

# Choosing a Nursing Home: Institutional Care

This pamphlet is part of a series on dementia-related diseases prepared by Kenneth Hepburn, PhD., Geriatric Research, Education and Clinical Center (GRECC) of the Department of Veterans Affairs Medical Center Minneapolis, Minnesota.

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Family members are the primary providers of care for persons with Alzheimer's disease and related disorders. In some cases, a family caregiver provides care at home right up to the person's death. But in most cases, caregivers find they cannot provide all the care the person needs. Then it becomes necessary to find a suitable care facility. If you think you may need or want to place the person in a nursing home, you are faced with three big choices. The first choice is **whether** to place. The second is **where** to place. The third is **when** to place.

If you are responsible for the patient's care, these occasions are yours to make. No one else can tell you to place (or when or where to place the impaired person). Others can **assist** you. This is an important time to call on all the resources you have developed over the years. You may want to call a family meeting to discuss the placement decision. Family and friends, clergy, health care professionals and support organizations such as the Alzheimer's Disease and Related Disorders Association (ADRDA) can help. They can help you think the issues through. They may even be able to take on part of the work of finding the right place.

You need to keep in mind that there is no perfectly "right" time for placement. It is not easy to decide about this issue. You may think that the time is coming to place the impaired person in a professional care setting. You may also still feel that you can or want to provide the care yourself. You may not be emotionally ready for the next step. Finances may also be a consideration.

Keep in mind that **planning** for placement and actually **placing** the person are two very different things. Shopping for a facility and even picking one that meets your requirements do not commit you to placing the person. Taking these steps now, however, will make placing the person much easier when you do decide the time has come.

Once you decide that placing the person in a care facility may be needed, you need to take three steps: **plan**, **shop** and **choose**. The rest of this pamphlet offers ideas to guide you in each phase. Each section contains a series of questions you will need to answer. Once you have worked out answers to the questions, you should be better able to make a decision about whether to place as well as when and where.

Ideas to keep in mind. . .

While planning. There are three factors you should think about when you begin to look for a nursing home.

### **The Impaired Person's Condition**

In a disorder like Alzheimer's disease, a person's condition can change suddenly. There can be a rapid decline in the ability to remain at home.

### **Your Needs**

You need to keep yourself in mind in all your planning. Your emotional, physical and financial well-being must all be included in your planning. Caring for an impaired person draws on your store of physical and emotional strength. The hard and lengthy process of choosing a care facility can add to your physical and emotional burden. Try to begin planning early enough that you will have time to do so gradually. You need to have strength left after the person moves into his or her new home. This will allow you to keep an active role with the person (if you choose) and to begin a new life of your own.

### **Care Facility Availability**

More and more, nursing homes have waiting lists, some as long as nine months. So, if you are thinking about placement and want to proceed as smoothly as you can, allow plenty of waiting time. In addition, give yourself ample time to shop for and choose a facility.

### **Research and Planning Stage**

This part of the pamphlet raises three questions. What kind of care facility does the impaired person need? What special features about a care facility matter most to you? What financial arrangements will be possible?

### **Kind of Care**

There are a number of kinds of care facilities, all offering different levels of care. These include "board and care facilities," "intermediate care facilities" and "skilled nursing facilities." These last two are generally known as nursing homes.

### **Board and care home serve persons who can care for themselves.**

Meals and some supervision are provided, but there is little direct care (or none at all). These homes might suit the needs of a dementia patient in the early stages of the illness; they would not do for a seriously impaired patient.

### **Nursing homes provide 24-hour care.**

The care is guided by a plan that is based on the needs of each patient. This plan covers the resident's physical care. It also attends to the person's need for emotional well-being, socializing and activities. Two levels of nursing care may be offered in nursing homes: "intermediate"

and "skilled:" These two terms refer to the kind and amount of nursing time a person needs each day. Your doctor or nurse can tell you what kind of care the impaired person needs. When you have chosen a care facility, you will be asked to provide a statement from your physician indicating exactly what level of care the impaired person needs. Note: Legislation passed in 1988 eliminates the distinction between "intermediate" and "skilled" levels of care. Effective in 1990, all nursing homes will be referred to as "nursing facilities" for purposes of meeting a single set of federal standards.

### **Special Features**

You will need to identify any special features which you or the impaired person especially want or need in a nursing home. Keep in mind, however: the nursing home market is not a buyer's market. You might not be able to find a home offering everything you want that is near enough, that will accept the person when you want, and that you can afford. You will need to establish priorities. What would you be willing to give up, and where are you not willing to compromise? Use the following questions to help clarify your thoughts.

### **What locations will you accept?**

How far away are you willing to place the impaired person? How much do you plan to remain involved in the person's care? Will you visit one or two hours a day, every day? Will you visit every few days or every week? Or will you plan to see the person less often, say every month or two? The larger the role you plan, the more important the question of location becomes.

### **What timing will be necessary?**

Since nursing homes often have waiting lists, you need to have at least a rough idea of when you might place the person. Next month? Six months from now? A year or more from now? Also, how much time will you need to set your finances in order? You will have to pay for the placement. And you may want to shift assets for your own protection.

### **What are the impaired persons special care needs?**

Does the person require any special treatments such as physical therapy or special care such as pre-cut food? Does the person have special problems like incontinence or wandering? Make sure the home can meet these needs.

### **Finances**

If you are the impaired person's spouse, keep in mind that financial planning must provide for the needs of the person to be placed and for your own needs. In doing this planning, you may want to refer to the

pamphlets in this series titled "Working with Financial and Legal Advisors" They may give you a clearer idea of what resources and options you have. The decision to place a person in a nursing home is complex. The decisions you make will greatly affect you and the person in your care. Get as much expert help and counsel as you can. Be very sure to get help on matters of finances.

In making financial plans, think about the expenses and the resources you will have. Then you can figure out what you can afford to pay for a nursing home. Start by planning for the five years that begin with placement. The following questions will help you in planning.

### **Aside from the costs of the nursing home, what expenses will you have?**

You may still have minor expenses for the impaired person (clothes and grooming needs, for instance). The major expenses apart from the nursing home charges will be for you. How much will you need for food, housing, clothing, travel and entertainment?

Will you remain where you are living or move? If you own your house, will you sell it? If so, how much can you afford for rent or for a new house? If you remain in your own house, include in your budget all of the annual costs such as taxes and insurance. Include also the average monthly expense of items whose costs vary during the year (such as heating). Will you face any other major expenses after placement? For example, will you need to replace a car? Will you need new furniture?

If you have been caregiving for a number of years, you may have become somewhat house bound. Things like entertainment and new clothes for going out have probably not been part of your recent budget. Include these in the post-placement budget.

You probably have some care expenses that will no longer be necessary if the impaired person is living in a care facility. For example, you will no longer need to rent any special equipment or purchase special supplies such as incontinence supplies. The income you formerly spent on these supplies will now be available for other spending needs.

### **Is the impaired person eligible for any free or low-cost nursing home care?**

As a veteran the person may be eligible for free or low-cost care at a VA facility, for example: A veteran may also be eligible for care in a state owned and operated veterans home at a cost which varies from state to state. Some facilities owned and operated by religious or fraternal organizations may offer free or low-cost care to members.

What current resources will not be available after placement! There may be some resources you have now that you won't have after the person is placed. For instance, the impaired person may now receive money from the state to hire cleaning and cooking help. Once the patient moves into a nursing home, that money will no longer be available.

### **What new resources may be available after placement?**

Will the impaired person become eligible for any new forms of assistance? There may be some resources available only after the person is placed that can help pay for care. For example, the person may become eligible for Medicaid or for VA benefits.

**Note:** Private medical insurance often does not pay for nursing home care for dementia patients. Do not count on income from insurance without checking very carefully on the terms of coverage. Medicare does not pay for long-term stays in nursing homes.

Who will share the expenses? Others in the family might bear part of the cost of care. If you call a meeting of the family to discuss the placement issue, be sure to discuss the question of finances. Each state has different rules about the financial responsibility of families for the nursing home care of their members. Spouses are almost always held responsible; children sometimes are. You will need to check on the rules which apply in your state.

### **A word on Medicaid and Medicare**

Medicaid is the most frequent method of paying for nursing home care. It is for people who do not have many assets and/or do not have pension benefits that can be applied to the cost of a nursing home. The program combines federal and state money and is run by the state.

Medicare is a federal health insurance plan, different from Medicaid. Medicare does pay for a limited amount of skilled nursing home care. It pays for care designed for rehabilitation and convalescence. Medicare does not pay for long-term nursing home care.

What you need to know about Medicaid There are several limits on eligibility for Medicaid and on how nursing homes handle Medicaid patients.

In order to use the program, you have to apply for it, usually through state welfare or health department office. You will be required to show that the combined assets of the person who is to go into a nursing home and that person's spouse are below a certain amount. The actual cut-off point varies from state to state, but the allowed total is only a few thousand dollars, excluding the value of the family home.

Not all nursing homes accept Medicaid patients. The payment they receive from the state may be less than they receive from patients paying through other means.

Some nursing homes will permit patients to change means of payment, and others will not. Some nursing homes will permit those who enter as "private pay" patients. That is, non-Medicaid patients to switch to Medicaid when their assets have dropped below the state limit. Other nursing homes do not allow such switch-overs and require patients to move to another facility when they run out of assets.

Eligibility for Medicaid may change if family circumstances change. If the spouse of a Medicaid patient sells the family home, for example, the proceeds from that sale are considered assets. The patient's eligibility for Medicaid is then revoked. The spouse must use those assets to pay for care. When those assets have been spent down below the state's limit, Medicaid will take over again.

This last point is very important if you might be using Medicaid as a payment resource for nursing home care. A spouse who remains in the community cannot sell or rent the family home. If you can foresee that the impaired person will be needing a nursing home, try to shift title of home ownership and other assets to the well spouse ahead of time. You may be able to use a legal agreement that permits a couple to split their assets. Ask a lawyer about such an agreement. The law changes often and varies from state to state, so be sure to seek expert advice.

### Questions to ask yourself.

What kind of care facility do you hope to find? When, roughly, might you place the impaired person? What location will you consider? What special aspects of care are you seeking? What can you afford to pay? What special legal and/or financial steps should you begin to take now?

### Shopping For a Nursing Home

You shop for a nursing home the same way you shop for a house or apartment, a car, furniture or clothing. You go out and look at the facility to see if it meets your basic needs, then you "try it on" to see if it really "fits" well. Finally, you figure out if you can afford it.

As you visit homes, keep in mind that, as a caregiver, you have experience and knowledge. Your judgment is well developed, trust it. You are an informed consumer. In many cases you will be more expert in providing care to a dementia patient than staff at the home. Also keep in mind that, in visiting these homes, you will be training yourself about what matters most in a good care facility.

### Setting Up Visits

Limit the number of homes you will visit (say three to five). Compare these to see if any one meets your needs. If not, you can look further. Use the following steps in setting up your visits.

Make a list of homes to call. You may know homes in your area that you want to visit. You can learn of others from family, friends, clergy and your doctor or nurse. The Alzheimer's Disease and Related Disorders Association in your area should be able to make suggestions. Local offices of your State Health Department will be able to give you the names of homes in the area. Most states have statewide hospital and nursing home associations. You can also get lists from the Joint Commission on Accreditation of Healthcare Organizations which surveys nursing homes as well as hospitals. Their toll free number is 1-800-621-8007.

Call the homes on your list Every home will have someone who is in charge of admissions. Ask to speak with this person. The purpose of these calls is to locate places that meet your needs. The calls are screening calls and need not be lengthy.

Ask about Costs. Ask, too, about additional charges. The monthly rate is usually not all that you pay. Nursing homes vary greatly in cost. Charges can run from \$45.00 to \$100.00 per day and more. (\$50 per day is more than \$18,000 per year.) You will want to cross off your list right away those places that are out of your price range Cost and quality of care do not always go hand in hand, so don't cross a place off just because its costs are lower than most.

If you might use Medicaid as a method of paying for care (at first or later), mention this. Find out if the facility will accept Medicaid patients or if they will allow patients to switch to Medicaid.

Ask, too, if the facility provides care to a certain kind of patient. Are there any kinds of patients the facility will not admit? You will want to cross off your list any homes that will not care for dementia patients.

Make appointments to visit three to five homes on your list. You will want to make appointments for two reasons. First, good facilities think of themselves as the home of the residents or patients. The staff does not encourage outsiders to drop in at just any time. Visitors are welcome, but visits must be made with the residents' schedules in mind.

Secondly, you want to be sure you have time to see certain things and meet with certain key staff members. A nursing home is a small world The Administrator and the Director of Nurses play major roles in shaping what that world is like Your response to them (trust or distrust, like or dislike will strongly affect your overall judgment about that home.

When you set up your visit, ask to include certain features in it. First, be sure you can meet and have time to converse with the Administrator and with the Director of Nurses. Second, you will want a tour of the facility that includes time to chat with staff from several departments (such as social service, dietary, and activities). Third, you should try to arrange to purchase a meal that you can eat with the residents.

Making the visit The purpose of your nursing home visits is to gather information about three general areas: patient care, finances and the environment.

The following questions can help you. There are many more questions that will come to mind, especially after you have made one or two visits. You might also want to look through Chapter 16 of *The 36-Hour Day* for more ideas.

What patient care is available? What experience and training does the staff have in working with patients like yours? What is their viewpoint about providing care to dementia patients? What is their attitude towards care? How does it match yours?

What programs do they have for patients with problems like those of the person in your care? How does the nursing staff approach the problem?

What do the social service, dietary and activities staff offer? Do they seem to have thought about these issues and tried different approaches?

How will the care of the impaired person be designated? Will he or she receive individualized care, or do individual residents become lost in the crowd?

What charges will be made? Ask again what the monthly charge is, and find out what is included in it. Ask for a list of the "extras" and their costs. For example, in most facilities physical therapy is extra; so is a haircut. Laundering a patient's personal clothing might be included or might cost extra. What about drugs, lab work and dental care? What are the charges for these? Go through the whole list of charges and come up with as accurate an estimate as possible of the actual monthly costs.

What increases in costs might there be in the first three years? What increases have there been over the last three years?

What kind of payments will each facility accept? Even though you've asked this on the phone, ask again. If you might at some point use Medicaid as a payment source, raise the issue. Will the home accept a patient who comes in on Medicaid? Will it keep a patient who switches to Medicaid after paying some other way for a while?

Is there a waiting list? How long would you have to wait before the person in your care might be admitted? What do you have to do to be put on the waiting list? Do you have to leave a deposit? Would the deposit be refundable if you change your mind?

Is the facility safe? Do you see safety equipment (fire alarms, fire extinguishers, lighted exit signs, smoke detectors, sprinklers, fire doors)? Does the staff have a plan for what to do in case of fire? Can they show you proof that they have had a fire inspection in the past year? Do they have a current license to operate?

How does the facility look and feel? Any health care facility will feel like an institution, to a certain extent. A nursing home is also a home, however. Does each place you visit feel "homey"? (Ask to see the part of the home where the person in your care would be placed. Is the home relatively clean, neat and free from bad odors throughout (not just the front hall)? What are the patients' rooms like? Are they large enough? Do they offer privacy? Are personal items permitted? What are the dining area and living room like?

At meantime, are residents who need help with eating given enough time and help? What seems to be the attitude of staff to residents? How good is the food?

### After each visit

After each visit answer the following questions. Then, when you have visited a number of homes--the number will be up to you, but try to see at least three to five--you will be able to put your lists of "answers" side by side



How was your meeting with the Administrator and Director of Nursing? Were you comfortable talking with them? Do you feel you trust them? How able did they seem? How did you react to the other staff you met? To what extent does the facility seem able to care for patients with dementia? Does the place "fit" the person in your care? Do the home programs match your patient's needs? Will the person be treated as a person? What will the home cost per month (basic charges plus expected regular extra charges)? Can you really afford this home? Will placing the person in this facility leave you enough to live adequately? Will the home accept Medicaid? Can the patient switch to Medicaid, if necessary? Does the home seem safe? Does the facility feel homey and comfortable? What are some of the features you particularly liked?

### Choosing a nursing home

Now that you have gathered information and visited a certain number of homes, you are in a position to choose. Your first step is to rule out any clearly bad choices.

There is no reason to place the person in a home you consider to be unsafe. If you feel any place you visit to be unsafe, cross it off your list. Don't dwell on a home that is out of your price range or that won't take the kind of payment you can offer. Cross any place like that off your list too. This should leave you with a short list of safe, affordable places from which to choose or just to keep in mind for the time when you decide to choose.

In arriving at a choice, rely on your own expertise, and trust your feelings. Does the place feel right for the patient and for you? Are you at ease there? Do you feel the impaired person will be at ease and well cared for there? Is this the home to which you want to transfer care? Will the staff allow you to maintain whatever role you choose? Will placing the person at this facility allow you to have the kind of life you want after the placement? Choosing a nursing home for the person in your care is not the same as placing the person there. When you have chosen the "right" home for the person and for you, you have still not decided to move the person there. Knowing where you would like to place the person, however, will make doing so much easier when and if you decide this step will be the best for both of you. But knowing where you would like to place the person does not commit you to doing so.

If you do decide to place the person in a nursing home, keep in mind that you can't simply call the place and reserve a room. Look through the pamphlet in this series titled "The Move to a Nursing Home" for a sense of the steps in and length of the admission process.

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