

# Living Arrangements in Later Life

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# Living Arrangements in Later Life

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Sooner or later most families face the question of "What shall we do?" when an aging relative begins to have difficulty living alone. We hear the concerns expressed all around us:

"Dad's so unsteady on his feet. I don't see how he can continue to live alone. He's already fallen twice this week. I'm scared he'll fall and really injure himself next time. He refuses help and he won't move. I don't know what to do."

"Mom had a stroke and the doctor says she can't return home. It looks like she'll have to live with us or go to a nursing home. We've never really gotten along but she'll be very angry if we place her in a nursing home."

"We thought we had everything settled when Dad moved into a retirement home 2 years ago. Now we've been told Dad has to move because he forgets to come to meals and has been found wandering in the halls at night."

"Grandmother has become increasingly depressed and isolated in her home. She won't cook and she hardly eats. She has outlived most of her friends. Wouldn't she be better off living with other people and where meals, activities, and social contact are provided?"

Such situations and decisions are never easy, and there is no single or easy answer. The emotions experienced by everyone can further complicate decision-making and make an objective evaluation even more difficult. We all want the best for our older family members, but it can be difficult to know what is best. And, sometimes our ideas about the most appropriate living arrangement are quite different from those of our older relative.

This publication suggests guidelines for effective decision-making when completely independent housing is no longer feasible. It also discusses a variety of living arrangement options for older adults. Although this information may not ease the emotional impact of a decision, it should help you and your family make decisions that are best for everyone concerned. ■

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# **Making the Decision**

It's difficult to watch a parent struggling to maintain a home and function independently. You probably feel emotionally torn between whether to allow your parent to be as independent as possible or to create a more secure environment. You may wonder if you should force a change, particularly if you feel your parent's choice is not in his or her best interest. And, you may find yourself feeling guilty regardless of the decision.

The following are important questions to ask yourself when faced with a decision.

# Yes No Do I know my family member's current and long-term care needs? Am I knowledgeable about his or her capabilities as well as his or her limitations? Have I gathered information on all available options to meet my relative's needs? Do I know and understand his or her preferences? Do I respect my family member's preferences, even if they conflict with Am I willing to allow him or her to take some risks which may have negative consequences for him or her (but will not affect others)? Am I fully informed about my relative's financial situation? Is my family member involved (as much as possible) in making decisions about his or her living situation? Is everyone who will be affected by a potential decision involved in making the decision? Do I know how other relatives (e.g. brothers and sisters) feel about the situation and how they are willing to help?

If you answered "yes" to the above questions, you are already on the way to making the best decision.

# **Understand Your Relative's Needs and Feelings**

Before deciding what must be done, you need to know how well your family member functions in daily activities, and the personal and environmental factors that make independent living difficult. The more you understand your relative's needs, the easier it will be to choose an appropriate living arrangement. Some of the areas in which people often need help are:

- meal preparation
- home maintenance
- health care
- mobility and transportation
- housekeeping
- overcoming loneliness
- assistance with taking medication
- management of finances
- bathing and personal care.

In addition to understanding the ways your family member relies on others for help, consider the ways he or she manages alone. And, also try to anticipate what his or her needs may be in the near future.

Answering the following questions will help you clarify your parent's situation and needs:

- What specific change(s) is my family member experiencing? What problems/needs are these changes creating for him or her?
- Are the needs temporary or permanent?
- Is occasional or continuous help needed? How long is my relative likely to need assistance?
- How does my family member feel about these changes? Does he or she see them as problems?
- In what ways has my relative compensated for these changes?
- Which, if any, of these changes are harmful to my family member's well-being or to others?

If you need help to determine your relative's level of functioning, seek professional guidance. Your relative's physician, a nurse, or a social worker can provide an objective assessment. A professional evaluation can help you feel more confident about your family member's needs and the assistance he or she requires.

Try to put yourself in your relative's situation and understand the significance of accepting help or moving to a new environment. Sometimes an older person welcomes a change when failing health, death of a spouse, limited income, or the upkeep of a home makes it difficult to maintain a home. Frequently, however, a change is traumatic and stress-producing even when it is "for the better."

Our home holds special meanings for most of us. It can represent personal identity, freedom, a familiar way of life, security, stability, and independence. Thus, a change in living arrangements is usually stressful. A move can mean not only the loss of a house, but also separation from friends, familiar surroundings, possessions, and ties between the past and present. For many people, accepting help or having to move can create a feeling of vulnerability and loss of personal identity and control.

### **Involve Your Relative in Decisions**

The older person for whom plans are being made should be actively involved in making decisions. It's vital to plan with, not for, your family member! Preferences should be discussed and alternatives evaluated together. No adult likes to have decisions made for him or her no matter how "wise" those decisions may be. It's easier to accept and adapt to an unwelcome change when one has been involved in planning for it.

Talk with your family member about his or her desires and priorities. Determining the importance of the following items will help you and your relative make a more informed decision.

	Very Important	Somewhat Important	Not Important
Staying in current home			
Staying in present community			
Living near family			
Living near friends			
Living near place of worship			
Availability of medical services			
Access to social and recreational activities			
Privacy			
Companionship			
Keeping costs affordable			
Keeping a pet			
Having own household and personal possessions			
Convenience of shopping			
Security			
Availability of transportation			
Help with household tasks			
Assistance with meal preparation			
Assistance with personal care (bathing, dressing, grooming)			
Help with taking medications			
Others?			

Involving your relative in decision-making does not necessarily mean decisions are left totally up to him or her. Decisions should not burden others unnecessarily. You can set limits on what you and other family members can do. Then, within those limits the person can make the decision.

If your older relative is very ill or mentally incapacitated, you may need to make the decision—but you don't have to make it alone! The physician and other professionals involved in your family member's care can provide guidance. Even then, you should involve your relative in the planning as much as possible. If a move is necessary, explain the move and the reasons for it, even if you think your relative cannot possibly understand. It may help reduce the stress of a move.

# **Express Your Concerns**

It's important to express your concerns to your relative. The most positive way to do this is to make "I" statements (which express your feelings) and describe specifically the situation or behavior that concerns you. An example might be, "Mom, I'm worried about your living alone because of your dizzy spells. I'm afraid you'll fall and hurt yourself. I need to talk with you about my concern." Your family member is more likely to listen and discuss your concerns when you express them in a caring way and respect his or her right to make decisions.

Even though your relative's current living situation may create concern and fear for you, your family member has the right to make choices and to take risks as long as he or she is not mentally

incapacitated and those risks do not endanger others. However, along with those rights goes the responsibility for accepting the consequences of a decision. Sometimes it helps to communicate this perspective to your family member and to set limits on the help you will give.

If your family member who chose to remain at home falls and breaks a hip, you'll probably feel terrible and guilty for yielding to his or her wishes. But remember, the decision was your relative's—not yours. If your relative places unrealistic expectations on you, you need to say so. For example, one 78-year-old man expected his 35-year-old daughter to take care of him even though she had three young children and her past relationship with him had not been a good one.

### **Investigate Options**

The goal should be to select an affordable living arrangement that meets your family member's needs and provides maximum independence. Before exploring options, know the financial resources available to your family member since these will determine potential private and public options.

Try not to have preconceived ideas about the best choice and consider the benefits and limitations of each option. Your family member will probably feel more control if he or she has at least two options from which to select.

Three major living arrangement options will be discussed: ways to maintain older persons in their homes, group living arrangements, and the older person and family living together.

# Maintaining Older People in Their Homes\_

Most older people want to live independently in their own homes as long as possible. Some struggle to live alone and retain their independence, freedom, and privacy, even when it becomes increasingly difficult because of frailty, poor health, or limited income.

Usually independence is not an all-or-nothing proposition, and a person's level of independence can change from time to time. Most older people who require help need it only in certain areas of their lives. If such assistance is received, they can continue to live independently. Occasional help—with grocery shopping, transportation, heavy housecleaning, or other specific tasks—from family, friends, neighbors, or community agencies is sometimes all that is needed.

Before considering a change in living arrangements, explore ways of maintaining your relative in his or her present home. Look back at the needs you outlined on page 4 and the priorities you checked on page 5. With these in mind, the following approaches may enable your family member to remain in his or her own home.

- Using community programs designed to assist the elderly
- Obtaining special aids for independent living
- Modifying the home
- Homesharing

# **Community Services**

In many communities, various support services enable older people to remain independent in their own homes. However, the types of services available vary depending on the community.

Before investigating services available in your relative's community, make a list of the types of assistance your relative requires and how frequently the help is needed. Then, explore your relative's community. Do not rule out anything at this stage. This is the time to consider all alternatives.

The local Area Agency on Aging (or the State Unit on Aging) can give you information about where to go for the help you need. Many social service agencies, home health agencies, and senior centers can also help you locate services, or may even provide some needed services.

If your family member has difficulty preparing meals or simply doesn't eat well, community programs that may be available include:

Congregate meals/nutrition site program.

Meals are provided in group settings, often located in senior centers, schools, churches, and housing projects for the elderly. The program emphasizes social contact as well as providing nutritious meals. Transportation is sometimes provided. Participants contribute what they can to the cost of the meal.

*Home-delivered meals/Meals on Wheels.* Meals are delivered to homebound elderly daily or several times per week.

For the person who is lonely and needs companionship, the following programs may help:

**Telephone Reassurance.** A daily telephone call is made to your family member at an agreed-upon time. If the telephone is not answered, the caller immediately notifies a designated person or agency (friend, neighbor, police, fire department) who investigates.

Friendly Visitors/Senior Companions.

Either volunteers or paid individuals visit homebound elders regularly, often once or twice a week. They do whatever a friend might do: talk with the person, play cards or games, write letters, read aloud, or just sit and listen.

**Senior center.** Depending on the geographic area, a senior center may offer a variety of recreational and social activities and supportive services—information and referral, meal programs, financial counseling, in-home services, legal assistance, health screenings, grocery delivery, help in applying for Medicare and Medicaid, and transportation.

**Adult day care.** A program for frail older adults who need assistance, but not continuous care. Services range from social and recreational activities to health care—therapy, assistance with medicine, and personal care. Transportation is sometimes provided.

**Bookmobiles/library services.** Local libraries often offer special programs and services for the elderly.

If your relative needs assistance with household tasks, but can otherwise care for himself or herself, help may be provided by:

**Handyman and chore service.** Workers are provided at reduced cost for minor home repairs, home maintenance (e.g. putting up storm windows, mowing the lawn), heavy household cleaning, and other chores. The service usually does not include major home improvements.

**Homemakers/Home Care.** Assistance is given with activities of daily living, such as meal preparation, essential shopping, laundry, and grooming. Health care and nursing services are not provided.

**Home improvement/weatherization.** Limited home improvement grants or loans are available to older persons who meet income eligibility guidelines. Funds can be used for roofing, ramps, and insulation.

For the person who no longer can drive or finds public transportation difficult, the following may be available:

**Senior transportation.** Frequently listed in the telephone directory under names such as "Dial A Ride," transportation may be available for medical appointments, grocery shopping, nutrition site programs, and other necessary travel. Some programs have buses or vans equipped with lifts or ramps for wheelchairs.

**Escort service.** A service often provided by volunteers who use their private vehicles to transport elders to and from their destination.

For the elderly who live alone and have little contact with others, there is often a concern that they will go unnoticed if they get sick, fall, or otherwise become unable to summon assistance. Available programs may include:

In-home medical alert program (Emergency Response System; Lifeline). An electronic device carried by the older person sends a signal to a central dispatcher, often located at a hospital, if he or she falls or needs help. Emergency assistance is summoned if the person does not answer the telephone. Help is available round-the-clock.

**Postal alert.** The postal service alerts a designated person when mail is accumulating in the mailbox of an older person. In some communities, as a part of a "Gatekeeper Program," utility meter readers, paper deliverers, and other people who have contact with the elderly in the course of their jobs are being trained to recognize older people who may need help.

If health care is the concern, help may be available from:

**Home health agencies.** Services generally include skilled nursing care; physical, occupational, and speech therapy; social work services; and personal care—assistance with bathing, dressing, grooming, and exercising.

**Hospice.** Program offers a range of care and support services to terminally ill patients and their families during the last stages of disease.

Hospital social workers and discharge planners or local home health agencies can provide information about home health care services available in your relative's community. Some home health care is reimbursable by Medicare, Medicaid, and some private health insurance policies, but only under very specific conditions. These conditions may include: person must require part-time skilled nursing care, physical therapy, or speech therapy; the older person is confined to home; and home health care was ordered by a physician. A home health agency also must be certified to be eligible for Medicare and Medicaid payments.

Contacting agencies. It will help if you are fully informed about your relative's needs and financial situation before you contact community agencies. Fees for the above services will vary depending on the type and extent of service provided. Some programs charge on a sliding scale, and the fee is determined by the ability of the person to pay. Others have a set fee based on the services provided and hours of staff time required. Some volunteer groups provide services at no charge or for a small donation.

To get the most complete information, develop a list of questions in advance of calling agencies. Although the appropriate questions will depend upon the assistance needed, you may want to consider the following questions:

- What kinds of help are available from your agency? Or, if you know the specific help you need, ask if the agency provides that assistance.
- During what hours can the service be provided?
- What is the length of time the service can be provided?
- What are the eligibility requirements? What medical or financial documentation, if any, is needed?
- How much does the service cost?
- What are the qualifications, training, and credentials of staff?
- Is the agency bonded?
- Who is liable and responsible if an employee has an accident on the premises of a person's home? if anything is stolen?
- Who can I contact if I have concerns about the services provided?
- What is the application procedure? Is there someone in the agency who can assist with the application process?

Write down the name, title, department, and telephone number of each person you speak with and their comments and recommendations. If an interview is required, be prepared with the necessary information and documentation. Some agencies also will conduct an in-home interview if your relative is extremely frail.

**Hiring your own helpers.** If you hire inhome help without going through a community agency, be sure to check credentials and references! This may save you considerable heartache later on.

The cost of services is generally lower when you hire your own help rather than purchase services from community agencies. However, employing your own workers does require additional time, supervision, paperwork, and responsibilities. You will also need to arrange for back-up help if the employee becomes ill or otherwise is unable to work.

As an employer, you may be responsible for withholding federal and state payroll taxes, Social Security contributions, unemployment insurance, and worker's compensation insurance. For specific information about your responsibilities as an employer, contact your local Social Security office, employment office, or state labor department. Also, check to be sure your family member's home owner's insurance policy provides adequate coverage for an in-home worker in case of injury.

Interviewing potential in-home workers is critical. In preparation for interviews, make a list of questions pertinent to your particular need. Also, write down information about your relative's situation and special problems that prospective employees should know about so they can decide if the job is right for them. Honesty is crucial during the interview. Since the success of in-home services will also depend on your family member's acceptance of the worker, it's critical to have your relative involved in the interview and selection process.

To avoid later misunderstandings, formalize your agreement in writing. The agreement should clearly define expectations, work responsibilities, hours of employment, salary and benefits, frequency of payment, and vacation. The more specific a contract, the less chance for confusion and disagreement. The contract should be signed by all parties before the worker begins employment and each party should have a copy of the signed contract.

Guides which provide detailed information on advertising for and hiring prospective employees, legal requirements, interview questions, and sample contracts include:

Hiring In-Home Help. Education and Family Support Services, Neurological Sciences Center, Good Samaritan Hospital, 1040 N.W. 22nd Ave., Portland, OR 97210.

How to Hire Helpers: A Guide for Elders and their Families. Task Force on Aging, Church Council of Greater Seattle, 475915th N.E., Seattle, WA 98105.

# **Aids for Independent Living**

Many inexpensive devices are available to make living easier and safer for older persons. For example, a long-handled shoehorn, touch fasteners on clothing, a bathtub stool, color-coded stove dials, a telephone amplifier, and metal tongs for reaching can enhance the independence of an increasingly frail older person. Health-related associations—Arthritis Foundation, Association for the Blind, Parkinson's Disease Association, Multiple Sclerosis Society, Alzheimer's Disease and Related Disorders Association and others—often have booklets available describing such aids and where to purchase them. Your local home health agency also may be a good source for information.

### **Home Modifications**

Relatively simple and inexpensive adaptations often can be made in the home to accommodate a person's changing physical needs. For example, installing grab bars and handrails by the bathtub, shower, and toilet can increase safety in the bathroom. The wheelchair-bound person's independence may be maintained by enlarging doorways, installing a ramp at the front door, adapting a shower to accommodate a wheelchair, and lowering kitchen and bathroom cabinets. Many home health agencies have professionals on staff who can help evaluate a home and recommend modifications.

When a home becomes a burden because of size, cost, or upkeep, an alternative may be converting a part of the home into an apartment. Often called an *accessory apartment*, this change can provide the older person with additional income and the security and companionship of someone living nearby. Sometimes arrangements are made for tenants to provide services—upkeep of yard, home repairs, one meal a day—in return for a rent reduction.

Whether or not such a major change is feasible depends on house design, zoning laws, and the cost of renovation (including increases in taxes and insurance) relative to the benefits gained.

### Housesharing

Housesharing can be one answer for the older person who has extra living space and needs added income, companionship, or assistance with household chores. And, living with a housemate is sometimes easier than moving in with family. A housesharing arrangement can be set up by renting space in the home, or through an exchange of services in lieu of rent or for a rent reduction. Housesharing, however, is not for everyone. If accustomed to living alone, your relative may not want another person living in his or her home.

If housesharing appears to be a possible option, talk with your family member about how housesharing might improve his or her situation. Discuss what would be essential to your relative in a housesharing arrangement. Would it be income? having someone nearby in case of an emergency? security? a companion for activities? assistance with household chores? or a combination of these? Also, discuss your family member's concerns and how those concerns can be handled.

The success of housesharing depends primarily on how well housemates get along. Therefore, it's vital that your family member is involved as much as possible in interviewing and selecting his or her housemate. Potential housemates should meet several times and talk about expectations, lifestyles, habits (smoking and drinking), preferences, and dislikes. If your family member is not able to

participate in such discussions, then you will need to assess the similarities, differences, and compatibility of your relative and any potential housemate.

Practical issues—such as the division of tasks, use of the kitchen, payment of telephone bills, use of common areas for entertaining—should be fully discussed. If your family member has a dog, does the prospective housemate like dogs? If one person goes to bed early, will the television played by the "night owl" be too disruptive?

A trial period—spending a week or month together before making a commitment for a more permanent arrangement—may help ensure greater success. Also, signing a formal agreement will help prevent future misunderstandings. Financial arrangements, responsibilities, and expectations should be clearly outlined in the agreement.

Zoning regulations and loss of government benefits are potential barriers to housesharing. For example, in some communities, zoning laws allow two or three unrelated people to live together, but not a married couple and an unrelated parent and child. Supplementary Security Income (SSI) or food stamp recipients may risk a reduction of benefits if they share housing because of its effects on income. If your relative receives government benefits, be sure to check with the appropriate federal or state agency.

In some communities, home-matching programs have developed that link people who have housing space with individuals seeking housing. Program staff try to match the older person with a live-in person and assist them in working out mutually agreeable financial and living arrangements. The availability of such programs, however, is limited. ■

# When Your Relative Refuses Help

It can be frustrating when you know your family member has difficulty functioning independently yet refuses necessary services. Although you cannot force your relative to accept help, you need to understand the reasons behind the resistance if you are going to have any success overcoming the reluctance. Ask yourself:

- Is my family member concerned about the cost of the service and its impact on his or her savings?
- Does my relative feel he or she does not have a problem?
- Does he or she view agency assistance as "welfare," "charity," or "going on the dole"?
- Is my family member fearful about having a stranger in the house or having possessions stolen?
- Does my relative feel the tasks(s) I want to hire someone to do are ones that he or she can do? Or that family should do?
- Does he or she view accepting outside help as a loss of control and independence?
- Are the requirements of community agencies financial disclosure, application process, interviews—overwhelming to my relative?

It's important to deal with your relative's perceptions and feelings. For example, if your mother feels she does not have any problems, be as objective and specific as you can in describing your observations. Indicate that you know it must be hard to experience changes. If your father views federal- or state-supported services as "welfare," emphasize that he has paid for the service in past years through taxes.

Try to approach your family member in such a way that he or she does not feel helpless. Many of us, regardless of age, do not find it easy to ask for or to accept help. It is best to present the need for assistance in a positive way, emphasizing how it will enable the person to live more independently. Try not to emphasize the person's dependence and what he or she cannot do. For example, avoid statements such as "you can't do that anymore." Pushing a person too hard or focusing only on limitations often increases resistance.

It usually helps to suggest only one change or service at a time and if possible, begin with a small change. People generally need time to think about and accept changes. Introducing ideas slowly rather than pushing for immediate action increases the chances for acceptance. The more your relative feels a sense of control in planning and making arrangements, the better off you'll both be.

Sometimes suggesting a trial period— "trying the service for a month"—will help. Some people are more willing to accept a service when they initially see it as a short-term, rather than a long-term, commitment. Some families have found that giving a service as a gift works. Examples include giving spring cleaning as a Mother's Day gift, a Christmas gift of hair appointments for the woman who has difficulty brushing her hair because of arthritic shoulders and hands, and home-delivered meals as a get-well gift after surgery.

Some individuals are more willing to accept assistance from someone they know than from a "stranger." Could a neighbor be hired to prepare a daily meal for your relative? Is there a responsible teenager in the neighborhood who could be hired to do grocery shopping or yardwork or provide transportation? Sometimes this person will have more success in getting your relative to accept an "outside service" for a short time when he or she cannot do it.

If your family member persists in asserting, "I'm okay," "I don't need help," try focusing on your own needs rather than those of your family member. For example, saying, "I would feel better if..." or "I care about you and I worry about....Will you consider doing this for me so I will worry less?" sometimes makes it easier for a person to try a service. Having a service suggested by someone your relative respects may also be an effective approach.

Be careful about how much assistance you volunteer to provide. Be realistic about what you can do, and communicate your limits to your relative. For example, if you volunteer to prepare your mother's meals, do your father's laundry and grocery shopping, or clean your grandmother's house weekly, are you really willing to do the task for as long as the person needs it? The need that appears to be for only a few weeks may turn out to be for several months or years. Family members sometime find that once they take on a task they encounter even greater resistance from their relative when they try to hire an agency or person to do the task.

# **Group Living Arrangements**

Despite the many advantages, living at home is not always the best choice for everyone. Sometimes it becomes impractical for a person to remain in his or her home because of costs, home maintenance, failing health, loneliness, lack of transportation, or the distance of home from stores, activities, and services.

When living alone is no longer desired or feasible, group housing may be an appropriate alternative. A variety of group living arrangements are available to meet the varied needs of the older population. These include:

- Retirement communities
- Congregate housing
- Residential care facilities
- Adult foster care
- Nursing homes
- Multi-level care facilities

The names of various housing/care arrangements are not universal. Different words may be used in different communities, regions or states. The local Area Agency on Aging and local housing authority are good resources to contact when investigating housing options available in a particular area. Also, look in the yellow pages of your telephone directory under "Retirement Homes" and "Nursing Homes." For information about religion-affiliated homes, call a local church of the particular faith or denomination.

The best housing choice depends on an older person's needs, level of functioning, and financial resources. These needs may change with time, requiring a person to consider another option. Therefore, it's wise to consider housing possibilities before the need for change arises. The goal is to select housing which offers the greatest degree of personal independence, while meeting safety, comfort and convenience needs. Generally, the more extensive the services, the more costly the housing. Thus, the resources of your family member will be an important factor as you consider group living.

With any group living, there are disadvantages. There can be a degree of regimentation and some loss of privacy. However, advantages often include recreational and social activities, less isolation, security, reduced home maintenance, companionship, and health services.

### **Retirement Communities**

Retirement communities are for active retired persons of at least a certain age. Thus, they separate residents from the noise and activity of young families.

Housing types and sizes vary greatly. They include single family dwellings, townhouses, duplexes, high-rise apartments, condominiums, and mobile homes. Living units may be for rent or sale. Retirement communities may or may not provide support services. In many communities, only the usual community services such as police and fire protection are provided. Others provide recreational and social activities, household maintenance, and repair. Some retirement complexes offer a range of services—housekeeping, group dining, and transportation for special events, shopping, and medical appointments—for an additional fee. A few have infirmaries for short-term nursing care; long-term nursing care usually is not available.

A potential resident generally must be independent in all aspects of daily living (for example, able to bathe, dress and take medication without assistance), mentally alert, have bowel and bladder control, and be able to walk. Some facilities allow walkers and wheelchairs.

Continuing Care Retirement Communities (CCRCs). A Continuing Care Retirement Community (also called "Life Care") offers lifetime housing and includes independent living, personal care, and nursing services. It can be a way to assure independent but supportive living as long as possible in the same setting with a guarantee that nursing care is available if needed. Residents may move from one care level to another as their needs change. The availability of multiple levels of support can be particularly advantageous to couples, enabling both to stay in the same community even when one partner needs nursing home care. Another advantage is that a person's support system can remain uninterrupted as needs change.

Continuing Care Retirement Communities usually offer a variety of services. These may include personal conveniences (beauty and barber shops, banks, library); organized social and recreational activities; educational programs; exercise classes; craft and woodworking room; gardening space; transportation; and health care.

Some CCRC's provide full health care benefits at no additional charge. Others offer full care, with additional charges after a specific number of days of health care per year. Still others charge for certain medical services. Because of the many services and activities available, living in a Continuing Care Retirement Community can be costly. There is usually a substantial entrance fee plus monthly charges.

Admission requirements are generally restrictive regarding minimum age, health, and finances. Some also have a long waiting list. A person may be on a waiting list for months or even years.

Before signing a contract, seek legal or financial advice. Learn all you can about:

- The reputation of the sponsors and the management
- The financial integrity of the institution
- Reserve funding to protect the residents
- Entrance requirements
- Conditions, if any, under which the entrance fee is refundable
- Services included in the fees
- How monthly charges are established
- Conditions under which fees may be increased
- Type of health care facility
- Health and personal care services available in independent living units and those available only in care facilities
- Limits to the health and medical care covered by the regular fees
- Conditions under which a person may be asked to move
- Policies for transferring a resident to and from different levels of care
- How long a living unit will be maintained if a person is temporarily transferred to a nursing unit
- Actions taken if personal financial resources are depleted.

Because of the financial investment required in a CCRC, a person should visit several times before making a commitment. If guest quarters are available, it may be wise to stay in the community a few nights to get a better feel of the surroundings, activities, residents, and staff.

# **Congregate Housing**

Congregate housing (sometimes called assisted independent living) is for the person who needs little or no assistance. Residents have their own private apartments, including a kitchenette for light meals and snacks. Limited services are available. These may range from a central dining room and

meal program to organized recreational activities, health, transportation, housekeeping, nonpersonal laundry, and security services. Some services may be optional. Many have emergency signaling devices in bedrooms and bathrooms for summoning help.

Most require residents to be able to live independently. Cost varies depending on the housing and services provided. Some facilities are privately financed; others are publicly financed.

**Low-income housing.** In recent years, many communities have built housing for older people with low and moderate incomes. Rents are subsidized and therefore lower than market rents. A person's rent is adjusted to a percentage of his or her income.

In some areas, a short supply of units requires a person to be on a waiting list for several months. For information about low-income housing, contact the local Housing Authority.

### **Residential Care Facility**

A residential care facility (sometimes called "board and care home," "personal care," "sheltered housing" or "domiciliary care home") may be the answer for a person who needs assistance with personal care—such as bathing, grooming, dressing, getting in and out of bed or bathtub, and medication supervision. Meals, social activities, laundry, and housekeeping services are also provided. Some facilities have studio or one-bedroom units. Typically they lack kitchenettes, but usually have private bathrooms and storage areas. Other facilities have private or shared rooms. Sharing a room can be a difficult adjustment for some older people.

Residential care facilities are generally licensed (however, not in all states) and must meet design and operating standards, including minimum staff requirements. Staff coverage is provided 24 hours a day. Prospective residents generally must be fairly mentally alert; able to dress, feed, and take themselves to the toilet; able to eat meals in a central dining room; and need no more than moderate assistance with personal care or behavior supervision. Some facilities will accept persons who use walkers or wheelchairs.

### Adult Foster Care

Adult foster care (also called "Adult Family Homes") is provided in a private home occupied by an individual or family who offers room, meals, housekeeping, and generally minimal supervision and personal care for a monthly fee. The care given varies depending on the resident's needs and the provider's background, training, and interests.

Care can range from simple room and board with laundry and transportation provided, to help with bathing, dressing, toileting, and feeding. Staff can remind a resident to take medications, but cannot administer it unless the provider is a licensed nurse. A few adult foster care homes, operated by nurses, provide some nursing care.

There are considerable differences in the services offered and the quality of adult foster homes. Call your local Area Agency on Aging for information about homes in your area. Before making a decision, tour and evaluate as many homes as possible. Talk to families and residents of the homes, as well as the care providers.

There are specific requirements for a "licensed" adult foster care home, including maximum number of residents; physical requirements such as zoning, type of construction, and bedroom size; furnishings; meal service; and medicine storage. Providers must live in the home and provide 24-hour supervision.

A potential resident is typically a person who is mentally alert to moderately confused, needs some assistance with personal care and/or 24-hour supervision. Usually, the person must have bowel and bladder control and be able to walk or use a cane, walker, or wheelchair. Foster care providers generally will not accept persons who wander because they cannot leave other residents to search for the wanderer.

# **Nursing Home Care**

If a family member is seriously ill and needs extensive or continuous nursing care or 24-hour supervision, a nursing home may be the best choice. In addition to nursing care, nursing homes usually provide rehabilitation programs and social activities.

In general, nursing homes provide two levels of care: intermediate and skilled. These terms refer to the intensity of nursing services offered by the facility. Intermediate care is designed for people who require assistance with activities of daily living and some health services and nursing supervision, but not constant nursing care. Persons who need certain rehabilitation services also may be appropriate for intermediate care. Care is ordered by a physician and supervised by a registered or licensed nurse.

Skilled nursing care is for individuals who need 24-hour medical supervision, skilled nursing care, or rehabilitation, but do not require hospitalization. This might be an appropriate placement for a person recovering from a broken hip or recent

stroke or suffering from an illness requiring round-the-clock nursing care. A physician's order is required for admission.

Some facilities offer a third level of care, sometimes called custodial care. This care level is suitable for people who do not need the care of a practical nurse, but do require supervision and assistance with personal care and other activities of daily living. Often this kind of care is required by persons suffering from dementing illnesses such as Alzheimer's disease. Some facilities have special units designed for the cognitively impaired person.

Preadmission screening is available or required in some states for nursing home admission. A team of professionals provide an assessment of the older person's functioning, the appropriateness of nursing home placement, and possible alternatives.

If you anticipate nursing home care may be needed in the future, investigate nursing homes in advance. It will make for a better, less frantic, and less emotional choice. Good nursing homes are in demand so you'll want to consider more than one facility as a possibility. At the time your relative needs a nursing home, your first choice may not have a bed available.

To receive Medicare or Medicaid coverage for intermediate or skilled nursing care, the facility must be government certified. Remember, too, the older person must meet certain requirements. Medicare provides only limited coverage for nursing home care. There are income and asset eligibility requirements for receiving Medicaid. For information about Medicare, contact your local Social Security office. Information about Medicaid is available from county welfare, health, or social service agencies.

### **Multi-level Care Facilities**

Some facilities offer a variety of living arrangements and levels of care under one roof. For example, one section of the facility may have independent units (apartments or cottages with kitchens); another section where limited support services such as meals are provided; a residential care section where assistance is provided with personal care; and a section where nursing care is provided.

A major advantage is that residents may be able to move back and forth between areas as their needs change. A multi-level care facility, like the Continuing Care Retirement Community, can be beneficial for couples who have two different levels of care needs.

# **Selecting Group Housing**

The primary goal in selecting a facility is to choose one that is affordable and will permit your relative to remain as independent as possible while meeting his or her needs. Although you will want to ask specific questions depending on the type of group living arrangement being considered, you may find the following general questions helpful:

- What is the reputation of the facility in the community? Have complaints been lodged against the facility with the Better Business Bureau or with the state regulatory office?
- What are the admission criteria and procedures?
- How long is the waiting list?
- What is the cost per month? How are the fees established? How often do they change? What services are included in the basic fee? What services are considered extra and what do they cost? Are there hidden costs?
- If meals are provided, is there a selection of entrees at each meal? Is the food attractive, nutritious, and tasty? Can a special diet be accommodated? Is there an additional cost? Is a tray available if a person cannot get to the dining room?
- What are the "house rules"? Are they overly restrictive?
- What are the policies regarding personal furniture and possessions?
- Are pets allowed?
- What is the size of a resident's living quarters? Is storage space adequate? Must the room be shared?
- How accessible are various areas of the facility if a cane, walker, or wheelchair is used?
- What security is provided? To what extent does management assume responsibility for the security of personal belongings?
- What assistance is available in an emergency?
- What is the policy about holding an apartment/ room for a resident who is hospitalized or needs a more intense level of care for a period of time?

- Under what circumstances would a resident be asked or forced to move? How much notice is given? What about refunds?
- Are there restrictions on having visitors? Are overnight accommodations available for out-oftown guests?
- What recreational, social and therapeutic activities are provided?
- What are the procedures for registering a complaint?
- Is there a resident's council or other organized means for gaining input from the residents?
- What is the general atmosphere of the facility and the attitude of staff?
- What is the philosophy of the administrator toward the residents? toward the residents' families?
- How are families involved?

Any group living arrangement should be carefully evaluated. For the most successful planning and placement, involve your relative to the greatest possible extent. Tour appropriate facilities together and visit more than once. For example, visit at mealtime, during an activity, and on weekends as well as during the week. Talk to staff and residents. Observe the environment and how staff interact with residents. Visit long enough to assess a normal day.

Talk with the housing manager, administrator, or care provider until all questions are answered. Also, when you make care arrangements, give an honest and complete picture of your relative's needs—medical, social, emotional, behavioral, and financial. This will help insure that you and your relative select the most appropriate living arrangement. Before signing any contract, be sure you and your family member fully understand the terms of the agreement. If you have concerns, ask a lawyer to review the contract.

# **Living with Relatives**

Sharing a household with a parent requires major adjustments by everyone. The same is true for two older siblings or any relatives who have not been living together. For some families it works well, enriching the lives of everyone; for others, it doesn't work at all! A lot depends on the people involved.

On the positive side, it can mean increased companionship, a sharing of expenses and work loads, a feeling of security and usefulness for the older person, and someone to care for young children. The arrangement can work well if there is a history of good relationships and everyone respects each other, shares common values, and agrees on roles, obligations, and responsibilities.

Joining households is not always the best option. In some families, it results in unhappiness for everyone. Values may conflict. Everyone may have different expectations for each other and how things should be done. Adult sons and daughters sometimes find themselves being treated and reacting as though they are children again. One woman, for example, found herself still fighting the same battles she fought with her mother at age 16. Parents may equally resent being told what to do by their children.

Before joining households, it's important for everyone to carefully weigh the advantages and disadvantages, and consider the possible consequences for each person involved. The decision should not be made hastily. Ask yourself: Is this something I really want to do? Or am I doing it out of feelings of guilt, a promise made years ago, sentimentality, a sense of obligation, or because others think this is what I should do? Does my family member really want to live with me? Thoughtful decision-making will save you and your family much guilt and resentment. Preventing hard feelings is easier than repairing them.

Although each family will have unique concerns to deal with, the following questions point to areas that should be considered and discussed before making a final decision. Honestly answering these questions and considering the implications of your answers will help you and your family to decide whether or not joining households is a good option. And if you do decide to live together, your answers may help you identify potential "trouble spots" and deal with them before problems develop.

Can you honestly expect to get along together day-to-day? How have extended visits gone in the past? Previous family relationships can tell you a lot. Both pleasant and unpleasant aspects of earlier relationships are likely to reappear when you live together. If you have unresolved conflicts from the past, they probably will worsen if you live together.

How do other members of the household feel about joining households? The feelings of your spouse and children need to be considered since they, too, will need to make adjustments.

Can the home physically accommodate another person(s)? Will everyone have adequate living space? Will ground floor living areas need to be reallocated to provide bedroom space for a person with limited mobility? Will anyone have to give up current space? If so, how do they feel about it?

### How will common living spaces be shared?

What arrangements will be worked out if there is only one bathroom? Will the older person, as well as younger family members, be able to have friends visit without the rest of the family present?

Cramped living quarters can ruin the best relationships. Think about the space another person will require in the family room (can you still sprawl out on the couch?), the hall closet, refrigerator, cupboards, and the bathroom, in addition to having his or her own bedroom.

Privacy is important for the person moving in as well as for those occupying the house. For most families, the greater the privacy, the better.

The temperature of a house can be an issue. How will the temperature be handled if your older relative needs more warmth than is comfortable for other family members?

If your older relative is healthy, the ideal situation is for him or her to occupy a separate apartment (accessory apartment) with private entrance, bath, and kitchen. However, remodeling costs and/or zoning regulations may prohibit this. If a separate apartment is not possible, at least a private room should be available.

Are family members willing and able to communicate with each other? Being able to discuss issues and needs not only with your older family member, but also with your spouse and children is important. The best situation is when all family members feel comfortable talking about issues together and with each other individually.

**Does your relative have personal habits that irritate family members?** Personal habits and "those little things" that can be tolerated at a distance or during brief visits can become magnified when living together. The "little things" added together can become catastrophic.

Is there agreement about who will do what in the household? Are you willing to allow your relative to complete tasks in his or her own way? Will your relative try to change the way other family members do things? Can your relative (or you) adjust to living in a household in which he or she is not the head? The best situation is when each person contributes to household tasks, but does not intrude on other family members.

*Can everyone agree on financial arrangements?* Specific plans are the best, including the older person's contribution, who will pay for what, and how financial decisions will be made.

Can you and your relative accept differences in each other's way of living or would these differences be too distressing?

Differences in lifestyle, ways of doing things, what one does or does not eat, alcohol and cigarette use, housecleaning standards, friendships, leisure activities, and religious practices can make daily contact difficult if such differences are not accepted.

**Will children be a source of conflict?** Is your older relative able to leave decisions to you and your spouse or is he or she likely to interfere and disapprove of your methods of child-rearing and discipline? What power of discipline will your relative have over your children?

What changes will family members have to make in activities, daily routine, or lifestyle? How do they feel about these changes? How routine matters are handled can make a difference in the relationship. For example, will a teenager's stereo upset Grandpa? Or, will the loudness of the television needed by the hearing-

impaired elder be disruptive to the rest of the family? If there is only one television set, who determines which programs will be watched? If your mother has a special diet or own food preferences, will family meals be planned to meet her needs, or will her food be prepared separately?

Will your relative be dependent on you and the family? If so, in what ways? What will be the impact? The type of dependency can be an important factor. Physical dependency can be particularly difficult. The older person may feel like a burden and you and other family members may have to adjust schedules and give up activities to provide care.

If your parent will need care, *make* caregiving plans prior to joining households. Will your relative be able to stay alone if you want to get away for the weekend or take a vacation? If not, will he or she accept someone else staying in the home? You need to plan for breaks! Find out if there is a respite care or adult day care program in your community. It's important to avoid becoming overwhelmed and emotionally and physically exhausted by caregiving demands. Hiring outside help may ease the emotional stress, but increase the financial burden.

Will your family member be dependent on you for companionship and activities or does he or she have interests, activities, and friendships? If your relative is moving in with you after living in the community, efforts may need to be made to help him or her to maintain these contacts. If a move into your home also means a move to another community, your family member could be isolated from familiar friends and activities. A crucial question then is, how well does your relative get along with people and how easy will it be for him or her to make friends?

When a person is financially dependent, everyone may feel the strain. The parent may feel uncomfortable if not able to contribute equally to family expenses or a family member may resent having to change spending patterns to support another person.

If your relative does not drive, how will transportation be provided? Will your parent be dependent on you for transportation? Can transportation be provided by friends? Is public transportation accessible? Is there a senior transportation service?

Although separate households prevent many sources of friction, good relationships can be worked out when generations live together, but it does require planning and a willing cooperation by everyone. Since no one can predict the outcome of a joint residence, consider a trial period first before making a long-term commitment. Also, consider options if living together proves not to be satisfactory or situations change. This provides a dignified way out for everyone.

Many potential problems can be prevented if ground rules are established and matters settled before joining households. This isn't always easy, but it can prevent a lot of grief. Everyone who will be living together should be involved in discussing and setting the ground rules. Consider holding a

family conference. Writing down agreements may help prevent subsequent family quarrels.

If you are married and/or have children, it's important for you and your spouse to discuss how you will maintain your privacy, your relationship with each other and with your children, and how you will deal with the frustrations that accumulate even in the best marriages. If joining households is likely to result in constant conflict with your spouse, then you should find another living arrangement for your older relative.

No matter how caring or loving your relationship is with your older relative or how much effort is put into reaching agreements prior to joining households, conflict will occur. Expect you'll have disagreements, then settle them quickly. Don't allow frustrations and conflict to fester!

# **Conclusion**

Few people plan for the possibility of not being able to live independently. Yet, planning before a crisis can give a person a sense of control. It's often difficult to find a comfortable time to raise the issue with your relative, and the conversation may not be easy. However, your family member is more likely to listen and talk if you say you are raising the topic because you care and want what is best for him or her. It's important that your relative feels you want him or her to maintain maximum control.

One way to open the conversation is to ask some "what if's." For example, "Mom, what would you want if you could no longer cook without help, or if your arthritis became so severe you couldn't maintain this house alone? What care facility would you prefer if you had an accident and broke your hip and the doctor said you needed nursing home care before returning home?"

A discussion of this nature can create anxiety. You can give some reassurance by saying something like, "Chances are this will never happen, but if it should, I want to know what you want so I can best help." Another way to open the

conversation is to look for "natural" opportunities to talk. For example, when a friend or another relative experiences a health crisis or can no longer live independently, you can use the situation to introduce discussion. Or, describe a situation of a friend who recently helped a parent move or an older person who had to make a change in living arrangement. Then, follow the story by asking, "What would you have done if you were in that situation?"

If your parent refuses to talk or denies the possibility of ever having to change his or her living situation, you cannot force discussion. You can only emphasize in a kind manner that you were raising the issue out of love and can understand how difficult it is to think about the possibility of not being fully independent and self-sufficient.

Sometimes just raising the issue of independence may open the door for your family member to approach you at a later date. Even if this never occurs, at least you can feel better because you made an effort.

# **Additional Resources**

The following publications are available from Agricultural Communications, Publications Orders, Oregon State University, Corvallis, OR 97333-2119. Please add 25¢ shipping and handling for orders up to \$2.50. For orders between \$2.50 and \$100, add 15 percent shipping and handling. For orders of \$100 or more, please call (503) 754-2513 for a price quote.

- Aging Parents: Helping When Health Fails by V. L. Schmall and L. Isbell. Pacific Northwest Extension publication PNW 246, Corvallis, Oregon State University, 1984. Reprinted 1987. Single copy 50¢.
- Coping with Caregiving: How to Manage Stress When Caring for Elderly Relatives by V.L. Schmall and R. Stiehl. Pacific Northwest Extension publication PNW 315, Corvallis, Oregon State University, 1987. Single copy 75¢.

- Families and Aging: A Guide to Legal Concerns by V. L. Schmall, J. McGinnis, V. Salvi, and G. C. Steinke. Oregon State University Extension Service Circular 1221, Corvallis, 1985. Single copy \$1.25.
- Growing Older: Sensory Changes by V. L. Schmall. Pacific Northwest Extension publication PNW 196, Corvallis, Oregon State University, 1980. Single copy 25¢.
- Helping Memory-Impaired Elders: A Guide for Caregivers by V. L. Schmall and M. Cleland. Pacific Northwest Extension publication PNW 314, Corvallis, Oregon State University, 1987. Single copy 50¢.
- When Death Comes: Funerals & Alternative Arrangements by V. L. Schmall and C. Pratt. Oregon State University Extension Circular 1243, Corvallis, Oregon, 1986. Single copy \$1.00.