

Making Decisions

ABOUT A NURSING HOME



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Note

The term *nursing home* in this publication refers to long-term care facilities that provide personal and nursing care to people unable to care for themselves. Other facilities—adult foster homes, assisted living facilities, residential care facilities, and other group living situations—also offer significant care. Guidelines in this publication might be helpful in evaluating these facilities also.

Making a decision about a nursing home is seldom easy. In fact, it may be one of the hardest decisions you'll ever face. However, in many instances, a nursing home is the most appropriate care setting for an older person who is frail or has a dementing illness. Sometimes, moving a family member to a facility is the most loving thing you can do.

Thousands of families face this decision each year. Many people have only a short stay in a nursing home, for rehabilitation or to further recover after an accident, surgery, or illness. For others, it will be an extended stay.

At least 40 percent of adults over age 65 will spend time in a nursing home at some point in their lives. Slightly less than 6 percent of adults age 65 and older are in a nursing home on any given day; nearly half of these are age 85 or older.



A nursing home usually is considered when an older person's health changes significantly and when community services have been exhausted, are no longer appropriate, or aren't available to meet the person's needs. Changes in the life of the caregiver—illness, exhaustion from caregiving, a move, changes within the family, or the death of the caregiver—also lead to placement.

Some think a nursing home is a place where old people go to die, but actually it's a place where people go to live. A nursing home also can have a positive effect on your relationship with your older relative,

allowing you to be together and enjoy each other without your having to devote all your time to caregiving tasks.

Although there are no easy answers to the nursing home decision, this publication gives some guidelines for making decisions, assessing family and community resources, selecting a quality care facility, and dealing with your feelings and those of your older relative. It also looks at ways to maintain positive contact with older family members who live in nursing homes.

When should you consider the possibility of a nursing home?

The best time to talk about the possibility of a nursing home is *before* the need arises. Although the decision is never easy, it's even more difficult if you face it first at a time of crisis and have

not prepared for it. All too often, however, the first contact people have with nursing homes *is* when they are in crisis.

If your family member is showing signs of deterioration or has received a diagnosis of a degenerative disease like Alzheimer's disease, or if your own health or relationships are deteriorating as a result of providing care, you should start considering the possibility that your family member could some day need a nursing home.

Sometimes it's difficult to know when nursing home care is warranted. When in-home care and community services are no longer adequate and other alternative living arrangements are not appropriate, you might need to look at a nursing home.

Consider your older relative's medical condition and nursing care needs. It's equally important to consider the caregiver's well-being.

A nursing home may be appropriate if:

- The person needs specialized health care services
- A nursing home is the only way the person can receive the amount and type of care he or she needs
- It has become emotionally and physically impossible for the caregiver to continue providing the needed care, or the



caregiver needs an extended break from caregiving to rest or take a vacation

- The person needs posthospital rehabilitation following a disabling illness such as a stroke or an injury such as a hip fracture
- Other alternatives have been exhausted in meeting the person's needs
- The person needs round-the-clock care for an extended time, and family and community cannot provide it
- Nursing home care is more cost effective than other alternatives

Who should be involved in the decision?

A decision about nursing home placement is best made using a team approach. The three essential participants in the decision are the older person, you and your family, and health care and social service professionals.

The older person If at all possible, the older person for whom care is needed should be involved in making the decision. It will help give the person a feeling of control and reduce the trauma if a move is made.

Even people who are very ill or confused should be informed about the alternatives for their care. However, if your family member suffers from memory

impairment, it's important to recognize that he or she may not be able to remember discussions or agreements you made. One son stated:

Talking to a parent about a potential move is good advice even if it does not always work out. I talked to my mother many times concerning her condition (in response to her own concerns) and we agreed on the appropriate plan. She could not remember even 30 minutes, however. The day we did go to the nursing home was about as smooth as it could be, but she did not understand the reason. It is well to understand that even when everything has been done with love and careful consideration, the loved one may not understand and may be unhappy. However, it is still a good idea to discuss the plan so that the family will have a feeling of doing what is right.

Only in extreme cases, such as advanced Alzheimer's disease or a massive stroke, is a person so out of touch that he or she cannot be consulted.

You may feel that discussing nursing homes with your older relative will be too complex or too emotionally painful, or you may fear your relative's possible feelings of anger or rejection. Although these feelings may occur, they will be much worse if the person is not consulted and is

A decision about nursing home placement is best made using a team approach: the older person, you and your family, and health care and social service professionals.

You have three basic tasks: sharing information, sharing feelings, and assessing individual resources.

moved suddenly to a care facility. You also might create an atmosphere of distrust with your family member.

Remember, considering a nursing home implies a potential major transition, which means many losses for the person no matter how desirable a facility might be. A move to a nursing home may signify the loss of health, familiar surroundings, personal possessions, privacy, self-esteem, and independence. If you can acknowledge these losses and share your own feelings, both of you will benefit. It's important to plan on investing time with your family member in making the decision.

Encourage your family member to participate in evaluating alternatives for care. If living with family members or using community services still are under consideration, inform your family member that help is available.

In considering a move to a nursing home, it's important to involve your older family member as much as possible concerning where, what, when, and how to move. Often, choice is limited to nursing homes with available beds, but it still may be possible for the person to select his or her room, furniture, and personal items to move into the room and/or when to move. Within the person's capabilities, try to give as much choice and decision-making power as possible.

Your family member's feelings may range from acceptance to resignation to anger. He or she may be fearful—about the future, about being abandoned, about being a burden to you, or because of “horror stories” associated with nursing homes. Or your family member may feel guilt or shame about his or her inability to be “independent.” Encourage your family member to share his or her feelings. Try not to take personally any negative feelings that may be directed at you. These feelings, too, need to be expressed, and unfortunately, they often are directed at the people who are the closest and providing the most care and support.

You and your family You and other members of your family are essential in the nursing home decision. You have three basic tasks: sharing information, sharing feelings, and assessing individual resources.

Sharing information is the first step in family decision-making. Disagreements about the needs of the older person are more likely if family members do not have a common understanding of the person's medical condition, functional abilities, and changes that have occurred. It is vital to gather accurate information about the older person and options for his or her care.

Second, don't ignore your own feelings or those of other family members. Sadness, anger, grief, guilt, relief, fear, and uncertainty about the future are common. You may feel a great deal of sadness and helplessness, particularly if you have struggled to avoid a nursing home or if the move appears permanent. You may grieve the loss of your family member as he or she was before, the loss of his or her companionship, and the loss of ability to provide the direct care.

You may feel anger at having to make this decision, especially if you have to do it alone. You and/or other family members may be frightened or even angry at the prospect of a nursing home. However, you also may feel relief that you no longer have to worry about your family member's health and safety.

Some family members may recall promises such as "We'll never put you in a nursing home." A move to a nursing home may be viewed as the worst possible event. One woman said:

When I was faced with the decision about a nursing home, all I could think about was, "My God, what am I doing to Mom?" I wished my mother could just die peacefully in her sleep so I would not have to make this decision.



The myth that families "dump" their older relatives into nursing homes can contribute further to feelings of guilt.

You also might experience some fears about your own future. If you have been the caregiver, you could find yourself feeling a loss of purpose.

The more you and other family members are aware of your own and one another's feelings, the better the decision you can make. It's important to acknowledge the feelings of everyone, but it's also important not to base decisions on emotions.

The third step is for the family to assess carefully its resources for supporting the older person. Discuss what each person is able and willing to do. Open, honest discussion is vitally important.

Two other tasks remain before you can make the best possible decision.

The first is to assess community resources that may help the person remain in the community.

The second is to evaluate nursing homes.

If you choose nursing home care for your family member, your relationship with him or her will not stop at the nursing home door. Discuss what each family member can do to continue to show their love and concern to your older relative. The “Staying in Touch” section (page 24) can help you identify positive ways to maintain this contact.

Professionals Health and social service professionals are an important part of the nursing home decision. Physicians provide critical information about the older person’s current medical condition as well as educated guesses about what you might expect in the future. Be sure the physician is interested in older people and does not write off your family member because of age with statements such as “Your dad is 80. These are the kinds of things you just expect to happen at his age.” Often physicians recommend nursing home care when a person’s physical or mental health severely limits self-care and his or her care needs are much greater than the family or community can provide.

Once you fully understand your family member’s medical condition and prognosis, social service workers or hospital discharge planners can help you and your older family member make plans. They also might help

identify the range of services, including in-home care, available in the community. Remember, however, that not every professional knows about all the community resources available. Community services and eligibility requirements frequently change.

If you decide nursing home care is needed, talk with nursing home staff, especially the administrator, director of nursing services, social worker, and/or coordinator of admissions. They can provide important information to you and your family. When evaluating a particular facility’s services, talk with as many staff members as possible.

Can community services help?

We’ve discussed key elements in the nursing home decision:

- Identifying your older family member’s present physical and mental condition
- Sharing feelings
- Assessing family resources
- Involving the older person, other family members, and professionals

Two other tasks remain before you can make the best possible decision. The first is to assess community resources that may help the person remain in the community. The second is to evaluate nursing homes.

Assessing community resources

Most older people prefer to live in the community as long as possible. Therefore, a fundamental part of the nursing home decision is to consider carefully the community resources that might prevent or postpone the need for nursing home care. (See also *Hiring and Working Successfully with In-home Care Providers*, PNW 547.)

A wide range of community services is available to help older people remain at home. Services include:

- Congregate and/or home-delivered meals
- Grocery delivery service
- Homemakers
- Housekeeping and chore services
- Transportation and escort services
- Home health services
- Visiting nurses
- Telephone reassurance
- In-home medical alert program
- Friendly visitor program
- Adult day centers
- Care management services

Of course, services that meet your relative's specific needs in the home may not be available or may be too expensive, especially if needed around the clock. Many people who are disoriented or require 24-hour

supervision are not good candidates for in-home services. Their needs simply are too demanding. Do not, however, dismiss the possibility of community services until you have checked out all the options.

A good place to start your investigation is the local Area Agency on Aging, senior center, Information and Referral agency, health department, adult and family services, or the human resources department. Hospital discharge planners also may help identify resources. You can find telephone numbers for these agencies in your telephone directory in the city, county, and state government sections. Sometimes you'll feel like a detective searching for these agencies, but the effort is worthwhile.

In some communities, private businesses offer services similar to those offered by government agencies. Many government and nonprofit agencies offer services for a "sliding scale" fee.



If you are considering having your relative live with you, give serious thought to these points.

- The impact that intergenerational living would have on you, your older family member, and others in the household

caregiving and delay the need for nursing home care.

If your relative needs considerable support but is able to care for himself or herself, you might explore adult foster care homes and residential care, assisted living, and congregate retirement facilities. Such facilities offer meals, housekeeping, social activities, and assistance with personal care but usually not nursing care (see *Living Arrangements in Later Life*, PNW 318).

When a nursing home is the best choice: Guidelines for choosing

Choosing a nursing home is a complex job. The goal is to find a facility that you and your older family member are comfortable with and that best meets your family member's needs and financial resources. The decision is seldom easy. These guidelines may be helpful.

Identify your family member's needs Before contacting care facilities, develop a list of your family member's medical, social, and emotional needs. The list might include the need for help with incontinence, walking, transferring, eating, and medications; personal care such as bathing, grooming, and dressing; and behavior management (for example, wandering and angry outbursts).



- Your older family member's needs—for example, for socialization and involvement in interesting activities as well as for health care—and how you will meet those needs
- Your lifetime relationship (if your relationship has been tense, living together is likely to be more stressful)
- Community services that can be offered in your home
- Your need for a break from caregiving. Respite services or adult day care can relieve you from the demands of

Know the level of care your family member needs In general, nursing homes provide two levels of care: *skilled* and *intermediate*.

Skilled nursing care is for people who need 24-hour medical supervision, skilled nursing care, or rehabilitation but do not require hospitalization. Skilled care might be appropriate 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.

Intermediate care is for people who need help with the activities of daily living and some health services and nursing supervision, but they don't need continuous nursing. People who need certain rehabilitation services also may be appropriate for intermediate care. A physician orders the care, which is supervised by a registered or licensed nurse.

Some facilities offer a third level of care, sometimes called *custodial care*, *residential care*, or *assisted living*. This care level is appropriate for people who do not need the care of a practical nurse but do need supervision and help with personal care and other activities of daily living. Often this is the kind of care needed by people suffering from dementing illnesses such as Alzheimer's disease.

Some facilities also have *special care units* (also called *designated* or *dedicated* units) to meet the needs of people with dementia.

In some states, preadmission screening is available or required for nursing home admission. A team of professionals assesses the older person's functioning, the appropriateness of placement, and possible alternatives.

Get recommendations Talk with people who know first-hand about local facilities. These may be families of nursing home residents, a physician, clergy, or hospital social workers. The Area Agency on Aging is also a good source of information about nursing homes in an area.

Screen by telephone Call prospective facilities to learn about vacancies, admission requirements, levels of care provided, and participation in Medicare and Medicaid. Also verify that the home has a current state license. Eliminate homes that do not meet your needs and put the others on your list of homes to visit.

Call during business hours. Talk with the admissions coordinator, administrator, or director of nursing. The people with whom you speak should be willing to take the time to answer your questions, which should include the following.

Before contacting care facilities, develop a list of your family member's medical, social, and emotional needs.

Observing and talking to other residents and their families can provide you with useful information.

- **Is your nursing home currently licensed by the state?** Also, ask whether the administrator has an up-to-date license. If the answer to either of these questions is no, look elsewhere for a nursing home.
- **What levels of care and range of services does your facility offer?** In addition to being sure that the facility can meet your family member's current needs, consider that his or her needs could change.
- **Is your facility Medicare certified?** Your family member may not be eligible for Medicare assistance now, but if hospitalized later, would he or she be eligible for readmission under Medicare coverage? It would be an advantage if your family member could return to familiar surroundings.
- **Is your facility Medicaid certified?** It's especially important to determine whether the nursing home will allow residents to remain if they exhaust their funds and must apply for Medicaid. If the facility is certified for Medicaid reimbursement, relocation often is unnecessary if your family member needs to go on Medicaid.
- **Can your facility meet the special needs of my family member?** Can the facility meet your family member's special dietary needs? If your family

member needs help with eating, will it be provided appropriately? If your family member needs therapy, can it be provided as prescribed? If your family member wanders, does the facility have a safe area for wandering? If religious services and observances are important to your family member, how will the facility meet these needs?

Be prepared to answer questions about your family member. Nursing homes are interested in meeting a prospective resident's needs, and the more information you give, the more helpful the facility can be to you.

Tour prospective facilities After you have completed your telephone screening, visit prospective nursing homes. It's the only way to truly evaluate a facility. Visit with the administrator and/or director of nursing until all your questions are answered. Your two primary questions are:

- What is the quality of care provided by the facility?
- How well will my family member fit in this facility?

Make an appointment to visit. Nursing homes do have busy times, especially at meals and also early in the morning when they are bathing and dressing residents for the day. Try to avoid these times.

If at all possible, take your family member with you on the tour. Remember, it is that person, not you, who will be living in the nursing home.

Observing and talking to other residents and their families can provide you with useful information. How do staff relate to the residents? How does the facility look? How do residents look? What are residents doing? Does the food look appealing? What sounds do you hear? How does the facility smell? All nursing homes have incontinent residents, so there will be an occasional odor. However, if you detect a general stale odor, a strong smell of disinfectant, or if on return visits the smell remains, cross that home off your list.

Look at residents' rooms. While most facilities don't have much room for personal furniture, there should be a place for at least a favorite chair or other small furnishing.

If this is the first time you have been in a nursing home, you might feel very uncomfortable. The sights and sounds may disturb you. One family member stated:

The first time I visited a nursing home, I was upset by the people sitting in wheelchairs along the hall. Now I understand this is a change of scenery and social

contact with the staff and visitors going up and down the hall.

Remember, most people are in nursing homes because they have significant physical and/or mental impairments. A confused resident might call out, "Help, help, help" as you pass by. It doesn't mean the person is in pain. A resident may reach out to you or act as if he recognizes you. Smile and say hello.

After your tour, consider returning at other times—on the weekend and in the evening—to assess the facility and staff at these times.

Be realistic It's unlikely that any facility will perfectly meet all



your family member's needs. You and your family member must decide which needs have priority.

Paying for nursing home care

Nursing home care is expensive. Few families can afford to pay for nursing home care for an extended time. The most desired facility may be out of the question because of cost, or the facility may be full and have a long waiting list. As you consider the cost of a nursing home, you might want to keep in mind these perspectives.

Nursing home care is costly, but it is not as expensive as a night in a good hotel, plus the "guest" is receiving food and nursing services.

We tried to keep Mother at home. But when she needed around-the-clock care, the cost

of bringing in the professional help she needed was twice as expensive as having her in a care facility.

A difficult but vital part of the nursing home decision is assessing your older family member's financial resources, including income and assets such as property, savings, stocks, bonds, and insurance. Find out whether your family member has an insurance policy for long-term health care. If so, make sure you understand the deductible period, the amount and duration of benefits, and the services covered. If the older person's financial resources are inadequate, decide how much, if anything, family members can realistically contribute.

Government programs

Government health insurance programs can help pay for nursing home care; however, they have very specific requirements.

Medicare Contrary to popular belief, Medicare covers only a very small part of nursing home costs. It limits the amount of time and circumstances under which it pays for nursing home care. It pays only for care that it defines as "skilled," which means that the nursing care is comparable to that received in a hospital. Federal guidelines for Medicare basically limit coverage to people who are recovering from an acute condition. That's a



minority, because most people in nursing homes need primarily intermediate or custodial care.

Medicare also pays only if the nursing home is certified by Medicare. Even if the older person is receiving skilled nursing care, Medicare will not pay if the nursing home is not Medicare certified. Some nursing homes choose not to be certified by Medicare, and Medicare will not cover the cost of care for people in those facilities.

The physician, hospital discharge planner, or the nursing home admissions coordinator or director of nursing can help you determine what, if anything, Medicare will cover. Rules governing Medicare change frequently; check current Medicare policies. Get additional information from your local Social Security office, or call 1-800-MEDICARE (1-800-623-4227) or visit Medicare's Web site at <http://www.medicare.gov>

Medicaid Medicaid helps low-income people of all ages who have exhausted their own funds for medical expenses, including nursing home care. Because of limited incomes and high medical costs, many older people in nursing homes eventually qualify for Medicaid. Medicaid covers care in a Medicaid-certified facility for an eligible person for as long as his or her condition merits it.

Medicaid eligibility and benefits vary from state to state. Generally, a person's income and assets or "resources" must be limited. When the older person's assets have been *spent down* to a specified level, Medicaid then might be available **if** the person's income does not exceed the "Medicaid cap."

A person who does not have the financial resources to pay for nursing home care can apply for Medicaid assistance. If the application is approved, the nursing home resident must contribute his or her monthly income, except for a small personal-needs allowance and income allowed for the spouse residing in the community. Medicaid pays the balance of the nursing home expense.

It's very important that spouses know federal and state laws about division of assets and limits on "spend down." The Medicaid Spousal Impoverishment figures change yearly, based on federal poverty guidelines. The spouse of a nursing home resident doesn't need to spend all the couple's assets before the nursing home resident becomes eligible for Medicaid. But if the spouse is unaware of the laws and does spend everything for care, Medicaid will not reimburse the spouse for any payments made for care.

A difficult but vital part of the nursing home decision is assessing your older family member's financial resources.

One of the most important features of a nursing home is its atmosphere—the physical and social environment and especially the staff.

If the older person has substantial income and/or assets, Medicaid coverage won't be available, and the person will have to pay for care himself or herself. People often object to spending their money for such care. Remember, it's better to cover the cost of care with the older family member's reserves than with those of younger family members.

Because a nursing home usually receives less from Medicaid than from Medicare or private-pay patients, many nursing homes do not accept people on Medicaid, or they limit the number of beds available for those on Medicaid.

To learn more about Medicaid eligibility or to apply, contact your local department of social services or welfare. Or, contact your State Medical Assistance office (Oregon 1-800-273-0557; Washington 1-800-562-3022; Idaho 1-877-200-5441).

Nursing home administrators and staff at most nursing homes also might be able to help you.

Veterans benefits The Veterans Administration (VA) can help offset nursing home costs for eligible veterans. If your family member was in service during wartime, ask your local VA office whether he or she qualifies. For more information, call the VA Health Benefits Service Center toll free at 1-877-222-8387, or contact your local VA office, or

visit the Web site at <http://www.va.gov/elig/>

Questions to ask

Here are some specific questions to ask about the costs of nursing home care.

- What is the basic monthly fee?
- What services are covered in the basic daily charge? Services typically covered are those common to all residents.
- What are the fees for additional services and supplies? Ask for a written list. Typical extra charges are for medications, incontinence products, therapy, and beautician services. Some services may be provided directly, contracted for, or arranged for by the facility. These may include mental health services, dental and specialized medical services, and beautician services. Additional fees usually are charged for private rooms.
- If a private-pay resident eventually must use Medicaid, will he or she be allowed to remain in the facility? If so, is this on a "bed available" basis?
- What happens to payments if the resident leaves the home or dies? Is the unused portion of any advance payment fully refunded?

After you select a care facility, be sure you thoroughly understand

all financial arrangements and the facility's contract agreement before you sign it. This is a legal contract; therefore, you might want a lawyer to review it before you sign.

Touring a care facility: What to look for

In addition to cost, the many other considerations in selecting a nursing home include the atmosphere and attitudes of staff, social and medical services, activities, and location.

Atmosphere and attitudes

These are perhaps the most difficult factors to measure when choosing a facility, yet they are critical to your family member's well-being. A beautiful building does not guarantee good care. How does the facility "feel" to you? One of the most important features of a nursing home is its atmosphere—the physical and social environment and especially the staff. Observe carefully how staff interact with residents.

- Are staff kind, caring, and friendly? Are they patient and gentle with the residents? Do they treat residents with respect and dignity?
- Do staff interact and speak warmly to the residents and show affection by words and touch?

- Are staff pleasant to you? Do they respond directly and courteously to your questions and comments?
- Are residents and staff smiling much of the time?
- Are residents encouraged to bring their personal possessions? Are the residents' rooms personalized, reflecting each resident's personality? Do residents have personal articles such as family photographs, a favorite bedspread, and wall decorations in their rooms?
- Are visits welcome at any time?
- Are volunteers and community groups encouraged to be involved in the facility?
- Is there a sensitivity to individual residents' social, emotional, and intellectual needs?



- Does the staff member giving the tour speak to residents as you pass by them?
- Is respect given to residents' privacy needs?



Ask yourself:

- Is the atmosphere one that your family member will find comfortable? Some people prefer a cozy, homelike environment; some prefer one that has a lot of activities; others prefer a more formal setting.
- Are some other residents' backgrounds similar to your family member's? This can enhance compatibility. It generally is much harder for a person to adjust to a facility if the background of most residents—for example, socioeconomic status or culture—is significantly different from his or her own.

- If your family member visited the facility, was he or she comfortable with the reception?

The importance of these questions is seen in one woman's comments about her 93-year-old friend who lived for 13 years in a nursing home.

The facility where my friend lived was very good, but Martha had few "comrades" because her mind was good until the end. This was not true for most people in the home. Mealtimes were particularly difficult for her because of this. Martha was fortunate to have one friend and confidant across the hall and did have a private room, which made a difference.

In many cases, a person must share a room. If so, be sure to find out how residents are matched. The relationship a person has with a roommate can make a big difference in his or her satisfaction.

Residents' appearance

Personal appearance is important to a person's self-image. It also affects how staff, residents, and visitors respond to a person.

- Are residents appropriately dressed?
- Are they well groomed?
- Are residents out of bed?
- Are residents involved outside their rooms?

- Are residents encouraged and, if necessary, assisted in dressing and grooming each day?

Location and physical facilities

You and other family and friends will visit more often if the facility is conveniently located. Physical facilities should be safe, clean, pleasant, and homelike, and residents should be encouraged to personalize their space.

- Is the nursing home convenient to family, friends, and the person's physician?
- Is the building safe, with well-lit halls, handrails, clearly marked exits, and sturdy equipment?
- Is the facility clean, pleasant, and generally odor free?
- Does the building feel pleasant and homelike?
- What is the noise level inside the facility and in the vicinity? Will it be comfortable for your family member?
- Is the facility well ventilated and warm or cool enough?
- Is there a safe, secure outdoor environment?
- Is reasonable personal privacy available to residents for solitude, for visits with family and friends, and in bathrooms and bathing areas?
- If residents share rooms, how is privacy provided?

- Are there lounges, gardens, kitchens, and other areas and equipment for residents' use?

People often feel a sense of loss when leaving their homes. A room in a care facility cannot replace a person's home, but if a part of what was "home" can accompany your family member, this often makes the adjustment easier.

Medical and social services

A move to a nursing home often is prompted by the health care needs of the older person. If your family member needs therapy, it's important to look for a nursing home with a quality therapy program. These programs may include speech, physical, or occupational therapy and treatment for chemical dependency. However, the social services provided to residents—and to family members—can be equally important.

- Will your relative's physician visit the home?
- Are other medical services (dentists, pharmacists, optometrists, podiatrists, etc.) regularly available?
- Are the family and resident encouraged to help develop the patient care plan?
- What is the procedure for residents to make complaints or recommendations?

It generally is much harder for a person to adjust to a facility if the background of most residents is significantly different from his or her own.

An active volunteer program often reflects a facility's commitment to meeting residents' needs.

- Is there a residents' council? A family council? If so, what is the level of participation?
- Is a social service worker available to help residents and families?
- Is there a program to support and involve families?
- Are residents supported in observing their religious preferences?
- How much community volunteer participation is there?

The best facilities encourage family and friends to be involved in residents' lives and nursing home activities. A family council is a forum for expressing concerns and recommendations to the administration. Active participation usually means the administration and staff are concerned about and receptive to dealing with issues presented.

The best facilities also will encourage you and your older family member to be involved in developing the care plan for your resident family member.

Volunteers generally are most involved with the social service and activity departments. An active volunteer program often reflects a facility's commitment to meeting residents' needs.

Activities

Activities can be important in enhancing a person's self-esteem.

Ask to see the activity schedule, which usually is posted.

- Is the activity program varied and stimulating? Or, are activities boring and childlike?
- Would the activities be interesting and meaningful to your family member?
- What mentally stimulating activities are available to mentally alert residents? For example, is there a library bookmobile, or outside speakers, or discussion groups?
- How are the spiritual needs of residents met?
- Are there opportunities for residents to feel useful; for example to do something for others if they are able?
- What individual programming is available? For example, are residents supported in their desire for solitary or group activity?
- Are shopping trips or other community activities scheduled for residents able to participate?
- If your family member is bedridden, how will his or her activity needs be met?
- Are there opportunities for both group and individual activities?
- Are there areas where residents can gather to socialize independently?

- Are activity and therapy rooms in use? Do you see residents participating in activities?
 - Is someone available to assist with letter writing, opening and reading mail, or making telephone calls if your family member is unable to do so?
 - Is assistance provided for residents to get to activities?
- Will the facility meet a person's special dietary needs based on religion?
 - Are residents given enough time to eat?



Meals

For many nursing home residents, mealtime is a highlight of the day. Ask to see a sample menu.

You also can

arrange to eat a meal at most facilities.

- Is a menu posted? Is the facility serving what's on the menu?
- Is there variety?
- Is food served that your relative likes?
- Are meals well balanced and attractive?
- Is the food tasty?
- Is the dining area cheerful?
- Are special diets available for people with specific health problems such as diabetes or difficulty swallowing?

- Are snacks provided to residents? If so, when? What are typical snacks?
- Do residents who need encouragement or assistance to eat get the needed help?
- Can family members arrange for guest meals? If so, what is the procedure?

Policies

Facilities have policies on using personal furniture, conditions for admission, notification of the family when the resident's condition changes, visiting hours, and outings. Request a copy of the



facility's policies and procedures and discuss them with the administrator. Be sure you fully understand and are comfortable with the facility's policies and procedures before your family member moves there.

- Are visiting hours open or limited?
- In times of crisis, can the family visit during the night?
- Can a favorite pet visit?
- If your family member smokes, is smoking allowed in the facility? Is the area safe and supervised?
- Are young children encouraged to visit?
- What is the policy for holding a room if a person is hospitalized?
- What is the policy for residents' travel outside the facility?

- Can residents bring their own furniture and mementos? Are there limits on what they can bring?
- Can food and drink be brought in for a resident?
- What is the policy on using restraints?
- When is the family notified about changes in a person's condition?

Base your choice of a nursing home on careful consideration of answers to the questions on pages 10 to 20. While no home is perfect, you can expect that most good homes will do well on your evaluation.

Moving day: What can you expect?

The day of admission into a care facility often is difficult for all family members. However, social service staff can help make the transition less stressful. Ask about the best time to move into the nursing home. Midmorning often is recommended.

Emotional strain is common for everyone. You may experience feelings of guilt or remorse or have doubts about whether you made the right decision. Your family member may feel abandoned, angry, sad, or resentful. Entering a nursing home means leaving behind a familiar and comfortable environment. Most

people eventually work through these feelings and adjust.

To ease the transition to the nursing home, consider the following.

Personalize your family member's room Make the person's room as homelike as possible. Consider decorating the room before moving day. Ask your family member to choose familiar and important items to bring; for example, family photos and favorite decorative items. Expect some grieving as your family member makes choices about what to sell or give away.

Do as much in advance as possible For example, put your family member's name on clothing and other items with permanent laundry ink, and complete necessary paperwork.

Have more than one family member present If paperwork has not been done beforehand, try to have at least two family members present—one who can do the necessary paperwork and another who can be with your older family member.

Plan to spend time Spend most of the first day at the nursing home. This will help your relative feel less abandoned and will help him or her get settled, feel more comfortable, and become

familiar with the new surroundings and schedule. It also can give you an opportunity to meet staff members who will be providing the care to your family member.

Schedule your next visit Before you leave, make plans for your next visit and set the date as soon as possible.

Adjusting to the nursing home

A difficult adjustment period often follows a move. The first few weeks will be the most difficult. It may take from 3 to 6 months for your family member to adjust. Recognize it is a time of change for both you and your family member.

Your family member At first your family member may be angry, and his or her goal may be to leave and go home. Try not to take the anger personally and resist the natural tendency to say that the nursing home is now home. Instead, let your family member express his or her feelings of loss and pain. It also may be helpful to talk about what he or she must be able to do to return home—for example, get dressed without help or walk 20 feet. Rather than ignoring or brushing off feelings, talk about them.

The move to a nursing home may be as difficult for you as it is for your older relative.

Consider the four Rs to helping a person adjust to a care facility: reassurance, routes, routines, and relationships.

Consider the four Rs to helping a person adjust to a care facility: reassurance, routes, routines, and relationships.

- **Reassurance** Try to be at the home often and to be available during the first few weeks. This will help reduce a major source of anxiety: the fear of being abandoned. Visits from family provide security in an environment that feels insecure.
- **Routes** Nursing home residents at first can be quite uncertain about getting around in a facility. This will be especially true for the person who has Alzheimer's disease or other dementia. You may need to demonstrate again and again how to get from one place to another.
- **Routines** Achieving some mastery of routines and "learning the ropes" bolsters self-confidence.
- **Relationships** Your older family member may need support in reaching out to and interacting with staff and other residents. Introduce him or her to other people. Your frequent presence and interest in other residents also may increase your family member's chances as a potential friend because the other residents enjoy your attention, too. Meet, talk with, and convey messages of

appreciation to staff. Staff's good feelings about you generally carry over to your family member.

It will take time for your family member to adjust to a nursing home. Once he or she has adjusted, there still will be good days and bad days.

What about you? The move to a nursing home may be as difficult for you as it is for your older relative. Family members experience varying degrees of emotional responses. The intensity of reactions depends on the circumstances leading to nursing home placement, your family member's response to the move, and past and present relationships among family members.

Feelings of loss, guilt, and fear often come sharply into focus in this adjustment period. Many of these feelings result from seeing the losses and declines experienced by your family member. It also may represent to you, as well as to your family member, the final stage of life and mark the beginning of mourning and bereavement.

Get support for yourself and share your feelings. Grief over your own losses needs attention. Once you face your own feelings, it will be easier to be more supportive of your older family member's experience of loss.

Because a social stigma still is associated with nursing homes, it's no surprise that feelings of guilt pervade nursing home adjustment. If you find yourself feeling guilty, you may feel you have broken some underlying rule—such as “a good daughter should take care of her parents”—and you expect to be blamed and punished. You may be totally committed to this “rule” but unable to provide the direct care for practical or emotional reasons, and you feel guilt as a result. Another person may be ambivalent about this rule and feel guilty for having mixed feelings. Often the family of a nursing home resident manifests its guilt by being overly protective of the older family member or critical of the nursing home staff—or by not visiting.

If you experience guilt, try to identify the “rule,” acknowledge any mixed feelings you may have, and try to reassess and rewrite the rule to make it more realistic and appropriate to the current situation. Most guilt “rules” are black and white, inflexible, and impossible to conform to completely. When they are examined rationally and in light of the current situation, guilt may diminish and more positive feelings surface. It also is helpful to reach out to others for validation of your reassessment of the “rule.”

Here are some suggestions for coping with the changes, adjustments, and feelings that nursing home placement may bring.



- Assess family relationships so you can be more realistic about the cooperation and support you can expect from other family members.
- Acknowledge the feelings you have and share what you are experiencing with others. Bottling up feelings only pushes them deeper and creates more distress.
- Talk with others about their experiences. It can help you feel less alone and help you cope.
- Seek help with unresolved feelings that continue to be

difficult to handle. The nursing home staff or a family support group may be helpful. If you still feel unable to cope with your feelings, professional counseling may be beneficial.

- Join an Alzheimer's Association support group or other caregiver support group. Look in the newspaper for meeting times and location. The facility also may have a support group for family members.



If you have questions about the care your family member is receiving or conditions in the facility, request a conference with the appropriate staff member. Mutual understanding is the first step to resolving a problem.

Staying in touch

For residents, time often revolves around visits from family and friends. Visits are important. They provide reassurance that someone still cares. In fact, residents whose families are involved in

their care generally have higher morale and receive better care.

Making your visits meaningful

While the nursing home can meet your family member's medical care, safety, hygiene, and nutrition needs, family and friends are particularly important in meeting his or her emotional and social needs. Here are ways to make your visits meaningful.

- To reduce disappointment, discuss with your older relative his or her expectations and limitations regarding visits. Give your family member a feeling of control and choice by asking when he or she would most like you to visit, within the limits of your schedule.
- Schedule your visits. This gives your older relative something to look forward to and helps to avoid conflict with facility activities in which he or she participates.
- Plan short and frequent visits, particularly if your family member is frail and tires easily or has a short attention span. Regular visits are opportunities to observe how your family member is doing.
- Plan one-on-one visits. This provides the person with some intimate contact. If your family member is confused by groups, one or two visitors at a time will be less confusing.

- Encourage family and friends to visit frequently during different times of the day. School-age children can drop by to say hello or to share some drawings from school. A brief stop before or after work can be meaningful.
- Plan to do things with your family member that he or she can no longer do alone. A son said:

Dad's vision is really poor, but he is still very alert mentally. He gets frustrated with small print, so I bring in newspaper or magazine articles and read them to him. Afterward, there's plenty to talk about. Not only is this activity stimulating to him, it is also rewarding to me.

A daughter shared:

The days Mother gets a letter she's more 'up.' Because of her paralysis, she can no longer write letters. During many of our visits, I write letters for Mom as she dictates to me. This keeps letters coming from family and friends to her.

- Take your older family member out, if possible, to dinner, church, and community events and for home visits, walks, or drives to previously enjoyed places.

Don't be surprised if, after your family member has adjusted and accepted life in a nursing home, he or she asks to go "home" to the nursing home during an outing.

- Join in facility activities with your family member.

Sometimes it can be difficult to visit, particularly if your family member does not remember who you are, cannot communicate, or has a severe hearing loss. Remember, "visiting" can include more than talking. In such situations, it may be more meaningful and less frustrating to do something with your family member—listen to music, go for a walk in the neighborhood, eat a meal together, look at family photographs, play a board game, or go out for an ice cream cone.

If your family member forgets you have visited, don't take it personally. Changes in brain function rob many nursing home residents of their ability to remember. Focus on the pleasure the person received for the moment during your visit.

Try using touch. It is one of the most powerful means of communication and can be particularly important when a person no longer comprehends speech. Holding hands, putting an arm around the person's shoulder,

*Remember,
"visiting"
can include
more than
talking.*

Participating in the patient care plan conference is another way to keep in contact with the needs of your family member.

giving a massage, stroking the person's arm, or brushing his or her hair can communicate caring and affection and that the person is valued. One daughter said:

During the more than 2 years Mother was in the nursing home, we often sat holding hands while I talked and she responded in ever more limited fashion as her disease progressed. I kissed and embraced her frequently. However, the hair-combing sessions were among the most precious of our hours together. When we could no longer carry on a conversation, touching and looking at each other in the mirror gave reassurance that a line of communication still lay open between us.

If you are frustrated or don't know what to do when you visit, speak with the social worker or the activities director. They may have some suggestions to make your visits mutually pleasant and rewarding.

Attending conferences about the patient's care plan

Participating in the patient care plan conference is another way to keep in contact with the needs of your family member and concerns that relate to his or her

care. You can provide valuable information about your relative's needs, interests, and background. You also will learn more about how the facility will provide care and about any concerns staff may have, and you can discuss any concerns you may have.

One daughter talked about benefits the patient care plan conference had for her father:

*The patient care plan meeting with my dad was a major turning point. He was impressed that people were concerned about how **he** felt about the care he was receiving. It also made a major change in staff understanding my father's sight and hearing limitations and in recognizing him as a person with problems who would cooperate if approached appropriately. Dad later asked several times about the team of people who were supposed to help him get well. When I explained to him that the dietitian was in the kitchen preparing food he could eat, the physical therapist was helping him with exercises, etc., he made more attempts to communicate his needs and participate in his care.*

Keeping in contact when you can't be there

Even if you can't visit regularly, you still can stay in touch with your family member who lives in a nursing home. Frequent letters and telephone calls are one way. If your family member has poor vision, try using a black felt tip pen and print in large, block letters on white paper.

Some families are using video visits. They talk to the person on videotape and record special occasions such as a trip, a grandchild's graduation or wedding, or a family gathering. Letters and videotapes have the benefit of being something your family member can keep and enjoy rereading or replaying again and again.

You also may be able to find a local volunteer who will visit your family member. The social services or activity departments



of the nursing home may be able to identify a volunteer. The local Area Agency on Aging also can tell you about community agencies that have volunteer "friendly visitor" programs.



One daughter, whose mother had been living in a nursing home for several months, said:
I think my mother is actually happier than when she was living with me, where she lay on the couch most of the day. In the nursing home there are other people around her—not just me. She is involved in exercise classes and other activities. What I considered a last resort several months ago, I now know was the best decision for both Mom and me.

Conclusion

The nursing home decision may be one of the most difficult decisions you and your family will ever face. It's even more difficult if you need to make a decision quickly at a time of crisis. Although it's a decision most of us hope we never have to make, there are times when a nursing home is the most appropriate place for a person. A nursing home can enhance an older person's quality of life and relationships between family members.

If you have given careful thought to the decision, examined options, involved the older person in decision making if possible, and decided that nursing home care truly is the best option, you need not feel guilty about making the decision.

For more information

OSU publications

Talking to Your Family and Doctor about Difficult Health Care Decisions, EC 1386.

When Death Comes: Funeral and Alternative Arrangements, EC 1243.

PNW publications

Sensory Changes in Later Life, PNW 196.

Aging Parents: Helping When Health Fails, PNW 246.

Loss and Grief in Later Life, PNW 439.

Depression in Later Life: Recognition and Treatment, PNW 347.

Driving Decisions in Later Life, PNW 510.

Helping Memory-impaired Elders, PNW 314.

Alcohol Problems in Later Life, PNW 342.

Living Arrangements in Later Life, PNW 318.

Using Medicine Safely in Later Life, PNW 393.

Hiring and Working Successfully with In-home Care Providers, PNW 547.

Other resources

A federal government Web site—www.medicare.gov—is designed to help families select, work with, and pay for nursing home care.

Order copies of OSU publications from:

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