

THE MOVE TO THE NURSING HOME

THE PLANNED AND UNPLANNED MOVE

This pamphlet is part of a series of 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

There are two kinds of moves to a nursing home: planned and unplanned. In many cases, placement in a nursing home is unplanned and takes place in a crisis. A person is admitted to a hospital for some urgent reason. The doctor says that a nursing home is the best place. The hospital social worker must quickly find a suitable home. In this case, the person's family is caught in an emotional whirlwind. They don't have much time to get their feelings sorted out. There isn't time to think about what they want or need in the nursing home setting.

Placing a person in your care into a nursing home is complex business. An unplanned nursing home placement makes it much harder to do things the way you want and to be clear about your feelings. You have invested a great deal of yourself in providing care to the person. You want to be sure that the home can provide the kind of care you want for the person. You want to know that the new setting will allow you to retain the kind of caregiving role you want with the person. You will also have a great many feelings about placing the person. You may feel grief and loss, anger, sorrow and a loss of control. After the person is in the home, you may find yourself enjoying the freedom of days not filled with caregiving tasks. You might feel guilt along with this sense of release.

At some point, you will decide nursing home placement may be needed for the person in your care. This is the time to begin planning for that move. You need time to select a home that you can afford and that is best for the impaired person and you. For help in making your choice, see the pamphlet titled, "Choosing a Nursing Home: Then, when the

time comes to move the impaired person, you want be ready. Once you have prepared for it, the move will be smoother, whether it is from your home or from the hospital.

Once you have chosen a home, sign the person up on the home's admission waiting list. Depending on how long the waiting list is, you can tell roughly how much time you have to get ready for the move.

The rest of this pamphlet offers suggestions to help you prepare for and make the move. It may help you see problems which may arise, and to plan your role after the move.

Preparing for the move

There are three major factors in preparing to move a person to a nursing home. You have to make sure that all financial matters are taken care of. You will need to see to the person's medical care. And you will have to decide who will oversee that care.

Financial Arrangements

You will need to see to the following financial matters

Ask for a written agreement.

Ask the home for a detailed written agreement about charges and services. This should be an agreement that is signed by someone in the nursing home with authority to make a contract. The agreement should spell out what the regular monthly fee will be and what services are included. The agreement should also say what regular extra charges you can expect to pay (for hair care, personal laundry service, physical therapy, etc.). Beyond this, you should receive a list of charges for all extra services available in the home.

Make careful payment arrangements

The details of this task will vary depending on how you plan to pay. You may, for instance, need to arrange to transfer Social Security payments to the home. You may need to apply for Medicaid on the patient's behalf. You may want to see a lawyer about setting up a trust account. (See the pamphlets on "Working with Financial and legal Advisors"). Or you may need to get agreements from members of the family about sharing in the cost of care. These arrangements should all be in place by the day

of the move. The home will expect you to pay in advance for the first month, so you should be prepared to do so.

Attending Physician

Every nursing home patient must have an 'attending physician' This is the doctor who will be responsible for the care the person receives in the nursing home. Almost all aspects of nursing home care need an order signed by a doctor. The doctor must order the drugs a person receives and the activities the person takes part in. The doctor must say what physical therapy the person will get. The doctor must write an order that the person may be physically restrained (and for what reason). If the person falls and might need to be taken to an emergency room for X-rays and/or treatment, a doctor's order is needed. Even the kind of special diet a person may eat requires a doctor's order.

At the time of admission, the attending physician provides basic medical information about the patient, including results from a recent physical. The doctor sets up a plan of care, and visits the patient on a regular basis. The visit schedule will vary, but the doctor should come at least once every month or two. The rest of the time, the attending physician can talk with the staff by phone.

As caregiver, you decide who will serve as the attending physician. You may find the following ideas helpful. Find out in advance if the person's current doctor can serve as attending physician at the nursing home. The nursing home may have a policy that all residents must switch to a doctor on staff at the home.

Find out, too, if your current doctor is willing to attend the patient in the nursing home. If the home you have chosen is not nearby, your doctor may not be able to be the attending physician. If you need to choose a new doctor, your choices may be limited. There may be only a few doctors in the area or on the staff of the home. Try to meet and talk with these doctors. See which one knows the most about dementia patients. Ask your current doctor to help you decide. Medical records. If a new doctor will be attending the patient in the nursing home, be sure all medical records are sent to him or her. Ask the impaired person's former doctor to call the new doctor and discuss the case. Your doctor should provide a summary of the patient's care up to this point. You may find

you need to follow up with the doctor to be sure this is done. Consultations on care decisions Let the new doctor know that you expect to be fully consulted on care decisions and look forward to being helpful. You have a wealth of information about the person. You can be a resource to the attending physician. Be prepared: it takes time to learn to work well with a new doctor.

Plan of Care

In almost every nursing home, the care each patient receives is governed by a "plan of care." The plan is based on a clear understanding of what the patient's needs or problems are. The plan sets care or management goals for each of these needs. The plan sets out how the staff will proceed in each of these need or problem areas. It says which departments; nursing, dietary or social service, for instance will do that part of the work. Generally, the plan of care is set up within the first two or three weeks of a person's stay. The plan is reviewed and revised every three to six months. Many nursing home invite families to participate in care planning.

Take part in setting up the care plan.

Plan to take part in setting up the patient's plan of care. You are an expert on the care needs of the impaired person. You know the best techniques for working with this person. Be ready to offer this information to the care planning group. Tell them what you have observed about the person's food preferences, strengths and weaknesses, likes and dislikes, habits and activities. List for the group the problems you have had and how you handle them. Tell them how you divert the person, how you received him or her, and how you communicate with each other. For example, if the person becomes agitated, how do you calm him or her? How do you tell if the person is in pain or unwell? Do certain gestures signal certain needs, such as the need to go to the toilet?

Put your observations down in writing.

Prepare for this planning session by putting your observations down in writing, if you can. Then they can become a permanent part of the patient's medical record and can be referred to as needed. Former doctor's detailed plan of care. Ask the patient's former doctor for a detailed plan of care. Even if this doctor will not attend the impaired person at the nursing home, ask him or her to submit a report to the new

doctor. The report should detail what kind of care the former doctor, who knows the patient's situation best, would prescribe.

The Day of the Move

Although emotionally hard, the day of the move itself is not as important as it might seem in ensuring the impaired person's adjustment to his or her new home. You're planning and your future efforts to assure the person's well-being matter much more in the long run. Still, the day itself may be charged with very strong feelings.

Keep in mind that these feelings are normal, but try not to let them get in the way of your task. You want to bring the person to the home and leave him or her there in as cheerful a manner as you can. Your task is to minimize any distress the patient may feel. The following ideas may help.

Plan what to tell or say to the person.

Think about what you want to tell or say to the person in your care about the move. Let your own knowledge of what the person can understand be your guide. Discuss the move at the person's level and be truthful. This way you will avoid too complex an explanation. Also you can be easy with yourself about not deceiving the person. If the person still has powers of memory and thought, you can give more details. Tell him or her about the home and what it will be like. If the person's powers have dwindled, just say that you have chosen a place where he or she will receive good care. In this case, the impaired person will have to adjust to a new home without the information you might like to give in advance. You can still help and reassure, though. Most meaningful will be the emotional tone you use in talking about the new home if you truly feel good about the home, this feeling will come across.

Bring a few favorite things.

If possible, bring a few favorite "things" with the person to his or her new home. Be sure to discuss **in advance** with the staff any items you wish to bring with the patient. The home may limit the amount and kind of items you can bring. Most nursing homes don't permit large items sofas or dressers, for instance. Almost every home has a rule barring certain kinds of electrical equipment, electric blankets, and extension cords. Most require that all other electrical items be checked before use in the patient's room. If you want the person to have a radio or TV, and if

you can easily do so, bring the items to-the home **before** the day of the move. That way they can be checked and placed in the room before you arrive. Prepare the essential clothes the person will need in the nursing home. Additional clothes can be bought at a later time. Make sure that the person's clothes and personal belongings are marked or labeled clearly with his or her first and last name.

Let the Staff take charge . . .

Once you have brought the person to the home, let the staff take charge. They have routines to help a new resident move in and feel at ease. Discuss, **in advance**, what they will want you to do. They might want you to remain for a while. They might suggest, based on their experience, a move will be easier for both you and the person in your care if you plan to leave soon after the person's arrival. You chose this home because you believed the impaired person would receive good care here. Trust that choice. Do what the staff suggests. They will be the caregivers now. You may see that the impaired person is confused, frightened, angry, hurt or any mix of these. Keep in mind that the staff remembers how hard it is to adjust. They are skilled in helping people through this period.

Dreading the moving day

If you feel anxious or dread the approaching moving day, try to get help. Ask someone else to drive you and the person to the nursing home and to drive you back home afterwards.

Continued role for you

The amount of contact you have with the person and the care team after placement is your choice. It is subject to many factors. A big factor is distance between your home and the nursing home. Your own health and resources enter into this. Events, demands and interests in the rest of your life will affect your choice. Whatever you choose, your role may be with both the patient and the care team.

Your role with the impaired person

Contact with the person in the nursing home may serve both your needs. You can see for yourself that the person is well cared for. The person can feel your presence even if other communication is no longer possible.

You may wish to invite the person's family and friends to visit them in the new home. Their care and concern for the impaired person doesn't stop with placement. The person can still feel this care. Keep in mind, though, that it may be hard for family and friends to visit the nursing home. They may not be able to handle seeing the person in this setting.

The impaired person's disease will progress and the person's powers will keep on dwindling. If you visit the person once in a while rather than daily you may seem to detect rapid or sudden declines in abilities. This is not because the nursing home placement is speeding up the person's decline. Rather, you are now a more distant observer. When you were with the person all the time, you were too involved with your care tasks to notice change. Now that you have "stepped back" the changes may be more noticeable.

Your role with the health care team

Try for a good working relationship with the nursing home staff. Go about this gently and be tactful. Check with the staff to see if there is anything you can do for them when you visit. You may be able to better understand what the impaired person asks for and convey this information to the staff. You may be able to coach the staff in how to understand the person better. Keep in mind that nursing home staffs work on a tight schedule. They may not have time to meet with you every time you visit.

Staff members are professionals and should know their jobs. But if you find a problem in the care the person is receiving, bring this up. If the problem cannot be resolved easily, you may need to go to a staff member's supervisor or to the Administrator. If you become very dissatisfied, you may have to think about moving the person to another home. Discuss this step with your lawyer or financial advisor. You may decide to move the person, but you need to think about the costs involved and the strain it will put on you and the person.

Your life after the move

What your life will be after the person in your care has moved to a new home depends on many factors. The main thing is to see that you do have a life of your own and a right to live it. Think about some of these ideas as you pick up your own life again.

Rest

Before you become very involved in making plans, take some time to rest and recover. Then you will have the strength you need to make and act on your plans later.

Allow time to adjust.

Let your feelings come out and work through them. You almost certainly have a lot of feelings stored up. These may be feelings about the person or about the loss of the person. They may be about the disease or about the fairness or unfairness of life. You may have strong feelings about the help you did or did not receive in caring for the person. A lot of grief, sadness, anger and loneliness can build in caring for a person with a dementing illness. Now that you are no longer providing round-the-clock care, these feelings may hit you quite hard. You may go through a period of grieving, even though the person is still alive. There are resources available to you. Your family and friends, your health care team, counselors and members of the clergy can help you. The Alzheimer's disease and Related Disorders Association can help you to locate a group of other caregivers in your situation. Such a group can provide support and practical suggestions.

Take pride in what you have done

Recognize how much you accomplished with your caregiving efforts. You took on a task for which you were unprepared, a task you would not have willingly chosen. You dealt with and learned to do things you never imagined you'd have to do. Perhaps you kept providing care long after your strength seemed gone. Sometimes people experience guilt when they place someone in a nursing home. If you feel guilty remember to look at all that you did.