

Guide to Elder Caregiving

Understanding Your Loved One's Needs

Every family is unique, and your family's needs may differ from those of others. But most families share some things in common when caring for an elderly loved one. This guide can help you answer those common questions we all have. For example:

- Is what is happening to my loved one normal?
- Is my loved one safe living at home?
- When do I or other family members need to step in for the sake of our loved one?
- What type of housing would be best for our loved one?
- How do we pay for long-term care?

You will find answers to these and other questions in this guide. Please ask if you need any additional information or help.

Contents

What care does my loved one need?

- Checklist for assessing needs 2
- What My Loved Is Doing, What This Might Mean, and What Can Be Done 6
- "A Few of My Favorite Things" 11

What housing does my loved one need? 11

- Home Safety and Accessibility 17
- Home Care Services 20
- Assisted Living 21
- Nursing Home Care 23

Caring for an elderly loved one 26

- Changing Roles in the Family 26
- Communicating with an Elderly Loved One 28
- Managing Behavior Changes 29
- Long-distance Caregiving 30
- Legal Aids for Decision Making 30
- Paying for Health Care 31
- Appendix A: Personal records 34
- Funeral Planning 36
- Words to know 37

What Kind of Care Does My Loved One Need?

Checklist for assessing needs

As our loved ones age, they may find it harder to do some daily activities. When should this become a cause for concern? When should we think about bringing in home services? When are home services no longer enough?

The following checklist can help you decide what help, if any, your elderly loved one may need now. It can also help prepare you for what might come.

The checklist is only a tool. It cannot make decisions for you. Talk with a doctor, health care professional or geriatric care manager for more help.

Check your loved ones needs regularly to track changes and adjust care as needed. It is possible for your loved one to become suddenly more dependent—for example, after an injury or illness. It is also possible for your loved one to regain some independence after treatment and rehabilitation.

Choose the one statement for each item that most closely fits your loved one at this time. Add up the numbers at the end of each statement to get a total. Then go to the end of the checklist to see what this may mean.

1. Able to take care of house and yard
 - Without help (1)
 - With some help (2)
 - No (3)
 - Lives in housing where this is not an issue (1)
2. Able to clean house and do laundry
 - Without help (1)
 - With some help or reminding (2)
 - No (3)
 - Uses an outside agency (1)
3. Able to identify strangers and seek help if necessary
 - Without help (1)
 - No (3)
4. Able to get help in an emergency
 - Without help (1)
 - With some guidance or instruction (2)
 - No (3)
5. Able to drive
 - Without help or uses public transportation (1)
 - Does not drive and needs help with other forms of transportation (2)
 - Needs special medical transportation (3)
6. Able to take part in social activities
 - Without help (1)
 - With help (reminders, transportation) (2)
 - Only with help (3)

7. Able to manage own money (such as balance checking account, pay bills)
- Without help (1)
 - With some help (reminding, writing out checks, reviewing mail) (2)
 - No (3)
8. Able to shop for food
- Without help (1)
 - With help (2)
 - No (3)
9. Able to make or arrange for meals
- Without help
 - With help (including meals on wheels) (2)
 - No (3)
10. Able to feed self
- Without help (1)
 - With help (because of physical difficulties, need for reminding) (2)
 - No (3)
11. Able to recognize surroundings
- Alert and aware of day, time and place (1)
 - Sometimes confused about day, time or place (2)
 - Always confused about day, time or place (3)
12. Able to make and keep appointments
- Without help (1)
 - With some reminding (2)
 - Only with help (3)
13. Able to understand and follow directions
- Without help (1)
 - Only after checking directions several times (2)
 - Not even with help (3)
14. Wanders or has gotten lost
- No (1)
 - Yes (3)
15. Able to do personal grooming (brush teeth, comb hair, shave, etc.)
- Without help (1)
 - With reminding (2)
 - Only with help (3)
16. Able to dress
- Without help (1)
 - With some help (reminders, choosing what to wear, etc.) (2)
 - Only with help (3)
17. Able to bathe or shower
- Without help (1)
 - With some help or supervision (2)
 - Only with help (3)
18. Able to control bladder and bowels
- Yes, or can use incontinence pads without help (1)
 - With reminding to use toilet or help using incontinence pads (2)
 - No (3)
19. Able to walk
- Walks on own without falling (with or without cane or walker) (1)
 - Has trouble walking alone and has fallen during past 6 months (2)
 - Needs help to walk or stand (3)
20. Able to transfer (from chair to walker, walker to bed, wheelchair to car):
- Without help (1)
 - Only with help (3)

21. Therapy and rehab

- Does not need therapy or rehab (1)
- Takes care of therapy or rehab without help (1)
- Needs help to manage therapy or rehab (2)
- Needs medical monitoring (3)

22. Able to manage medicines

- Without help (1)
- With help (to identify, open bottles, remember to take) (2)
- No (3)

When you have completed this checklist, add up the numbers. Then see what your total means.

If your total is 30 or less:

Your loved one is doing well without much help. There may be no need for special services at this time. Now would be a good time to look ahead:

- **Plan:** What medical, financial and legal arrangements are in place or need to be put in place?
- **Ask:** What are the thoughts, wishes and feelings of your loved one and family?
- **Do:** What can be done to help your loved one remain as independent as possible? (Keep in mind your other responsibilities.)
- **Learn:** What community resources exist?

Here are some things that you may want to do:

- Review all financial and legal documents. Make sure that all forms are up-to-date and reflect the current situation. See pages 23–24 and 27 for more information.

- Complete a durable power of attorney, health care advance directive and will. See pages 23–24.
- Tour some of the senior housing in your area. Find out what levels of care are given at each. Even if certain services are not needed at this time, you need to plan ahead. Most senior homes have waiting lists. See pages 14–19.
- Assess the home for safety and accessibility. There are some simple, inexpensive things you can do to reduce the risk of falling and make the home safer. See pages 12–14 for more information.

If your total is between 31 and 50:

Your loved one can no longer do many daily activities without supervision or help. Consider some of the following options for community-based services and senior housing.

Community-based services

Most communities offer a range of services to seniors. You will have to decide which of these services are practical and affordable for you. Some seniors may qualify for financial help through their county or state social service office. Home services are often an option, although they may not be practical for those with Alzheimer's or other forms of dementia. Generally, the more needs a senior has, the higher the cost of meeting those needs. Here are some types of community-based services:

- **Adult day care:** A community-based program offering planned activities and meals. Some may offer medical services for an added fee. Transportation may be provided. Most programs run during the week and can be attended full or part time.

- **Companion program:** An in-home service in which “companions” help with shopping, meals, housework and other daily duties. Companions usually do not provide personal care, such as bathing, dressing or grooming. And they provide no medical care. Companions usually come into the home for at least 3 hours at a time and for as long as 24 hours. Twenty-four-hour care can cost more than **\$200 a day**. *Still a valid number?*
- **Home health care:** Medical care is given in the home. The services may be given by a nurse, occupational therapist, speech therapist, physical therapist or home health aide. Services may include help with bathing, dressing and grooming as well as with managing medicines and other nursing care. The time spent in the home ranges from 2 hours to 24 hours. Twenty-four-hour care can cost more than **\$230 a day**. *Still a valid number?* See [page 20](#) for more information on home health care.

Senior housing

- **Assisted living:** Long-term senior housing that provides health care services. Residents can purchase the level of personal and health care services that they need. Many services can be purchased in 15-minute blocks. Most assisted living facilities offer 24-hour security and on-site staff. Residents have their own living area, which can be as large as a two-bedroom apartment. Many units have kitchens, or you may choose to eat in a common dining room. See [pages 14–16](#) for more information.
- **Memory care:** A residence for those with Alzheimer’s or another form of dementia. Residents may have a single or shared room. The staff are trained to manage the special needs of people with memory loss. This type of residence offers residents companionship and independence in a safe environment.

If your total is 51 or higher:

Your loved one can no longer take care of his or her self. Your loved one may have serious health problems as well.

24-hour home health care

Some seniors prefer to remain in their own home and receive 24-hour services from a home health agency. For this option, be sure to consider the availability of staff and the need of your loved one to socialize.

Senior housing

- **Nursing home:** A facility that provides health care to people who cannot live independently in the community. Nursing homes may provide short-term rehabilitation as well as care for long-term, chronic conditions. See [pages 16–19](#) for more information.
- **Memory care:** A residence for those with Alzheimer’s or other forms of dementia. Residents may have a single or shared room. The staff are trained to manage the special needs of seniors with memory loss. This type of residence offers residents companionship and independence in a safe environment.

Hospice

Medical and social services for patients with end-of-life illness and their families. Care is given either at home or in a facility.

What my loved one is doing, What this might mean, and What can be done?

Below is another tool to help you decide what type of care your aging loved one may need at this time. This table focuses on specific behaviors, one at a time. To use the tool, read down the first column (**What My Loved One Is Doing**) until you find a behavior that you have seen your loved one do. Then look to the right to see what this behavior might mean and what your options for care are (**What Can Be Done**).

As with the checklist, you will want to repeat this assessment regularly. You will also want to talk with your doctor and other care team members for more information.

What My Loved One is Doing	What This Might Mean	What Can Be Done
Often forgets things.	<ul style="list-style-type: none"> • Loss of mental function • Can lead to problems in other areas of daily living over time. Depending on severity of memory loss, may need to live where there is constant supervision. 	<ul style="list-style-type: none"> • personal attendant / companion • home health aide • assisted living facility • power of attorney • residential care / memory loss home
Has trouble recognizing where he or she is.	<ul style="list-style-type: none"> • Loss of mental function • May need help doing daily activities; depending on extent of memory loss, may need to live where there is constant supervision. 	<ul style="list-style-type: none"> • personal attendant / companion • home health aide • assisted living facility • power of attorney • residential care / memory loss home

What My Loved One is Doing	What This Might Mean	What Can Be Done
Is not taking medicines properly.	<ul style="list-style-type: none"> • loss of vision or memory • low health literacy • lack of money/financial support 	<ul style="list-style-type: none"> • health care services for medicine set-up and reminders • home medical / accessibility devices • assisted living / residential care
Wanders.	May need to live where there is constant supervision.	<ul style="list-style-type: none"> • personal attendant / companion • home medical / accessibility devices • assisted living / residential care
Talks about being a burden or wanting to die.	Depressed or lonely	<ul style="list-style-type: none"> • personal attendant / companion • medical care intervention • mental health evaluation
Is angry, belligerent, or hard to get along with.	Physical problem or condition Side effect of medicine Can lead to abuse or neglect of others or self; can create safety issues.	<ul style="list-style-type: none"> • medical care intervention • mental health evaluation
Says “what?” a lot; turns the volume up on the tv; stares vacantly while others talk; is withdrawn.	<ul style="list-style-type: none"> • Loss of hearing • Medical condition • Can lead to vulnerable adult issues. 	<ul style="list-style-type: none"> • medical care evaluation • home medical / accessibility devices

What My Loved One is Doing	What This Might Mean	What Can Be Done
<p>Squints, holds small things at arm's length to see them; has trouble driving at night.</p>	<ul style="list-style-type: none"> • Vision problem. • May need help with legal and financial forms and other printed documents; can cause safety issues or isolation; can lead to vulnerable adult issues. 	<ul style="list-style-type: none"> • personal attendant / companion • medical care evaluation • home medical / accessibility devices • assisted living / residential care
<p>Wears dirty clothes or neglects appearance.</p>	<p>May not be able to care for self properly care due to memory loss, depression or a physical problem such as incontinence.</p>	<ul style="list-style-type: none"> • personal attendant / companion • assisted living / residential care
<p>Has lost or gained a lot of weight.</p>	<ul style="list-style-type: none"> • physical condition • depression or memory loss • side effect of medicine • lack of money/financial support • problems cooking or grocery shopping 	<ul style="list-style-type: none"> • meal or grooming service • personal attendant / companion • financial assistance (e.g., food stamps) • medical care intervention • assisted living / residential care
<p>Has trouble walking; has fallen more than once.</p>	<p>May need exercise or therapy to strengthen muscles and improve balance; may need a cane, walker, or similar device.</p>	<ul style="list-style-type: none"> • physical therapy • home health aide • home medical / accessibility devices • assisted living / residential care

What My Loved One is Doing	What This Might Mean	What Can Be Done
Has trouble chewing or swallowing; often chokes.	<p>physical problem or condition</p> <p>dental problem</p> <p>Can lead to nutritional concerns.</p>	<p>dental services</p> <p>speech evaluation</p> <p>change in diet</p>
Has bruises on arms or legs.	<ul style="list-style-type: none"> • falling (due to poor balance or problems walking) • Could indicate vulnerable adult issues. 	<ul style="list-style-type: none"> • home medical / accessibility devices • medical care intervention • assisted living / residential care
Cannot get out when the weather is bad.	<p>inability to drive or clear a safe path</p>	<ul style="list-style-type: none"> • personal attendant / companion • transportation services • assisted living / residential care
Has trouble using utensils to cook or eat.	<ul style="list-style-type: none"> • physical problem • May need occupational therapy or adaptive equipment; can lead to nutritional concerns. 	<ul style="list-style-type: none"> • home medical / accessibility devices • occupational therapy
Has trouble cooking or using appliances safely.	<ul style="list-style-type: none"> • memory loss or physical problem • May need to shut off gas line for safety; may need help with meals. 	<ul style="list-style-type: none"> • homemaker or meal services • personal attendant / companion • assisted living / residential care

What My Loved One is Doing	What This Might Mean	What Can Be Done
Has trouble shopping for groceries.	<ul style="list-style-type: none"> • inability to access transportation • lack of money / financial resources • physical problem • Can lead to nutritional concerns. 	<ul style="list-style-type: none"> • grocery service • financial assistance (e.g., food stamps) • personal attendant / companion
Has trouble cleaning house.	<ul style="list-style-type: none"> • poor physical condition • inaccessible home 	<ul style="list-style-type: none"> • homemaker service • personal attendant / companion
Cannot drive or use public transportation on his or her own.	Will need companion or other help with transportation.	<ul style="list-style-type: none"> • transportation service • assisted living / residential care
Has trouble keeping up the yard or house.	<ul style="list-style-type: none"> • physical problem or lack of exercise • lack of money / financial resources • May need different housing. 	<ul style="list-style-type: none"> • yard service • financial assistance • assisted living / residential care
Is not paying bills on time, balancing checkbook, or accounting for spending.	<ul style="list-style-type: none"> • lack of money / financial resources • mental confusion or forgetfulness • May indicate deficiencies in other areas. 	<ul style="list-style-type: none"> • financial assistance • power of attorney

What kind of housing does my loved one need?

You may already know that choosing the right living situation is an essential part of giving the care your loved one needs. Senior housing can range from independent living in a private home to 24-hour care in a group medical facility. In between there are many options, depending on the level of health care needed, ability to pay, location and other factors.

To help you choose the kind of housing your loved one needs, ask yourself these questions:

- **Why are you are looking for a different living arrangement?**
- **Does your loved one want or need to be with other people?**
- **Is your loved one's ability to socialize limited by weather, access or other factors?**
- **Would your loved one like to have**
 - planned activities
 - prepared meals
 - group shopping
 - pharmacy delivery service?
- **Would your loved one like help with:**
 - shopping
 - cooking, cleaning or laundry
 - medicines and reminders
 - personal care?
- **Would your loved one be better off living on one level (no stairs to climb)?**
- **Should your loved one have:**
 - an emergency contact system?
 - a security system?
- access to 24-hour staff?
- **Would your loved one like access to:**
 - a meeting room
 - a craft room
 - a gardening plot
 - a library
 - a beauty or barber shop
 - guest rooms for visitors
 - a convenience store
 - an exercise room
 - a post office
 - a music room
 - a workshop
 - a garage
 - a health clinic
 - a storage room
 - physical or occupational therapy
- **Would your loved like to have a pet?**
- **Does your loved one have a car?**
- **What are your loved one's smoking preferences?**
Remove?
- **Are there extra costs in the housing agreement, such as association dues and maintenance charges?**
- **What level of care is offered? When will your loved one's needs exceed this level of care?**
- **Are you able to sublease or rent your unit if you need to be out of town or in another facility for a short time?**

The following pages contain information on housing options, including living at home, assisted living, and nursing homes. Use the assessments in “What kind of care does my loved one need?” and the answers to the questions above to choose the best housing for your loved one.

Living in your own home

If your loved one is living in his or her own home, use these two pages to assess how safe the home is.

Emergencies

- Do you know how to call for emergency assistance?
- Have you considered a personal medical alert system (for example, Lifeline)?

Fire response

- Do you have a home fire safety plan?
- Are exits available from all locations in the house?
- Do the following areas have smoke detectors?
 - Hallways
 - Kitchen
 - Bedrooms
 - Attic
 - Basement
- Is there a carbon monoxide detector?
- Does the fireplace have a smoke screen?
- Is the fireplace or wood stove cleaned and checked regularly?
- Are curtains and other flammable items kept away from open flames?
- Do you avoid smoking, especially in bed?

Electric outlets and devices

- Are outlets used properly, avoiding multiple plugs and extension cords?
- Are appliances disconnected when not in use?
- Are electric cords free from fraying or cracking?
- Do electric plugs fit snugly into their sockets?
- Do electric cords run along walls and not across rooms?
- Do you know the proper use of heating pads and space heaters?
- Does the electrical system meet the power requirement for special medical equipment: such as ventilators and oxygen concentrators?

Floors

- Is nonskid wax used on floors?
- Are scatter rugs secured at the edges?
- Are pathways and hallways clear of excess furniture and debris?

Stairwells

- Are there nonskid treads on stairs?
- Are different colors used to mark changes in levels?
- Are handrails present and securely fastened?

Lighting

- Do the rooms have enough lighting?
- Are burnt-out light bulbs replaced?
- Are night lights used in areas traveled after dark?
- Are light switches easily visible and within reach?

Bathroom

- Are there hand grips by the tub/shower?
- Are there hand grips by the toilet?
- Is there a nonskid mat in the tub/shower?
- Is there a secure seat in the tub/shower?
- Is there a seat by the sink?
- Is the bathroom easy to get to?

Bedroom

- Is there a bedside toilet, if needed?
- Is there a telephone within easy reach?
- Is there a need for a hospital bed or trapeze?

Kitchen

- Is the kitchen free of clutter?
- Are expired foods thrown away?
- Are cabinets easily and safely accessible?
- Are adaptive devices (extended graspers, eating devices, etc.) available, if necessary?
- Are sharp objects kept in secure areas out of reach of confused adults?

Miscellaneous

- Are the following items out of reach of confused adults?
 - medicines
 - dangerous tools or equipment
 - cleaning substances
 - poisons (bug or weed killers)

- Are snow and ice adequately removed?
- Are sidewalks, curbs and outside stairs maintained?
- Is there a ramp for wheel chairs (if needed)?
- Is the temperature of the water heater kept below 110 degrees °F?

Medical equipment

- Do you know how to safely use all medical equipment?
- Do you understand the safety requirements of the equipment?
- Do you know the proper storage and cleaning of the equipment?
- Do you understand the hazards of the equipment and how to avoid them?
- Do you know whom to contact if the equipment stops working?

Oxygen safety

- Are you aware of the dangers of smoking in the presence of oxygen equipment?
- Is a No Smoking sign posted?
- Do you know the proper way to store oxygen cylinders?
- Do you know the how to place oxygen concentrators?

If you find safety hazards or you require help in completing a safety assessment, talk to a care manager or home health agency.

Home care services

Your loved one may need help to continue living at home. Home health care services are provided by a visiting nurse agency, home health agency, hospital or community group. Services may include nursing, speech, occupational or physical therapy and homemaker services.

Before choosing home care services, know what your loved one needs. You will work with the agency that provides the care to set up payment and billing. Medicare or other insurance policies may cover some services. Find out if your insurance policy will cover the agency and type of care you seek. Services may be as basic as helping with home chores and meals or as medically complex as IV infusion therapy.

Choosing home care services:

- Does Medicare certify the agency?
- Does the agency have a contract with your insurance company or HMO?
- Does the agency bill Medicare or your insurance company, or is the family responsible?
- What type of training, supervision and monitoring does the agency provide its staff?
- Does the agency develop a plan of care? If so, how often is it reviewed and by whom?
- Does a nurse conduct an initial assessment? Is there an added cost for this?
- Does the agency provide the family with training on high-tech equipment in the home?
- Is there a 24-hour emergency contact?
- How does the agency assure that staff can be there for the requested times?
- How does the agency insure consistency of care providers?

- Is there a charge for canceling a scheduled day?
- How does the agency screen their staff? Do they do criminal checks?
- If you are hiring a home care person not working for an agency, it is important to:
 - Check references.
 - Check with any state licensing boards (for example, your state Board of Nursing).
 - Complete a criminal background check (for example, local police, sheriff, bureau of criminal apprehension, drivers license division and credit bureau).
- Check with the IRS about tax issues.
- Have a back-up plan for when the worker is sick or on vacation.

Assisted living

Assisted living offers a wide range of personal and health care services in a professionally managed residence. Assisted living is for people who need help with daily activities, such as bathing, dressing, cooking and cleaning.

Residents can live in their own apartments. They pay rent and they may also pay a service charge, deposit or entry fee. Private long-term care insurance may cover some of the services. State, county or other local assistance programs may also cover some of the costs.

Who should use assisted living?

Seniors often explore assisted living when they can no longer live on their own, but do not yet need ongoing nursing care. Some residents may have limited needs and be able to live on their own. Others may have serious mobility issues or suffer from memory loss or dementia.

How does assisted living differ from other types of senior housing?

Assisted living housing offers more services than most retirement communities. Twenty-four-hour security and on-site staff are standard. Residents can purchase care on an as-needed basis. Many services can be purchased in 15-minute chunks. Those who live at home and need similar care would be charged a minimum of 2 hours a visit. Residents have their own living area, which may be as large as a 2-bedroom apartment. Many units have kitchens, although residents may choose to eat in a common dining room.

Choosing an assisted living residence

You will want to tour several communities before making your final decision. Because the residence you want may have a waiting list, it will be important to begin looking before the need arises. When comparing communities, find out what is included in the monthly rent. Some residences may quote a low basic rate, then charge separately for each added service, while other residences may bundle many services together.

Atmosphere

- Are the common areas kept clean? Do residents use common areas, or does it appear that most residents stay in their own apartments?
- Are the staff visible and available to residents?
- Is there a safe and accessible outdoors area for walking and gathering?

Apartments

- What are the various apartment floor plans? Can you make changes to an apartment after you move in?
- Do the bathrooms have accessible showers? Is there a tub room in the building?

- Is there a full kitchen in the unit? Can stoves be disabled if it is unsafe for the resident to cook?
- Are there emergency call cords in all rooms of the apartment? Do residents also wear an emergency pendant that is active throughout the building?

Services

- Are housekeeping services included in the rent? Are linens provided?
- Is there a laundry facility on every floor? Is there an extra charge for the machines?
- Can you request that staff regularly check on a resident? Is there a charge for this service?
- Is there an activities director on staff?
- Do they offer van service or other transportation? What are the costs? When or how often is it available? Is it used only for residence-sponsored events?

Health care services

- Are health care services provided by an outside agency or by in-house staff? If by an outside agency, how are questions and concerns handled?
- Are health care staff on-site 24 hours a day? Are staff able to meet unscheduled needs?
- How are health care services billed? Do you receive a separate accounting for these services?
- Are any health care services included in the monthly rent?
- Is there a written plan of care for all residents? How often are these plans evaluated?
- What medical diagnosis would not be acceptable for this residence?

Meals

- How many meals (if any) are included in the monthly rent? Do they have tray service? If so, what is the cost?
- Do residents have choices at mealtime, or are the menus set?
- Can guests eat in the dining room? Are there assigned seats in the dining room?

Contracts and lease terms

- Do the residents sign an annual lease, or are the terms month to month?
- Is a security deposit required? Is this deposit refundable?
- What kind of penalty is there for ending a contract? Can the penalty be waived due to medical need?

Nursing home care

The decision to place a loved one in a nursing home is one of the most important yet difficult decisions a caregiver can face. The purpose of a nursing home is to help people care for themselves and return to living as independently as possible. Choosing a nursing home depends on your loved one's needs. Knowledge is an important tool in making the right decision. Don't be afraid to ask questions.

When visiting a home, talk with staff from various departments: nursing, dietary, social services, activities and administration. Talk with residents and their families and listen to their thoughts and experiences. Allow your loved one to visit and help choose the home as their situation allows.

Tour several places. This gives you a chance to do some comparison shopping. Make an appointment with the social services director or the staff person who handles admissions. You might also make a later, unannounced visit at a different time of day.

Let your senses guide you during your visit. If something doesn't seem right, it probably isn't. Are there unpleasant smells? Is the noise level unusually loud? Are the residents well groomed, dressed in day clothes, and out of bed? Are residents taking part in activities? Does the place feel warm and friendly? Or is it cold and impersonal? Does the home look clean? Do the staff greet you and appear friendly?

During your tour, it is important to consider the overall feel of the facility. Don't discount a place on looks alone.

Pick up a copy of the admissions agreement. Read it carefully and mark any areas you don't understand or that concern you. Then ask the social services director to explain these points. Ask for a copy of the Nursing Home Residents' Bill of Rights and read it.

Today, nursing homes are safer and better managed than ever before. This is due in part to improved regulation and inspection. Unfortunately, some homes still do not meet state legal standards. And others might not meet your own standards for comfortable living. It is important to choose carefully and regularly check on the care of your loved one over time.

Compare your cost of living with ours:

Use this chart to compare your monthly expenses with our our monthly lease (at the level you choose)

• Expense Item	• Present costs	• Our costs
Mortgage payment		
Real estate taxes		Included
Home insurance (renter's insurance)		
Heat and Air		Included
Electricity		Included
Sewer and water		Included
Telephone		
Trash removal		Included
Property maintenance		Included
Home repairs		Included
Lawn Care		Included
Snow removal		Included
Television (expanded basic cable)		Included
Wireless internet		Included
Health club membership		Included
Meals off the menu or continental breakfast		
24-hour emergency call system		Included
24-hour on site staff		Included
Spiritual care (in building)		Included
On-site recreation activities		Included
Concierge services		Included
Library, computer with internet		Included
Transportation to events		Included
Social, cultural and educational activities		Included
Exercise room and equipment		Included
Massage therapy		
Salon		
Home care		
Housekeeping		
TOTAL MONTHLY	_____	_____

Nursing home tour form

Nursing home _____

Phone _____

Address _____

Admissions coordinator _____

Social worker _____

Director of nursing _____

Date(s) and time(s) visited _____

Items to review:

___ Facility complaint records and annual inspection reports

___ Admissions contract and other financial documents

Medical care

- How does the home assure regular medical attention? How often do doctors visit?
- Does the home offer physical and occupational therapy on site?
- Are there regular nursing inservices and educational programs for staff?
- What is the turnover rate for nurses and nursing assistants?
- What is the patient-to-resident ratio?

Outside grounds and overall environment

- Are the grounds well lit?
- Are staff present when residents are outside?

- Are special considerations taken in the design of outside areas for residents with memory loss or wandering issues?
- Are exits clearly marked?
- Is there someone at the front entrance to greet you and sign in visitors?
- Is there ample parking space for visitors?
- Is the facility on a bus line?

Interior space and rooms

- Are rooms clean and cheerful?
- Is there a urine smell throughout the building?
- Are rooms well lit?
- Do rooms have accessible call bells?
- In shared rooms, does each resident have private space, room for individual belongings and space for visitors?
- Is the facility or family responsible for furnishing the room?
- How are room changes and roommate concerns addressed?

Community living space

- Do residents have access to common areas throughout the building?
- Are residents limited to the common areas on their wing or floor, or can they move about the building and grounds?
- Can families reserve rooms for private parties and meetings?

Dining

- How are the dining rooms staffed?
- Are snacks available upon request?
- Can families be present during meal times? Can they purchase meals?
- Are residents allowed to have food and snacks in their room?
- Is there a specific time for meals or a range of time for eating?
- Is seating flexible or are seats assigned?

Activities

- How does the home staff therapeutic recreation? Do they encourage community volunteers?
- Where are most activities held?
- Are activities tailored to different resident groups?
- Are there activities outside the facility? If so, is there an added cost?
- Are there structured activities on weekends and evenings?
- Are residents personally encouraged to participate in activities?
- Are there established visiting hours?
- How are activities communicated to residents?

- Does the facility have a resident and family council? Do staff or volunteers conduct these groups?
- Are there support groups sponsored by outside agencies (for example, Alzheimer’s, stroke, Parkinson’s or multiple sclerosis organizations)?
- Are residents encouraged to take part in developing their care plan?
- Is there someone on staff to address residents’ concerns or complaints?
- How are discharge plans developed for residents returning to the community?

Religious affiliation

- Are religious services offered?
- Do they have clergy who are on staff or who visit regularly?

Overall impressions

I want more information about:

Before choosing a nursing home, review the facility’s most recent inspection survey. You can obtain information about facility complaints from your state department of health.

Resident self-determination

Resources for caring for an elderly loved one

Changing roles in the family

The relationship between a parent and an adult child often includes unresolved feelings. This may not be apparent when the relationship involves only occasional casual visits. However, conflicts can re-emerge when an adult child steps in to help an aging or ill parent. Unfortunately, by the time a family realizes it's time to intervene in a loved one's care, the situation is often critical, and there is little time to resolve past issues.

Family caregivers should ask themselves the following questions as the need for care and assistance begins to grow:

- What level of care am I able to provide my parents?
- At what point will I need to involve a professional, like a care manager or lawyer?
- How has my family resolved difficult and complex issues in the past?
- How did my parents manage the care of their aging parents?
- What is my relationship with my siblings or other care providers, and what are our roles?
- Do I have the feeling my parents are making the right decisions about their future? Do my siblings agree with me?

Relations with parents

Frequently, adult children don't feel their parents are making the right decisions. We ask ourselves "why can't our parents just cooperate with us?" Ongoing

conflicts with siblings can increase the level of frustration. What can be done to prevent or relieve such frustration?

First, it's important to reflect on what role your parents can play in developing the plan for their future. Remember that few of us will buy into something we've had no part in creating. Involve your parents in all conversations about their future. Even older adults with memory loss should be included in these discussions, even though much of the information will be forgotten. The fact that you involved them in decisions will be remembered and appreciated on some level.

Sometimes even families who have involved their parents in this process may not be able to agree on a basic course of action. In this case, you must think about the following: Are my parents at risk to themselves or others?

Separate your thoughts about quality of life from your thoughts about risk and danger. You might conclude that you're not comfortable with their present living situation, but your parents pose no significant risk to themselves or others. In this case, you're in the same boat as most other caregivers.

The best course of action might be to accept that your parents are still ultimately in charge of their lives. Tell them your concerns, if you feel strongly. However, a better approach is to provide information and options. See if your parents will tour some facilities and investigate other housing options without the pressure of imminent transition. Make clear the final decision will be theirs.

If you think that your parents are at risk and you have the legal authority to proceed (see Legal Aids

for Decision Making on page 23), then continue on your course. At this point you may want to ask a doctor, care manager or lawyer to assess the situation and discuss the options with your parents. Sometimes someone from outside the family can have more influence on your parents than family members themselves.

If you believe that a risk exists but you have no legal authority to proceed and your loved one refuses to cooperate, then seek the advice of an attorney experienced in elder law and competency issues. You can also contact your county's health and human services department and talk with someone in the vulnerable adult division.

Relations with siblings

The last time you and your sibling made a tough decision together might have been on a family vacation when you fought about who had more room in the backseat. Now, your family is in crisis mode, and you're trying to figure out how to work as a team.

As with most teams, one of you will probably emerge as the natural leader. This might be the one who lives closest to your parents or has professional training suited to the task (nurse, social worker, lawyer). Or it might be the sibling who has always played this role, even as a youngster. As long as you have confidence in this sibling's ability to play the leading role, and he or she is willing to carry out the plans of the group as a whole, try to accept your sibling in this role. In this capacity, he or she will be the one who has to answer the phone in the middle of the night, leave work in the middle of the day and communicate with the other family members whenever necessary.

Since you're reading this book, you may be the sibling who has accepted this leading role. If so, it will be important for you to think about the roles that other siblings can play. Some siblings may be able to contribute money but not direct care due to distance, family commitments or other barriers.

Some siblings may be available to give you a break, even if it's just once in a while. Regardless of your role, make sure you have a clear understanding of what you'll be expected to contribute and a planned course of action.

Communicating with an elderly loved one

Communication can be challenging even in the best of situations. Caregivers must discuss many difficult issues with their loved one. The problem may be further complicated if the older adult is suffering from memory loss and confusion. The following are suggestions to help caregivers talk with older adults:

- Hold discussions in a quiet setting at a time of day that is best for your loved one.
- Listen. Effective communication requires that you listen to and acknowledge the other person's opinions and feelings.
- Stay positive. Use constructive suggestions instead of blanket statements.
- Provide accurate information to your loved one. Do not try to spare them by telling half-truths and by making promises you may not be able to keep. It's better to say, "We will work on keeping you in your home as long as you are able," instead of saying, "I will never put you in a nursing home," unless you are able to commit to 24-hour caregiving.
- Allow your loved one time to process the information without rushing him or her into a quick decision. You don't want your loved one to react out of fear or guilt. Be patient. Some older adults need extra time to express themselves and process information.
- Involve other care providers in conversations. For example, if you are discussing a legal matter, it may be useful to involve an attorney who can provide the information in a more emotionally detached manner.

- Don't be afraid to share your own feelings and emotions.

Loved ones who are hearing impaired:

- Check hearing aids (if used) regularly to be sure they are working.
- Speak slowly and clearly. Face your loved one directly.
- It may be useful to write down parts of the conversation so that important points are not misinterpreted.

Loved ones having memory loss or dementia:

- Use simple words and sentences. Speak slowly and in a calm but clear voice.
- Supplement your words with nonverbal cues.
- If you are giving directions, don't assume that they are being understood. Have your loved one repeat instructions back to you and explain what they mean. People with dementia may talk fluidly, but the words may have no meaning.
- When communication is difficult, listen for words that are repeated or seem especially meaningful, as these may indicate the core of what your loved one is trying to communicate.
- Don't provide too much information or detail if you know your loved one can't process it or if the information will trigger disturbing thoughts.

Managing behavior changes

Family members should be prepared to face certain inevitable changes that come with aging, including physical frailty, illness and disease. More difficult to accept are the changes that affect a person's personality and memory. Witnessing such a transformation can be heartbreaking. However, there are things you can do to help lessen some of or

cope with the symptoms of behavior change and find support for yourself when you need it.

At the first sign of behavioral change, it's important to have a medical exam. This can rule out brain impairment, neurological damage, drug complications or sub standard nutrition.

If your loved one is suffering from memory impairments or dementia, you can:

- Use written cues to trigger memories.
- Keep the surrounding area free of clutter and unnecessary stimulation.
- Avoid arguments.
- Create a structured routine.
- Respond clearly, slowly and briefly to questions.

If your loved one is engaging in wandering behaviors, it is important to:

- Keep the area free of hazards.
- Find out if the person is trying to reach a certain destination (such as food, security or familiar person or object).
- Provide enough opportunity for exercise and physical activity. During certain phases of dementia, people can become restless and engage in pacing behaviors.
- Make sure that the person is well supervised. You may want to alert neighbors to your loved one's condition so that they can respond if necessary.
- Make sure that your loved one has a medical alert bracelet or tag with ID and emergency contact information.

If your loved one becomes combative or physically aggressive:

- Assess the danger to your loved one and to others.

- Keep sharp items and other potential weapons out of reach.
- Remove your loved one (if possible) from upsetting situations.
- Avoid arguments.
- If your loved one is safe to be left alone in a room, try to give them some time and space.
- Seek the services of a doctor to assess any neurological imbalances.
- Look for a pattern to episodes and try to avoid similar situations.
- Consider all the options before moving your loved one, but begin talking about this possibility early on. You may be surprised to learn your loved one is willing to move closer to you, but hasn't mentioned this for fear of burdening you with his or her problems.
- Retain a copy of the Yellow Pages that serves your loved one's community. The next time your loved one calls and you need to locate resources, you won't need to search out numbers or call long-distance for information. *Still practical? Wouldn't most use the internet?*

Long-distance caregiving

Families are now living further apart from each other. This can make caring for a loved one very difficult. There are several ways to help manage long-distance caregiving:

- Visit as soon as possible to assess the situation. Take notes of possible problem areas and gather information about senior resources in your loved one's area.
- Make sure legal and financial affairs are in place. Keep copies of important papers and telephone numbers of contacts. (See the contacts forms on pages 28–29.)
- Plan ahead in case you need to make an unexpected visit to your loved one. It is a good idea to bank some vacation or sick days from work for such visits.
- Set up a system of support. Ask a friend or relative in town to check on your loved one regularly. Stay in close contact with that person to learn of any changes.
- Seek help from a professional care manager. They specialize in assessing and monitoring the needs of the elderly.

Legal aids for decision making

Laws and regulations can be complex and confusing. It is important to plan in advance to ensure that your loved one's wishes about the future will be respected. It is possible for anyone to become incapacitated through injury, illness or general physical decline. Planning in advance is important so family members and health care professionals don't have to guess what their wishes would be.

There are two types of written documents, called **advance directives**, that can guide health care decisions should someone become incapacitated or terminally ill: the **health care directive** and the **durable power of attorney for health care** (health care agent).

A **health care directive** is a legal document in which a person can specify the types and extent of health care treatment preferred should they become unable to make their own health care decisions. The law defines end-of-life as a condition that is incurable and for which medical treatment will only prolong the dying process.

A **durable power of attorney for health care** is a legal document that appoints an agent to make health care decisions for a person should they become unable to communicate or make their own decisions. It is important to include written

instructions so that future care decisions will be based upon their beliefs and preferences.

The health care directive allows you to write down your specific wishes regarding pain management, resuscitation and other aspects of health care delivery. Your health care agent can use your health care directive as a guide to determine your medical plan of care. It is advisable to have both to be sure that your wishes will be respected.

In addition to advance directives, you should also consider updating your will and creating a power of attorney. A **power of attorney** is a document that allows you to let another person act legally on your behalf—sign checks, enter into contracts, buy or sell properties, etc. It will not strip you of your legal powers. You can still make decisions, vote and control your own legal and financial affairs. It simply names a person who can, if you choose, handle some or all of these matters for you. A durable power of attorney will remain in effect even if you are deemed incompetent. Upon death, the power of attorney is no longer valid. A power of attorney does not give anyone the right to make health care decisions for you. .

A **conservator** is someone appointed by a court of law when it has been demonstrated in a court hearing that someone is incapable of making or communicating his or her own decisions. It must be proved that there are no less restrictive alternatives in meeting that person's needs. This is an expensive option, so it is important to plan ahead with other forms of decision-making powers.

Paying for health care

Understanding the ins and outs of health care financing can be confusing. Because everyone's financial situation is unique and each state has slightly different guidelines for their economic programs, you may want to seek the advice of a financial planner or attorney specializing in elder care.

As you consider the following financing options, it is important for you to understand what costs you may be facing, how they have been determined and how they will be paid.

Medicaid is a medical assistance program for people with little income or few financial resources. A person is eligible based on need, income and assets. Medical expenses that fall under Medicaid include:

- Care from hospitals, doctors, nurses, dentists and other health care providers
- Drugs, medical supplies and equipment
- Health insurance premiums
- Transportation for medical care

To qualify for Medicaid you must:

- Meet financial requirements in terms of income and assets
- Apply through your local county economic assistance department

In recent years, federal and state governments have imposed stricter regulations on the transfer of assets before applying for Medicaid. It is important to talk with an experienced attorney or estate planner before transferring any assets.

Medicare is a federal health insurance program for those age 65 and older (as well as some disabled persons under age 65). Unlike Medicaid, Medicare is not based on need.

Medicare is divided into two parts: Part A (hospital insurance) and Part B (medical insurance). Part B benefits require a monthly premium and entitlement to Part A. Medicare has co-pays and deductibles.

Medicare Part A pays for the following:

- Cost of normal hospital services.
- Extended care services in a “skilled-nursing facility” assuming the following:
 - Minimum 3-day hospital stay before being admitted
 - The patient is admitted to a skilled-nursing facility within 30 days of hospital release
 - Treatment in skilled-nursing facility for same condition as
 - Need for skilled care on a daily basis
 - Condition shows measurable improvement
 - Facility is Medicare-certified, and doctor writes a care plan.
- Home Health Services that meet certain terms:
- Short term; skilled nursing care needed on occasion
- Physical and/or speech therapy if ordered by doctor and patient is homebound
- 80% of durable medical equipment
- No more than 35 hours per week or 8 hours per day of skilled nursing care
- Hospice Services:
 - In-home or facility
 - Doctor certified that patient is terminally ill with less than six months to live
 - Care provided by Medicare-participating program

Medicare Part B covers:

80% of reasonable charges from physicians and other health care professionals after deductibles are met, including:

- Medically necessary ambulance service
- Physical, speech, and occupational therapy
- Home health services, certified by a doctor as medically necessary
- Medical supplies and equipment
- Outpatient (same-day) surgery

It is important to be aware of what Medicare does not cover:

- Most nursing home care
- In-home daily routine care/maintenance
- Routine physical exams and X-rays
- Hearing aids and hearing loss examinations
- Dental care

Filling Medicare's gaps

Given the expense of medical care, you may want to consider ways to fill the gaps in Medicare coverage. The following are options for more coverage:

- Medicare Supplements
- Managed Care Plans
- Long Term Care Insurance

Medicare Supplements are designed to supplement Medicare's benefits. Federal and state law regulates these policies.

Medigap policies pay most, if not all, Medicare coinsurance amounts and may provide coverage for

Medicare's deductibles. Some of the benefits have dollar limits. Medigap policies generally pay the same supplement benefits regardless of your choice of health care provider. You can purchase Medigap Supplements for a limited time after your Medicare becomes effective.

Managed care plans, also called coordinated care or prepaid plans or HMOs, allow you to select care providers from those who are part of the network. You will have a primary care doctor who is responsible for managing your medical care, admitting you to a hospital and referring you to specialists. Most plans require a fixed monthly premium and small co-payments when you use services. You continue to pay the Part B premium to Medicare. You do not pay Medicare's deductibles and coinsurance, however.

Long-term care insurance are policies that cover nursing home care costs as well as some home health care costs (depending on your policy). While premiums for these policies can be more expensive than other types of insurance, they are a good protection against long-term care costs that can be devastating. Look to your financial advisor or insurance agent specializing in long-term care insurance to discuss the right policies for you.

It's the thought that counts

What is a suitable gift for an elderly person, someone in a nursing home or the person who has everything and needs nothing? Here are some suggestions:

- DVDs of family events, special outings, favorite television shows or old movies
- Large-print books or magazine subscription
- Long-distance phone card
- Stationary, envelopes, variety of greeting cards and supply of stamps
- Gift certificates to grocery store, taxi service, restaurants, or home-chore services
- Supplies suitable for a favorite hobby or craft
- Magnifying glass or adjustable lamp
- Donation to a favorite charity in the person's name
- Season tickets to local theater, museum or sports team
- Newsy note or card on a regular basis (always a winner)
- Calendar with a family photo illustrating each month

Appendix A

Personal documents

It may be helpful for you or your loved one to list important personal documents. The location of the records should also be recorded.

Item	Location
birth certificate	
citizenship papers	
passport	
social security card	
Medicare card	
medical assistance card	
health insurance policy and card	
disability insurance policy	
safe-deposit box key(s) and name of bank	
checkbook	
savings account book	
income tax returns	
home insurance policy	
will	
health care directive	
durable power of attorney for health care	
pension and retirement information	
marriage license	
divorce / separation decree	
military records	
property deeds and titles	
mortgage	
automobile title and registration	
auto insurance policy	
letter of instruction in case of death	
funeral instructions	
burial property certificate	

Health care contacts

Primary doctor: _____

Address: _____

Phone/Fax: _____

Other doctor: _____

Address: _____

Phone/Fax: _____

Home health agency: _____

Address: _____

Phone/Fax: _____

Pharmacy: _____

Address: _____

Phone/Fax: _____

Hospital: _____

Address: _____

Phone/Fax: _____

Other: _____

Address: _____

Phone/Fax: _____

Legal and financial contacts

Attorney: _____

Address: _____

Phone/Fax: _____

Accountant: _____

Address: _____

Phone/Fax: _____

Financial advisor: _____

Address: _____

Phone/Fax: _____

Insurance agent: _____

Address: _____

Phone/Fax: _____

Other: _____

Address: _____

Phone/Fax: _____

Other: _____

Address: _____

Phone/Fax: _____

Funeral planning

Funeral Home _____

Location of papers / certificate _____

Burial or cremation _____

Cemetery _____

Type of Casket _____

Headstone / marker _____

Crypt or vault _____

Preferred readings _____

Officiator _____

Information for obituary _____

Special wishes _____

People to notify upon death

- doctor(s)
- funeral director / funeral home / cemetery
- family and friends
- employer of deceased
- insurance agents
- local paper(s) (obituaries)
- religious, fraternal and civic organizations
- attorney, accountant, executor of estate
- social security office

Words to know

Activities of daily living (ADLs): bathing, dressing, grooming, eating, bed mobility, transferring, toileting, and walking.

Adult day care center: A community-based program that offers activities and meals. May offer health services for an additional fee. May provide transportation. Most programs run during the week and your loved one can attend full or part time.

Advance directive (health care directive, living will): A written statement of an individual's preferences regarding medical treatments. An advance directive protects your rights even if you become mentally or physically unable to communicate your wishes. It may appoint an agent to make health care decisions if you becomes unable.

Care manager: A social worker or health care professional who provides assessments to identify care needs. They can locate and coordinate senior resources for older adults and their families.

Chore or housekeeping services: Yard and house maintenance, housekeeping, meal preparation, shopping, transportation and similar services that do not involve medical care.

Companion: A personal care attendant who helps with shopping, meal preparation, supervision, companionship and light housekeeping. Companions usually do not provide personal care, (bathing, dressing or grooming).

Conservator: Person appointed by the court to act as the legal representative of a person who is mentally or physically incapable of managing his or her affairs.

Durable power of attorney: A power of attorney that stays in effect even after the principal becomes incompetent.

Durable power of attorney for health care: A legal document that allows you to appoint an agent to make health care decisions for you should you become unable to communicate or make your own decisions.

Emergency response systems: Electronic monitors on a person or in your home to provide automatic response to medical or other emergencies.

Estate planning: Steps you take to determine what happens to your property when you die.

Guardianship: An extreme measure that restricts the legal rights of an elder based on a court's finding of legal incompetence.

Health care agent: A person given the power to make health care decisions when another person becomes unable to make or communicate decisions.

Home health agency: An agency that provides medical services in the home. Services may be provided by a nurse; occupational, speech or physical therapist; social worker; or home health aide.

Home health aide: Health worker who provides personal care such as bathing, dressing and grooming. May include light housekeeping services.

Hospice: Palliative and social programs for end-of-life patients and families. Support may be given at home or in a medical or residential setting.

Incapacity: Loss of ability to make decisions for oneself because of a mental or physical condition. It may be temporary or permanent. Incapacity is not the same as incompetence.

Incompetence: A legal determination that someone is not competent to make legal or financial decisions.

Long-term care: A range of places that provide health care to people who are unable to live independently. These residences may provide short-term rehabilitative services as well as chronic care management.

Medicaid: A jointly funded federal and state government program in which the states provide health care for people with low-income and minimal assets. Eligibility is based on need.

Medicare: Federal program providing health care coverage for people over 65 and some disabled persons. Part A covers in-patient care, skilled nursing in a facility, hospice and short-term health care. Part B covers doctors' services, outpatient hospital care and durable medical equipment. Medicare does not generally provide for long-term care.

Ombudsman: An person who investigates consumer complaints against a nursing home or community resident facility.

Power of attorney: A legal document allowing one person to act in a legal matter on another's behalf.

Respite: Services to relieve the caregiver from caregiver duties. Respite care may last from a few hours to several days.