- ☐ A special cap that counts openings of a prescription vial to tell if the day's doses have been taken

Available at most pharmacies.

Addressing concerns in the last years of life

Most of our older years are spent healthy and active. However, due to acquired disability, aging-related conditions and/or other illnesses at some point, we all face the end of our lives. Ideally, we will reach the end of our lives with the physical, emotional and spiritual support that we need and desire.

Talking about end of life care wishes and needs with our aging parent is often a difficult topic to broach. Using an advanced directive such as a living will, power of attorney for health-care (POA-HC), or 5 Wishes form (available at www.agingwithdignity.org) can be helpful in guiding your discussion (see legal eagle section).

To manage pain and provide your parent the support and care that he/she desires as the last months of life approach he/she may want to consider enrolling in hospice or palliative care program.

Palliative care is a comfort rather than curative approach to care. Hospices are organizations/agencies that have a team of professionals and volunteers with a palliative approach to care including; doctors, nurses, social workers, chaplains and volunteers working together to provide pain and symptom management, physical care, respite care, emotional and spiritual support and bereavement care to individuals and their families as they face the end of their life's journey. Hospice care is generally available during the last 6 months of life and paid for by Medicare and Medicaid, as well as some private insurance companies and managed care organizations. Some hospices offer palliative care programs which provide pain and symptom management prior to hospice eligibility. To learn more visit www.NHCPO.org

Getting Around Town

For the most part, older drivers are safe drivers, and driving represents freedom for an older adult. They want to be able to stay connected with the community—visit friends, go to the movies and shop—without relying on anyone else. But driving skills can diminish with age. If an aging parent becomes a danger to himself and to others, it may be in everyone's best interest for that parent not to drive.

It's crucial to involve your parent in any decision about driving. It's also a good idea for both you and your loved ones to discuss driving issues with other family members, doctors and others they respect.

It's a good idea to ask your parent whether he or she:

- Has had vision and hearing tested recently
- Has had a physical exam within the past year to test reflexes and make sure there are no illnesses that would affect driving
- Is taking medications that might cause drowsiness or confusion
- Has reduced or eliminated alcohol intake to compensate for lower tolerance
- Experiences difficulty when climbing a flight of stairs or walking
- Has fallen (other than a trip or stumble) once or more in the last year
- Has had a physician say that he or she should stop driving

Like everything else, you should regularly evaluate your aging parent's driving skills. Together, you and your parent can determine if driving habits need altering, or if driving should cease altogether. In that case, other options exist and should be explored. Public transportation, volunteer driver programs, and more coordinated transportation programs among human service agencies are on the rise in response to an aging America.

There are many ways for older drivers to adjust so they are not a danger to themselves or others. Among them are:

- Avoid driving at night, dawn or dusk
- Drive only to familiar locations
- Avoid driving to faraway places
- Avoid expressways and rush-hour traffic
- Allow plenty of time to get where they are going
- Don't drive alone

Helpful programs

AARP sponsors the AARP Driver Safety Program (formerly called 55-Alive Mature Driver Program), which helps older people address such issues as how to compensate for vision problems associated with aging. For further information on this program visit the AARP Web site at www.aarp.org

The Association for Driver Rehabilitation offers referrals to professionals trained to help people with disabilities and older adults how to evaluate and improve their driving. Visit their Web site at www.driver-ed.org

“Driving Safely while Aging Gracefully” was developed by the USAA Educational Foundation, AARP, and the National Highway Traffic Safety Administration. This informative booklet describes many of the physical changes associated with aging, and includes tips on coping with them so that older people can remain safe drivers. “Driving Safely while Aging Gracefully” can be found along with additional information and booklets for older road users at www.nhtsa.dot.gov/people/injury/olddrive

Easter Seals has been deeply involved in helping mature adults gain easy access to public transportation and other alternate transportation

options and to support a smooth transition to non-driving through:

- **Easter Seals Transportation Solutions for Caregivers**

Spearheaded by Easter Seals and funded through the Administration on Aging's National Family Caregiver Support Program, this initiative developed tools and resources to improve delivery of transportation services for older adults and their family caregivers in the areas of safety, community-based alternatives and education on accessing existing resources and services.

The Caregiver Transportation Toolkit (a handy booklet and video to assist family members in transporting their loved ones in their own vehicle), Solutions Package for Volunteer Transportation Programs, Transportation Escorts for Seniors and a Senior Transportation Options Template for Communities--can be downloaded or ordered through the National Center on Senior Transportation Web site www.seniortransportation.net

- **Easter Seals Project ACTION**

Since 1988, Easter Seals has worked to promote cooperation between the transportation industry and the disability community to increase mobility for individuals with disabilities under the Americans with Disabilities Act. A wide array of resources is available, ranging from a pamphlet for taxi drivers to a comprehensive resource catalog. For more information, visit www.projectaction.org

National Center on Senior Transportation

In 2006, Easter Seals Inc. teamed up with the National Association of Area Agencies on Aging and other organizations to establish the National Center on Senior Transportation, funded through a cooperative agreement with the U.S. Department of Transportation, Federal Transit Administration. The NCST's mission is to increase transportation options for older adults and enhance their ability to live more independently within their communities throughout the United States. Learn more about the services and wealth of information available through the NCST at www.seniortransportation.net

What if your parent shouldn't drive at all?

Many elderly people know they need to limit their driving or that they

shouldn't drive at all. Some refuse to accept their impaired driving ability, often due to the sense of independence attached to driving or the absence of accurate judgment of his/her own driving skills.

If this happens, there are several approaches that can be taken in order to help your parent limit driving or give up the keys. Be sure to remain sensitive to your parent when approaching him/her about driving concerns. Before moving forward with any of the approaches listed below, research local transportation options and/or devise a plan among family and friends that can be presented to your parent in order to make the transition to non-driving as smooth as possible.

1. Consult your parent's doctor. For many older adults, advice from the physician is the advice that is most respected.
2. Ask a trusted peer or friend to discuss his/her concerns with your parent. Sometimes hearing concerns and advice from a peer who can sympathize and/or may have experienced a similar situation can be helpful and reassuring.
3. Organize an intervention. Respectfully confront your elderly parent as a group of concerned caregivers. The group should include family members, health care workers and anyone else respected by your parent. The intervention needs to be handled firmly but with compassion to break through the barrier of denial.
4. Contact the local Department of Motor Vehicles and report your concerns. The DMV may do nothing more than send a letter, but this might help convince your parent to stop driving.
5. Eliminate all access to the car. While this may seem extreme, it can save lives.

Again, many elderly people who shouldn't drive accept this fact. Whatever your circumstances are, be sure to be particularly sensitive to your parent on driving issues.

Alternate transportation options

Encourage your aging parent to use public and other transportation options. This will reduce time behind the wheel and help prepare your parent for the day when he or she can no longer drive. Many cities offer special discounts for seniors on buses and trains. Senior

centers and community service agencies often provide special transportation for older adults depending upon an individual's destination and physical needs. Links to additional information about the many transportation options and resources (e.g., buses, vans, taxis, curb-to-curb or door-to-door paratransit, volunteer drivers from human service or faith community organizations, travel training, transportation vouchers) that may be available within a community are provided on the NCST Web site at www.seniortransportation.net

HERE'S YOUR HANDY DRIVING SKILLS CHECKLIST

You and your parent should evaluate driving ability based on these questions. Does your parent...

- ☐ Drive at inappropriate speeds?
 - ☐ Ask passengers to check if it is clear to pass or turn?
 - ☐ Respond slowly or not notice pedestrians, bicyclists and other drivers?
 - ☐ Ignore, disobey or misinterpret street signs and traffic lights?
 - ☐ Fail to yield to other cars or pedestrians who have the right-of-way?
 - ☐ Fail to judge distances between cars correctly?
 - ☐ Become easily frustrated and angry?
 - ☐ Appear drowsy, confused or frightened?
 - ☐ Have one or more near accidents or near misses?
 - ☐ Drift across lane markings or bump into curbs?
 - ☐ Forget to turn on headlights after dusk?
 - ☐ Experience difficulty with glare?
 - ☐ Find it hard to turn their head, neck, shoulders or body while driving or parking?
 - ☐ Ignore signs of mechanical problems, including underinflated tires?
 - ☐ Lack the strength to turn the wheel quickly in an emergency?
 - ☐ Get lost repeatedly, even in familiar areas?
- If the answer to one or more of these questions is "yes," be sure to explore whether medical issues are affecting your parent's skills.*

A list of helpful resources

Aging in Stride (available from Easter Seals)

This book is a guide to healthy and successful aging. It covers many diverse topics of aging. To order, visit www.AgingInStride.org/EasterSeals or call 800-448-5213.

Aging Parents: The Family Survival Guide

This guide is designed to help family members respond to eldercare crises and to plan ahead for long-term care giving. To order, call 888-777-5585 or order online at www.agingparents.com

Caring From a Distance

A web site dedicated to serving the needs of long-distance caregivers
Web site: www.cfad.org

Guide to Retirement Living

800-394-9990
E-mail: proaging@retirement-living.com
Web site: www.retirement-living.com
Call for a free single copy of this magazine.

Other Organizations

Academy of Elder Law Attorneys

520-881-4005
www.naela.org

Alzheimer's Association, Inc.

800-272-3900
www.alz.org

American Association of Homes for the Aging

202-783-2242
www.aahsa.org

AARP

800-687-2277
www.aarp.org/caregiving

The Caregivers Marketplace

800-888-0889

www.caregiversmarketplace.com

Discounts on goods and services purchased via enrollment

Choice in Dying/Partnership for Caring

HelpLine: 800-658-8898

www.partnershipforcaring.org

Elder Care Locator

800-677-1116

www.eldercare.gov

Assists in finding your area agency on aging

America's Health Insurance Plans

202-778-3200

www.ahip.org

Publishes insurance-related consumer guides including:

A Guide to Long-Term Care Insurance

National Association of Private Geriatric Care Managers

520-881-8008

www.caremanager.org

Provides free referrals nationwide

National Council on Aging

202-479-1200

www.ncoa.org

National Institute on Aging

301-496-1752

www.nia.nih.gov

Produces health-related publications and information

National Guardianship Association

877-326-5992

www.guardianship.org

National Hospice and Palliative Care Organization

703-837-1500

www.nhpco.org

National Center on Senior Transportation

866-528-NCST (6278)

www.seniortransportation.net

National Family Caregiver Association

800-896-3650

www.nfcacares.org

National Alliance for Caregiving

301-718-8444

www.caregiving.org

Family Caregiver Alliance

800-445-8106

www.caregiver.org



Easter Seals thanks the National Association of Chain Drug Stores Foundation for its generous gift to underwrite this second edition of Loving Conversations.

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Why Easter Seals is relevant to you and your parent

For more than 20 years, Easter Seals has put hope within reach for thousands of people, including adults of all ages who have developmental disabilities, are frail or have Alzheimer's disease.

Easter Seals' center-based care provides an affordable alternative to at-home or nursing home care and allows both younger adults with disabilities and older adults to socialize, participate in recreational activities and receive medical supervision and personal care assistance. Easter Seals services also include rehabilitative activities such as physical, occupational and speech therapies. Easter Seals adult day services help alleviate the tremendous responsibilities placed on primary caregivers, allowing them to continue working, managing their family life and maintaining their personal health while caring for an aging parent. In addition, Easter Seals provides in-home care for older adults.

Since 1919, Easter Seals has been providing services that help children and adults with disabilities gain greater independence. Our primary services—medical rehabilitation, job training and employment, inclusive child care, adult and senior services and camping and recreation—benefit more than a million individuals and their families every year.

Helping your family decide what's best with the people who brought you into this world



A special thank you to MassMutual Financial Group for its ongoing support of the families Easter Seals serves.

www.easterseals.com