

# Placing Your Relative With Dementia in a Nursing Home

This booklet has been created to help ease the stress associated with placing a family member who has dementia in a nursing home; and to provide guidance in such matters as the application process, financial issues, and steps to follow in choosing a facility. Also included is information on selecting nursing homes, and how to establish a good relationship with nursing staff.

*Agencies that can provide assistance specific to your situation are noted in the Appendix.*

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## **MAKING THE PLACEMENT DECISION**

How do you know when it is the "right time" to consider nursing home placement for your relative? You have probably explored all of the options available, such as: home care, day care, respite care, and in some cases, psychiatric and drug therapy. You may have come to the understanding that the person you love is deteriorating. You also realize that your own resources--energy, patience, time and money--are simply not boundless. Perhaps you are concerned about the limited social stimulation and lack of physical activity your relative has at home, or that he may no longer even know whether or not he is at home.

You may have reached a point where nursing home placement seems to be the best or only alternative, but it is quite normal and understandable for you to waver in this decision. After all, the patient may sometimes be lucid, and he may not even be physically disabled. Even if this option can be put off for a while, it is wise nonetheless to plan ahead by beginning to make some preparations now. Know that even if you have made an application and are called to bring the patient to a nursing home, you can always defer placement to another time, and simply request that the patient's name be placed on a list to be called in the future.

If you need help in making this important decision, it is a good idea to involve other family members, close friends, your physician, your clergyman, professional counselors and social agencies. (*See Appendix*).

You will want to have your patient participate in the decision process, whenever possible. If you are a member of a family support group, you will find it helpful to discuss this decision with the group, especially if some of the members have already gone through the placement process. You may want the consultation of qualified family counselors; they do, however, charge for their services.

Keep in mind that while it is virtually impossible to obtain the level of care or the individualized attention the patient has received at home, the quality of care provided by the nursing home should meet the patient's needs and provide the socialization, stimulation, and security not usually available at home.

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## **LEGAL AND FINANCIAL PLANNING**

Ideally, financial planning for dementia patients should begin while the patient is still able to participate and provide information, such as the

location of bank books, stocks, etc. It is also very important to consider having the patient sign a health care proxy or other advanced directives at this time.

Even if you are not considering nursing home placement right now, it is wise to plan for this possibility in the future. It's a good idea to consult a specialist in elder law who can help you with issues such as the management of assets, guardianship, spousal responsibilities, and Medicaid eligibility. **Do not take steps on your own!** (*See Appendix for agencies that can assist you in locating these specialists*).

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## **PAYING FOR THE NURSING HOME**

Nursing home care is very expensive. There are four ways to pay for nursing home care. They are: Medicare, Medicaid, private pay, and long term care insurance.

### **Medicare**

Medicare is the federal health insurance program for older people. It does not provide for nursing home care for dementia patients unless they require highly skilled care and placement is preceded by a hospital admission of at least 3 days. If patients do qualify under Medicare, the maximum coverage period is 100 days a year.

### **Medicaid**

Medicaid is the government program that offers financial assistance to medically needy individuals who meet the required financial criteria. Since the Medicaid nursing home criteria differ from homecare criteria, and from state to state, your relative may qualify for nursing home Medicaid even though he is not eligible for Medicaid at home. Remember that the spouse in the community does not have to become impoverished in order to have the institutionalized spouse qualify for Medicaid.

### **Private Pay**

Currently, the monthly cost of nursing homes in New York City ranges from \$6,000 to \$9,000. When a nursing home resident has exhausted his savings, he will still be able to remain in his facility while Medicaid pays the costs (as long as his income remains limited). It is important to notify the nursing home a few months prior to the depletion of these savings, since the Medicaid application takes time to process.

## **Long Term Care**

Insurance companies now offer nursing home INSURANCE coverage plans. You may want to look into these, keeping in mind issues of affordability and the insurance limitations that apply to dementia.

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## **DETERMINING THE APPROPRIATE CATEGORY OF NURSING HOME CARE**

Nursing home placement evaluations differ from state to state. New York State requires a formal evaluation to be conducted by a specially certified registered nurse to determine the category of nursing home care your relative needs. The evaluation forms used to assess the patient's situation, condition and behavior are the Patient Review Instrument (PRI) and the Screen. The PRI evaluates the patient's medical needs and functional capacity. The Screen additionally evaluates the patient's present environment, and the possible suitability for a non-nursing home alternative. It is advisable to have an evaluation conducted by a neurologist prior to the Screen so that the diagnosis of dementia is formally documented.

Both the PRI and the Screen must be done by a certified assessor.

Call either the Visiting Nurse Association or another certified home health care agency or certified individual to come to the home to evaluate the patient. There is a charge of approximately \$100-\$175 for the PRI and the Screen, which Medicaid will cover, providing the patient is on Medicaid; Medicare does not cover this charge. (*See Appendix for a list of agencies that can help you obtain the PRI and Screen*). In situations where the patient does not need extensive physical assistance, it may be advisable to have the PRI done by a skilled nurse who is especially aware of the needs of patients with dementia. Most of these nurses do not accept Medicaid.

Do not minimize the patient's needs. Nursing homes are reimbursed by Medicaid at a higher rate for sicker patients. The more assistance the patient needs with toileting, eating, and getting up from a bed or chair, the better the chance of being accepted by a nursing home. Therefore, be sure the certified assessor is aware of all the patient's physical limitations, behavior patterns, degree of incontinence, etc. In the event you disagree with the formal assessment, you can always request that a new PRI and Screen also be conducted. If your relative has Medicaid, the second PRI

and Screen will also be covered.

Some nursing homes will not schedule appointments for family visits or send out an application unless the PRI and Screen are completed and reviewed by them. When you receive the completed admission PRI and Screen (usually within two weeks), make several copies, including one to keep for yourself. Call the nursing homes that you are interested in and schedule an appointment to submit the PRI and Screen. It is a good idea to **take** these documents to the facility so that you will have an opportunity to see the home and meet the staff. However, you can call the facility and send the documents by mail or fax. Make sure to get the name of the person you spoke with.

Make a follow-up call to check the status of the application about a week after the nursing home has received your application. When your relative has been accepted and placed on a waiting list, call weekly to check the status of the application.

Both the PRI and the Screen remain in effect for 90 days. If your patient has not been accepted by a facility in this time, the PRI and Screen will have to be completed again to be considered current. (Medicaid will continue to reimburse you for the PRI and Screen). If your relative experiences a marked deterioration in functions that affect his level of care, you should have a new PRI done before the expiration date of the old one.

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## **ENTERING A NURSING HOME FROM THE HOSPITAL**

The placement process varies if your relative enters the nursing home directly from the hospital. While placement from a hospital may be easier than from home, you are likely to lose some control of the process. Remember that you do have rights.

It is essential to advise the hospital social worker or discharge planner as soon as possible after admission of the need for placement. When your patient no longer requires acute hospital care, the PRI and Screen will be completed by the hospital nursing staff. You will be asked to supply the names of at least five nursing homes to which the hospital will then apply. It is important to select carefully since you will be expected to accept the first available bed from among these facilities.

If you refuse the first available bed, the hospital may bill your patient directly for the remainder of the hospital stay. You may also be asked to add additional facilities to the list if the patient is not accepted within the

first few weeks of application. When you find a nursing home that meets your needs, establish a good rapport with the admissions staff and call every few days to inquire about available beds. Do not leave this to the hospital staff. *(See Appendix for agencies that can assist in selecting appropriate nursing homes).*

If your relative is eligible for nursing home Medicaid, the hospital's Patient Accounts department can help you apply. Your cooperation in providing the necessary documentation is essential, since it is doubtful that a nursing home will accept an application without either Medicaid or private funds to pay for care.

If you think your relative is not ready to be discharged from the hospital or is being discharged to an inappropriate facility, there are avenues of appeal. When you receive the written notice of discharge, it will let you know how to ask for review of the discharge decision. This appeal must be made immediately by calling the phone listed on the discharge notice. *(See Appendix for agencies that can assist you).*

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## **FINDING A NURSING HOME**

### **Factors To Consider**

The location of the home should be easily accessible and convenient, since frequent visits help ensure better adjustment and care. Also, consider religious, ethnic and dietary preferences and languages spoken by staff, as well as the patient's particular medical needs. A special dementia unit or program is important if the patient can still benefit from participation in an activity program. In order to avoid exhaustion and confusion, it may be wise to limit your initial search to four or five facilities. Since beds are difficult to secure, particularly for dementia patients, do not settle for just one facility. *(See Appendix for agencies that can help you limit your selection).*

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## **WHAT TO LOOK FOR IN THE NURSING HOME**

Once you have made your decision, call the selected facilities to set up an appointment for a visit. If these facilities haven't already seen the PRI and Screen, bring them with you. It is advisable to bring a family member or friend (not the patient) with you to share observations and offer support. Since the meal time is such an important part of the patient's day, try to schedule your visit so that you can observe a meal being served. During

your visit look for the following:

### **General Concerns**

- Is the facility clean?
- Is there a permeating odor?
- Are the residents groomed and dressed?
- Are the rooms cheerful or depressing?
- Are the majority of residents out of bed?
- Do individual rooms have the resident's personal possessions?
- Are there bathrooms in the individual bedrooms?
- Does the staff seem to be caring? How do they interact with the patients?
- Are there aides in the dayrooms, or are the patients unattended?
- If you observe a meal, does the food look appetizing? Are portions reasonable?
- Are those who need assistance with eating being helped?
- Are there musical or other recreational activities going on?
- Activity schedules are always posted. Ask if you can observe an activity.

### **Special Concerns**

- How do staff members relate to dementia patients?
- Do they speak in clear and simple terms?
- Is the atmosphere geared to dementia patients?
- Are there calendars around or are the day and date posted for reality orientation?
- What security measures are in place? Security is crucial since dementia patients frequently wander.
- Is there a special unit or program for dementia patients?
- Have staff received special training to work with dementia patients?
- Does the home have volunteers assisting staff?
- How do staff members handle agitated patients?
- Is there sufficient room for pacers to walk? Enough space is critical for those who pace a great deal.
- If your relative has been accepted as medically appropriate and the facility has placed him on a waiting list, it is up to you to keep in touch with admitting staff. Call at least every ten days.

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## **PREPARING YOUR RELATIVE FOR PLACEMENT**

Preparing your relative for the move will require sensitivity and strength on the part of the family. There is no tried and true method that works best. In

general, the dementia patient should be told why and where he is moving. Perhaps some discussion about the move prior to admission will have a cumulative effect and help to ease the transition. Also, while it is important to be truthful and clear, reducing feelings of uneasiness and distress should be the priority.

If your relative is being treated by a psychiatrist, notify the doctor that admission is imminent. Discuss the possibility of the doctor making available a mild sedative for use on the day of admission, particularly if you anticipate a very anxious or difficult first day in residence. Be sure to let the nursing home staff know which sedative has been given to the patient that day.

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## **WHAT TO GET DONE PRIOR TO ENTERING THE NURSING HOME**

You may be given very short notice that there is a bed available for your family member. Careful planning and completion of certain tasks prior to admission will make the transition less stressful. Taking the following steps in advance will help:

- Complete the admission agreement prior to the admission date, if at all possible. Read the agreement carefully, or have a lawyer review it. Make sure you fully understand those services for which there may be additional financial responsibility--such as medication, rehabilitation therapy, or specialized medical services. The focus of your relative's arrival and introduction to the facility should be on making him comfortable in this new environment, not on last minute questions about the admission agreement.
- Arrange in advance for time off from work, if possible, for yourself, as well as for other members of the family. Try to make the transition as smooth as possible. Visits by family members familiar to the patient during the first few days are very important.
- Make sure the patient is accompanied to the nursing home by a relative, whether coming from home or from the hospital. Optimally, an additional person should also be present to support the family member.

- Prepare a patient information folder that includes important facts and insights about your relative, such as pertinent medical, nursing, and recent hospitalization data. In a brief "resident profile" you can describe the patient's likes, dislikes, habits, interests, needs, and known behavior problems. List some hints that help distract the patient from inappropriate behavior. Describe the person's strengths, capacities and areas of independent functioning. Some families include a videotape of the dementia patient to show how he functions at home.

Make several copies of the "resident profile" and distribute them to staff members you meet who will be working with your relative. In this way you can introduce yourself to key people, and also ensure safe transmission of relevant information that will help both your relative and the staff during the adjustment.

- Label your relative's belongings prior to admission, including his name and room number. (Some nursing homes prefer to do their own labeling, so ask the facility about this). Because storage space is limited and items are easily lost in any nursing home, especially in the case of dementia, you will want to pack two or three weeks' worth of washable, practical, inexpensive clothing. Do not forget such items as eyeglasses, dentures, and hearing aids; anything that is important and not readily replaced.

Photographs have an important place in the new home. Both displayed in the patient's room and given out to certain staff members, they can be used to help calm, reassure or distract the patient in the event of agitation. Photos of the patient are good to distribute to staff for identification purposes, especially if he tends to wander.

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## **WHEN THE NURSING HOME CALL COMES**

A common reaction to being notified that a bed is now available is to panic and postpone the admission. As noted earlier, the bed can be refused, of course. But consider carefully, since you cannot be assured that another bed will be available when you are ready to follow through. Keep in mind that some facilities permit you to hold or reserve a bed on a private-pay basis for a few days if you need extra time to prepare.

Remember, after placement you can always transfer the patient to another

facility or take him home again. For this reason, it is wise to maintain the patient's prior at-home living arrangements for a few months, if possible. A Medicaid patient may be allowed to retain his apartment for at least three months, provided his physician states in writing the possibility of the patient's return to the community.

You must sign an admissions agreement now that you have accepted the bed and have accompanied your relative to the nursing home. As noted earlier, it is important to take the time to read the admissions agreement carefully before signing, making sure that you fully understand those services for which there may be additional financial responsibility--such as medication, rehabilitation therapy, or specialized medical services.

Take your cue from your relative as to how much time to spend the first day. The patient's mood should dictate the limits of your visit. If your relative is cooperative and not agitated, the first day should be spent settling him into his room, meeting the roommate and key personnel, and possibly attending a recreation program. Concentrate on staying as relaxed as possible, since your mood and attitude will affect your relative. Also take your cues from the staff, who have had a good deal of experience with the adjustment process.

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## **SAYING GOODBYE TO YOUR RELATIVE**

Probably the most difficult part of the day will be when you have to leave, particularly if your relative is anxious, nervous or fearful. You may want to tell him that this is a trial period and it is important to receive the medical care offered at the nursing home. Assure him, of your love and your plans to visit soon. Leave a note with your phone number and ask a staff member to assist him in telephoning later. If possible, you may want to mark on a calendar the date you next plan to visit.

Be confident you have done your best for the well-being of your relative. Most new patients in a nursing home require a period of adjustment of a few months, but do eventually adjust. Many actually do better in a structured environment that provides more socialization than at home. Often, the patient may regress initially because of the trauma of placement, but will acclimate after a while. As the patient becomes more familiar with his surroundings, he may actually accept the nursing home as his residence.

You, the family caregiver, also need time to adjust to changes in your role, as you are no longer the day-to-day care provider. You may experience feelings of ambivalence. On one hand, you may feel relieved (or guilty

about feeling relieved) about giving up the physical care of your relative. On the other, you may feel that no one can take care of your relative as well as you. Be assured that you have not relinquished your role as a significant caregiver. There are many ways you can continue to have an impact on the care of the patient.

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## **NOW THAT YOUR RELATIVE IS IN THE NURSING HOME**

### **Advocating For Your Relative**

It is the family's responsibility to speak on behalf of the patient, A dementia patient cannot competently speak for himself. When you advocate, keep in mind that a courteous and appropriate manner is the most effective. It is best to appoint one member of the family as the spokesperson.

If you are unsuccessful in arriving at agreement on issues and concerns, you can follow the grievance procedures developed by the facility. In the event you cannot get satisfaction from the facility itself, you can turn to other resources (*see Appendix*). Many facilities have a family support group or family council. These are usually excellent outlets for making your involvement more meaningful, and for sharing your concerns with others who may be dealing with similar issues.

### **Ways To Continue Easing The Transition For Your Relative**

By spending time with your relative during the first days, your family can help lessen possible feelings of abandonment.

Some facilities assign special staff to facilitate this adjustment, while others suggest that the family arrange for a companion or private aide. Clearly the private aide can provide extra attention and can assist in orienting the patient to a new and sometimes overwhelming environment. Hiring a private companion, however, can be expensive, and in some cases might delay your relative's adjustment to the facility. Also, it is possible that the nursing home staff may not fully participate in the care of your relative, since they may assume that the private companion is taking care of your relative's needs. Since there are advantages as well as disadvantages to hiring a private companion, trust your own judgment in this matter.

Spend the first few days introducing yourself and creating relationships with floor staff, the social worker, who is an important liaison to other disciplines and services, and with your relative's roommate and family. All these people will have an impact on your relative and how he accustoms

himself to this new environment.

Establish a rapport with key members of the facility. Establishing respectful relationships with the staff from the outset will go a long way toward enhancing not only your visits there, but your relative's adjustment. Within the first few weeks of admission, you will be invited to meet with the physician, head nurse, nurse's aide, social worker, recreation staff, dietician and rehabilitation staff at a **patient care conference**. It is critical for you to attend this meeting. Staff will discuss your relative's needs and form a care plan. It is very important for you to provide as much information as possible about your relative's likes, dislikes, daily routine, special abilities and talents. Where appropriate, the patient should also be at the meeting. You will continue to be invited to attend follow-up patient care conferences.

If staff are not available in a team setting, request individual meetings with key members. Be sure to prepare a list of your questions and concerns in advance--such as your relative's care plan, residents' rights, grievance procedures, and the like.

### **Understanding Your Relative's Medication**

Let staff know you must be notified **prior** to all medication changes, as nursing homes may use medication to control such patient behavior as agitation, wandering, verbal or physical disruption, etc. Make the appropriate staff (physician, psychiatrist, nurse, social worker) aware, preferably in writing, that you require this notification, particularly with the use of psychotropic drugs (medication that has an altering effect on the mind). If the medical staff recommends a medication with which you are not familiar, you have the right to ask for an explanation of its purpose, dosage, and possible side effects.

### **In The Event Of Your Relative's Hospitalization**

You are entitled to be informed immediately if your relative requires hospitalization, whether it is planned for ahead of time or is an emergency. Hospitalization can be extremely traumatic, especially for a dementia patient. It is also your right to accompany your relative to the hospital to relieve some anxiety. It is possible that the hospital may require physically restraining a confused or wandering patient. As an advocate for your relative, you may want to spend some time at the hospital. If this is not possible, you could arrange for a private companion to assist the patient. If Medicaid is paying for your relative's nursing home stay, the patient's bed in the home can be held for up to 20 days.

## When To Visit Your Relative

Try to schedule your visits for the benefit of your relative, keeping in mind that each facility determines specific hours for visits. For instance, if your relative needs help with eating, encouragement to join in activities, help with transportation off the floor, or is agitated at certain times of the day, plan your visits, where possible, around these events.

Ask what areas of assistance you are permitted to give your relative, such as the above-mentioned situations, as well as walking, toileting, and going outdoors. These efforts can contribute significantly to your relative's overall state of well-being, particularly if specific friends and relatives visit often.

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## IN CONCLUSION

Placing your relative with dementia in a nursing home is a major step for the whole family. Keep in mind that a great deal of the stress you are feeling is normal, and that you have reached a point where your relative undoubtedly will receive more help for his condition now that he is in a nursing home. You have not, by any means, surrendered the care of your patient. In fact, as this guide has outlined, there is a great range of activities you can and should undertake to ensure that the transition process is as comfortable and comforting as possible for your relative.

If you are personally experiencing difficulty with the transition, do not hesitate to meet with the nursing home social worker or consult with the agencies listed in this publication that assist with nursing home placement, to help you work toward a more positive adjustment. Share this transition with family members, with support groups and with health professionals, if necessary. And please remember to **stay well**, since **your** physical and mental well-being should be a first consideration.

If you have further questions, you may want to consult one of the agencies listed in the Appendix, or call:

The New York City Department for the Aging  
Alzheimer's and Long Term Care Resource Center  
2 Lafayette Street, Room 727  
New York, N.Y. 10007  
(212) 442-3086/442-3092

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## APPENDIX

### Selected Agencies

#### A. Agencies that assist with nursing home placement

The following agencies offer information and assistance to individuals faced with nursing home placement. Assistance is given with a variety of concerns, including how to finance nursing home care, evaluating the nursing home needs of the patient, the level of care required, and choosing the appropriate facility.

New York City Department for the Aging  
Alzheimer's and Long Term Care Resource Center  
2 Lafayette Street, Room 727  
New York, N.Y. 10007  
(212) 442-3092/442-3086

Alzheimer's Association  
New York City Chapter  
420 Lexington Avenue, Suite 610  
New York, N.Y. 10170  
(212) 983-0700

Friends and Relatives of the Institutionalized Aged  
11 John Street, Suite 601  
New York, NY 10038  
(212) 732-4455

New York City Human Resources Administration  
Medicaid Long Term Care Unit  
330 West 34th Street  
New York, N.Y. 10001  
(212) 630-1292/630-1241  
*(HRA assists with Medicaid-related issues only)*

#### B. Agencies that assist following placement

These agencies assist residents and families who have questions regarding regulations or have complaints and concerns about the care received.

New York City Department for the Aging  
Alzheimer's and Long Term Care Resource Center  
(212) 442-3092

*(see address above)*

Alzheimer's Association  
New York City Chapter  
(212) 983-0700  
*(see address above)*

Friends and Relatives of the Institutionalized Aged  
(212) 732-4455  
*(see address above)*

New York City  
Sub State Long Term Care Ombudsman Program  
150 Nassau Street, Suite 2919  
New York, N.Y. 10038  
(212) 962-7817

New York State Department of Health  
Patient Care Investigations  
5 Penn Plaza  
New York, N.Y. 10001-1803  
(212) 613-4707

### **C. Agencies that provide help with issues of Alzheimer's disease**

These agencies provide information and assistance in such matters as helpful strategies for caregivers, diagnostic evaluations, legal and financial issues, support groups, and community options (e.g. home care and day care programs), and other relevant issues.

New York City Department for the Aging  
Alzheimer's and Long Term Care Resource Center  
(212) 442-3086  
*(see address above)*

Alzheimer's Association  
New York City Chapter  
(212) 983-0700  
*(see address above)*

Alzheimer's Association  
Staten Island Chapter  
460 Brielle Avenue  
Staten Island, N.Y. 10314  
(718) 667-7110

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