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MAKING A DECISION ABOUT A NURSING HOME



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Note: This publication uses the term “nursing home” to refer to long-term care facilities that provide personal and nursing care to people who are unable to care for themselves. However, there are other facilities—adult foster homes, assisted living facilities, residential care facilities, and other group living situations—which offer significant care. The guidelines in this publication may also be helpful in evaluating these facilities.

MAKING A DECISION ABOUT A NURSING HOME

V.L. Schmall and C. Pratt

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

Thousands of families face this decision each year. Before we die, at least 25 percent of us will live in a nursing home. For many people, it will be a short stay—for rehabilitation or to further recover after an accident, surgery or illness; for others, it will be an extended stay.

A 1990 U.S. government study estimated that 43 percent of people who reach the age of 65 will need nursing home care at some point, and over half of that 43 percent will be in a nursing home for a year or more. The longer we live, the greater our chances of spending some time in a nursing home. A large proportion of people who live past age 85—the most rapidly growing age group in the United States—will spend the last few months or years of their lives in a nursing home.

A nursing home usually is considered when a significant change occurs in the health of an older person and when community services have been exhausted, are no longer appropriate, or are not available to meet the person's needs. Changes in the life of the caregiver—illness, exhaustion from

caregiving, a geographic move, changes within the family, or the death of the caregiver—also lead to placement.

Although to many people a nursing home is “a place where old people go to die,” a nursing home actually is 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 having to devote all of your time to caregiving tasks.

Although there are no easy answers to the nursing home decision, this publication provides you with 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 explores ideas for maintaining 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 when one *is not* needed. Advance planning can make it easier for everyone involved if you and your family are ever faced with this decision.

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Although the decision isn't easy, it's even more difficult if you are first faced with it 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 may someday need a nursing home. With preplanning you will be better informed and prepared to make the decision if the need arises.

WHEN IS A NURSING HOME APPROPRIATE?

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 may need to look at a nursing home.

In deciding whether a nursing home is required, you should consider your older relative's medical condition and nursing care needs. However, it's equally important to consider the caregiver's well-being.

Indicators that a nursing home may be appropriate for an individual include:

- The person needs specialized health care services.

- A nursing home is the only option where 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 post-hospital 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 based on a team approach. There are three vital participants in the nursing home decision: 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 a 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 a few 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 facing 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 suddenly moved to a care facility. You also may create an atmosphere of distrust with your family member.

Remember, considering a nursing home implies a potential major transition, and a move will involve many losses for the person, no matter how desirable a selected 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 about the availability of help. 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 the choice of a nursing home is limited to those with available beds. If this is the case, 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 the “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 any 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 made 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 may further contribute to feelings of guilt.

You also may experience some fears about your own future. If you have been the caregiver, you may find yourself suffering from a loss of purpose.

The more you and other family members are aware of your own and each other's feelings, the better decision you can make. It's important to acknowledge the feelings of

everyone, but it's also important not to base decisions on feelings.

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.

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 32) 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 may be helpful in identifying 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 to help you. Community services and eligibility requirements frequently change.

If it's decided that 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; and
- 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.

A wide range of community services is available to help older people remain at home. Services that may provide assistance 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 care; and
- case 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 round-the-clock. Many older persons 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 be helpful in identifying resources. You can find telephone numbers for these agencies in your telephone directory under "city, county, or state government offices." 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 non-profit agencies offer services on a "sliding scale" fee.

If you are considering having your relative live with you, give serious thought to:

- The impact intergenerational living would have on you, your older family member, and other persons in the household.
- 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 his or her 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.

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- Your need for a break from caregiving. Respite services or adult day care can relieve you from the demands of caregiving and delay the need for nursing home care.

If your relative needs considerable support, but is able to care for him or herself, you may want to 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. One of

these housing arrangements may be the answer for your family member (see the OSU Extension publication *Living Arrangements in Later Life*, PNW 318).

Your family member's physical, mental, and social service needs are central to any decision about appropriate services. As these needs change, services likewise must change. Community services may enable your older relative to remain in his or her home, or in your home. However, if the needed services are not available to meet the needs of your family member, then a nursing home may be the best alternative.



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 can feel comfortable with and that best meets your family member's needs and financial resources. Although the decision is seldom easy, there are things you can do to make the best decision possible. In addition to involving your relative in the decision-making process, these guidelines may be helpful to you.

Identify your family member's needs. Before contacting care facilities, develop a list of your family member's medical, social, and emotional needs. This list will help you in your assessment of the best facility. It might include the need for assistance with incontinence, walking, transferring, eating, and medications; personal care like bathing, grooming, and dressing; and behavior management (for example, wandering and angry outbursts).

Know the level of care your family member needs. In general, nursing homes provide two levels of care: *skilled* and *intermediate*. These terms refer to the intensity of nursing services offered by the facility.

Skilled nursing care is for persons who need 24-hour medical supervision, skilled nursing care, or rehabilitation, but do not require hospitalization. This 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 designed for people who require assistance with activities of daily living and some health services and nursing supervision, but not continuous 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.

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 require supervision and assistance with personal care and other activities of daily living. Often this is the kind of care needed by persons suffering from dementing illnesses such as Alzheimer's disease.

Some facilities also have *special care units* (also called designated or dedicated units) that are specifically designed to meet the needs of persons with dementia.

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

Get recommendations. Talk with those persons who have first-hand knowledge about local facilities. These may be other families, the physician, clergy, or hospital social workers. The Area Agency on Aging is also a good source for information about nursing homes in an area.

Screen by telephone. Call prospective facilities to get answers to questions about vacancies, admission requirements, levels of care provided, and participation in Medicare and Medicaid. You also will want to verify that the home has a current state license. Calling first also will help eliminate homes that do not meet your needs, and will narrow your choices of homes to visit.

Call during business hours. Talk with the admissions coordinator, administrator, or director of nursing. The person(s) with whom you speak should be willing to take the time to answer your questions. Your questions should include:

- **Is your nursing home currently licensed by the state?** Also, ask if the administrator has an up-to-date license. If the answer to either of these questions is “No,” then you should look elsewhere for a nursing home.
- **What level 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 future needs could change.
- **Is your facility Medicare certified?** Although your family member may not be eligible for Medicare assistance now, if later hospitalized, is he or she eligible for readmission under Medicare coverage? It helps if your family

member is able to 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 assistance with eating, will it be appropriately provided? 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 any information you can provide will be useful. The more complete the information you give, the more helpful the facility can be to you.

Tour prospective facilities. After you have completed your telephone screening, personally visit prospective nursing homes. It's the only way to truly evaluate a facility and determine whether it's right for your family member. Visit with the administrator and/or director of nursing until all your questions are answered. Two primary questions you will be seeking to answer are:

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

Make an appointment before you visit. Nursing homes do have busy times, especially early in the morning, when they are getting residents bathed and dressed for the day, and at meal times. Try to avoid these times.

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

Use your senses and observe, observe, observe. How do staff relate to the residents? How does the facility appear? How do residents look? What are the 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, you will want to cross that home off your list.

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

If your visit will be the first time you have been in a nursing home, you may 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 may call out to you "Help, help, help" as you pass by. It doesn't mean the person is in pain. A resident may reach out to you or think you are someone they recognize. Smile and say hello.

Following your tour, consider returning to the facility 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 be "perfect" in meeting all of your family member's needs. You and your family member need to decide what are his or her priority needs. Observing and talking to other residents and their families can provide you with useful information.



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 may want to keep in mind the perspectives offered by two family members:

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 to have 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, property, savings, stocks, bonds, and insurance. Also, find out if your family member has a long-term health care insurance policy. If he or she does, make sure you understand under what circumstances the policy will cover expenses, what level(s) of care it will cover, and for how long it will provide coverage. If the older person's financial resources are inadequate, how much, if any, can family members realistically contribute?

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 portion of nursing home care costs. It has limits on the amount of time and circumstances under which it pays for nursing home care. It pays only for care that it defines as "skilled," and its definition is more restrictive than that applied to the level of care a facility offers. Federal guidelines for Medicare basically limit coverage to persons who have the potential for recovery. 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 Medicare certified; Medicare will not cover the cost of care for persons in these 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. Because rules governing Medicare are revised frequently, it's advisable to check current Medicare policies. You may obtain additional information from your local Social Security Office.

Medicaid. Medicaid helps low-income people of all ages who have exhausted their own funds pay for medical expenses, including nursing home care. Because of limited

incomes and high medical costs, many older persons in nursing homes eventually qualify for Medicaid. Medicaid covers nursing home care for eligible persons as long as the person's condition merits it.

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

When a person does not have the financial resources to pay for nursing home care, an application can be made to Medicaid for 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 will pay the balance.

It's very important that spouses know federal and state laws regarding division of assets and limits on "spend down." Spouses of nursing home residents no longer need to become impoverished to pay for a mate's care before Medicaid can be used. But if the spouse is unaware of the laws and spends everything for care, the impoverishment will not be reversed by the government.

If the older person's financial situation is substantial, Medicaid coverage probably will not be available and it will be necessary to pay for care from the person's income and

financial reserves. 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 Medicaid payments to nursing homes usually are lower than those paid by Medicare or private-pay patients, many nursing homes do not accept persons on Medicaid, or they place a limit on the number of beds available for individuals on Medicaid.

To learn more about the specific requirements for qualifying for Medicaid, or to complete an application, contact your local department of social services or welfare office. Social workers at most nursing homes also can help you.

Veterans Administration. The Veterans Administration Veterans Aid and Attendance Program can help offset nursing home care costs for eligible veterans. If your family member was in the service during wartime, inquire about the program to determine whether he or she qualifies. For more information, contact your local VA office.

QUESTIONS TO ASK

Specific questions you may want to ask regarding the costs of nursing home care include:

- 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 of these fees. Typical extra charges are for medications, incontinence pads, 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 paying 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 payments fully refunded?

If you are an adult child of the person entering a care facility, you are not legally responsible for the costs of your family member’s care; however, his or her spouse is responsible if income and resources are above the exemption limits.

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 may want to have a lawyer review it before signing.



TOURING A CARE FACILITY: WHAT TO LOOK FOR

In addition to finances, there are many other considerations in selecting a nursing home, including 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, but especially the staff. Observe carefully how staff interact with residents. Look for these things:

- 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?
- 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, wall decorations in their rooms?

- Are visits welcome at anytime?
- 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 the residents as you pass by them?
- Is respect given to the privacy needs of residents?

Three important questions to ask about the atmosphere in relation to your family member are:

- Is the atmosphere one in which your family member will be comfortable? Some people prefer a "cozy," homelike environment; some prefer one which provides a lot of activities; others prefer a more "formal" setting.
- Are there other residents with similar backgrounds to your family member? 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 the answers to these questions is exemplified by 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 this will be the case for your family member, 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.

APPEARANCE OF THE RESIDENTS

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

- Are residents appropriately dressed?
- Are the residents well groomed?
Are male residents clean shaven?

- Are residents out of bed?
- Are residents involved outside of 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, with residents encouraged to personalize their space.

- Is the nursing home convenient to family, friends, and the person's physician?
- Is the building safe, with well-lighted 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? Is it a level that will be comfortable to 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?
in bathrooms and bathing areas?

- If residents share rooms, how is privacy provided?
- Are there lounges, gardens, kitchens, and other areas and equipment for recreation?

People often feel a sense of loss when leaving their home. A room in a care facility cannot replace a person's home. Therefore, having a personalized space in a care facility is important. If a part of what was "home" can accompany your family member, this often helps to make 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, then 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 participate in the development of the patient care plan?
- What is the procedure for residents to make complaints or recommendations?
- Is there a resident council? a family council? If so, what is the level of participation?
- Is a social service worker available to provide assistance to 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 the lives of residents and activities of the nursing home. A family council is designed to provide a forum for expressing concerns and making recommendations to the administration. Active participation usually means the administration and staff are concerned 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 family member who is now a resident.

Volunteers generally are most involved with the social service and activity departments. An active volunteer program often is

a reflection of a facility's commitment to meeting the needs of residents.

ACTIVITIES

Activities can be important in enhancing a person's self-esteem. Ask to see the activity schedule, which usually is posted in a facility.

- Is there a varied and stimulating activity program? Or are activities boring and childlike?
- Are activities offered that are interesting and meaningful to your family member?
- What intellectual and mentally stimulating activities are available to mentally alert residents? For example, is there a Bookmobile from the library, 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?

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 persons with specific health problems such as diabetes or difficulty swallowing?
- Will the facility meet a person's special dietary needs based on religion?
- Are residents given enough time to eat?
- 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 regarding the use of 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 policies and procedures of a home before moving your family member into it.

- 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 to travel outside of the facility?
- Can residents bring their own furniture and mementos? Are there any limitations about what they can bring?
- Can food and drink be brought in for a resident?
- What is the policy regarding the use of restraints?
- When is the family notified about changes in a person's condition?

Your choice of a nursing home should be based on careful consideration of the questions on pages 19 to 23. While no home is perfect, you can expect that most good homes will do well on your evaluation. Your decision should reflect this evaluation, together with the preferences of your older relative.



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 assist in making the transition less stressful. Ask about the best time to move into the nursing home. Mid-morning 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 bring, sell, or give away.

Prepare as much in advance as possible. For example, in advance of the move, 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 provide needed reassurance. It also 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 make it as soon as possible.



ADJUSTING TO THE NURSING HOME

Once a move has been made, a difficult adjustment period often follows. The first few weeks will be the most difficult. It may take 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, dressing himself or herself or walking 20 feet. Rather than ignoring or brushing off feelings, talk about them.

It has been suggested that there are four R’s to helping a person adjust to a care facility: Reassurance, Routes, Routines and Relationships.

- **Reassurance.** Be present and available during the first few weeks. You can help reduce a major source of anxiety—the fear of being abandoned. You probably are the “piece of security” in an environment that feels insecure.
- **Routes.** Nursing home residents can experience considerable uncertainty about getting around in a facility, such as to the dining

and activity rooms. This will be especially true for the person who has Alzheimer’s disease or other dementia. You may need to repeat 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. When staff have good feelings about you it generally will 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 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 during 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 have faced your own feelings, it will be easier to be more supportive of your older family member's experience of loss.

Because there still is a social stigma associated with nursing homes, it's no surprise that feelings of guilt pervade nursing home adjustment. If you find yourself feeling guilty, you likely have broken some underlying "rule" and you expect to be blamed and punished. An example of such a rule is "A good daughter should take care of her parents." The daughter may be totally committed to this "rule," but unable to provide the direct care for practical or emotional reasons, and yet feel guilt as a result. Another person may be ambivalent about this rule and feel guilty for having mixed feelings. Often families of nursing home residents manifest their guilt by being overly protective of their 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."

To cope with the changes, adjustments, and feelings that nursing home placement may bring, we suggest that you:

- 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 will only push them deeper and create more distress.
- Talk with others about their experiences. It can help you feel less alone and assist you to 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 a support group of the Alzheimer's Association or other caregiver support group. Look in the newspaper for times and location of meetings. 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 some suggestions for making your visits meaningful:

- Discuss with your older relative expectations and limitations regarding visits to reduce his or her disappointment. You can 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. Scheduled visits give your older relative something to look forward to and help 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

also provide 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-aged 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 mentally alert. He gets frustrated with the small print so I bring in the newspaper or magazine articles and read them to him. Afterward, there's plenty to talk about. Not only is this activity stimulating to him, but 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, 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, giving a massage, stroking the person's arm,

or brushing his or her hair can communicate caring, affection, and that the person is valued. One daughter commented:

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 provided 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 helpful suggestions to make your visits mutually pleasant and rewarding.

ATTENDING PATIENT CARE PLAN CONFERENCES

Another way to keep in contact with the needs of your family member and the concerns that arise in relation to his or her care is to participate in the patient care plan conference. 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. This also is an opportunity to discuss

any concerns you may have. One daughter talked about the benefits the patient care plan conference also 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 can still 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. This may increase the ability of the person to read your letters.

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 the resident can keep and enjoy re-reading or re-playing 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 give you information about community agencies that have volunteer "friendly visitor" programs.

CONCLUSION

The nursing home decision may be one of the most difficult decisions your family will ever face. It's even more difficult if you are confronted with the 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 an individual. A nursing home can enhance an older person's quality of life and relationships between family members. 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 laid on the couch most of the day. In the nursing home there are 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.

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 FURTHER READING

In July 1992 the OSU Extension Service publications warehouse was destroyed by fire. We are replacing our supplies. The publications listed below may be available in the office of the OSU Extension Service that serves your county. Check with that office for current prices.

You also may call Agricultural Communications at Oregon State University, (503) 737-2513, to learn the availability and current price of the publications.

**Publications Orders
Agricultural Communications
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Aging Parents: Helping When Health Fails by V.L. Schmall. Pacific Northwest Extension publication 246, Oregon State University, Corvallis, Oregon, 1992. 50¢

Alcohol Problems in Later Life by V.L. Schmall, C.L. Gobeli, and R.E. Stiehl. Pacific Northwest Extension publication 342, Oregon State University, Corvallis, Oregon, 1989. 75¢

Coping With Your Loss and Grief by V.L. Schmall. Pacific Northwest Extension publication 438, Oregon State University, Corvallis, Oregon, 1993. \$1.00

Coping with Caregiving: How to Manage Stress When Caring for Elderly Relatives by V.L. Schmall and R.E. Stiehl. Pacific North-

west Extension publication 315, Oregon State University, Corvallis, Oregon, 1991. 75¢

Depression in Later Life by V.L. Schmall, L. Lawson, and R.E. Stiehl. Pacific Northwest Extension publication 347, Oregon State University, Corvallis, Oregon, 1992. \$1.50

Families and Aging: a Guide to Legal Concerns by V.L. Schmall, T. Nay, and M. Weinstein. Extension Circular 1221, Oregon State University, Corvallis, Oregon, 1988. \$1.25

Financing Health Care in Later Life by V.L. Schmall. Pacific Northwest Extension publication 345, Oregon State University, Corvallis, Oregon, 1989. \$1.00

Grief in Children by J. Hare. Pacific Northwest Extension publication 391, Oregon State University, Corvallis, Oregon, 1992. 75¢

Helping Memory-Impaired Elders: A Guide for Caregivers by V.L. Schmall and M. Cleland. Pacific Northwest Extension publication 314, Oregon State University, Corvallis, Oregon, 1992. 50¢

Helping Your Older Family Member Handle Finances by V.L. Schmall and T. Nay. Pacific Northwest Extension publication 344, Oregon State University, Corvallis, Oregon, 1992. 50¢

Continued on back cover

FOR FURTHER READING *continued*

Living Arrangements in Later Life by V.L. Schmall and R.E. Stiehl. Pacific Northwest Extension publication 318, Oregon State University, Corvallis, Oregon, 1989. \$1.00

Loss and Grief in Later Life by V.L. Schmall. Pacific Northwest Extension publication 439, Oregon State University, Corvallis, Oregon, 1993. \$1.00

Managing Urinary Incontinence for Healthy Aging by N. Kershaw and V.L. Schmall. Pacific Northwest Extension publication 408, Oregon State University, Corvallis, Oregon, 1993. \$1.00

An Oregon Guide to Special Care Units for Persons with Dementia by S. Baggett and C. Pratt. Extension Circular 1425, Oregon State University, Corvallis, Oregon, 1993. \$1.25

Sensory Changes in Later Life by V.L. Schmall. Pacific Northwest Extension publication 196, Oregon State University, Corvallis, Oregon, 1991. \$1.00

Talking to Your Family and Doctor About Difficult Health Care Decisions by J. Hare. Extension Circular 1386, Oregon State University, Corvallis, Oregon, 1992. \$1.25

Using Medicine Safely by V.L. Schmall and J. Leno. Pacific Northwest Extension publication 392, Oregon State University, Corvallis, Oregon, 1992. \$1.25

Using Medicine Safely in Later Life by V.L. Schmall and J. Leno. Pacific Northwest Extension publication 393, Oregon State University, Corvallis, Oregon, 1992. 75¢

When Death Comes: Funeral and Other After Death Arrangements by V.L. Schmall and C. Pratt. Extension Circular 1243, Oregon State University, Corvallis, Oregon, 1990. \$1.25



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