

1 BEFORE YOUR MOTHER ENTERS THE NURSING HOME

PART ONE

Helping your mother get the most out of her nursing home stay is a job that starts before she enters the home. If she is moving into the home because of some kind of medical or personal crisis, you may not have the time to do all the things we talk about in this chapter. But do take the time to read it, and then use your best judgment about what you are able to do. Read this chapter even if your mother has already moved into the nursing home: it almost certainly will give you information you do not now have and should know.

1. Make a list.

Before your mother enters the nursing home, make a list of her immediate needs, even those you think are obvious. Although the staff will do formal assessments¹ **after** your mother moves in, there are some things that you know best, or that have to be taken care of from the very first day.

Your list should include:

- if she has difficulty seeing, hearing or communicating, and any devices she uses to help her see, hear or communicate;
- if she has an injury, wound, or contagious disease;
- all medicine she is taking, including prescription drugs and over-the-counter drugs;
- if she has a surgical dressing or other wound covering, a cast, a catheter, a feeding tube, or a prosthesis;
- if she uses special stockings (such as “ted hose”), padding, or devices to prevent muscle contraction or the development of bedsores (**pressure sores**), including an eggcrate mattress or other special bed;
- what kind of help, if any, she needs to walk;
- if she uses a wheelchair, walker or cane; if she does use a wheelchair, if she needs help moving it;
- what help, if any, she needs in moving (the nursing home jargon is “transferring”) to or from her bed/wheelchair/chair/toilet, including if she uses special equipment;
- if she has osteoporosis or any other disease, injury or wound that requires particular care during a transfer;
- if she needs help eating or drinking, or has difficulty swallowing;
- if she has any food allergies or strong food preferences or dislikes, or she has a special diet;
- if she has any other allergies, including to any medicine;
- if she has any habits, likes or dislikes which should affect the choice of a room or a roommate. This includes if she likes to wake up early or go to bed late, or stay in bed listening to the radio or watching television;
- if she has any personal habits which may be a safety hazard to herself or others. These may include “wandering,” which is common in persons in the early stages of Alzheimer’s disease and other kinds of dementia, and smoking habits such as smoking in bed or dropping lit cigarette butts on the floor or on herself.

Before your mother enters the nursing home, make a list of her immediate needs.

2. Talk to the nursing home staff.

If you can, bring your list with you to the nursing home before your mother moves in. Go over your list with the **Director of Nursing** before your mother enters the home, so the staff can be prepared for her admission.

Ask the Director of Nursing what needs to be done to make sure the kitchen staff will meet your mother's special dietary needs as soon as she moves in.

Ask the Director of Nursing what your mother should bring with her when she first moves in.

Also ask her what your mother should bring with her when she first moves in. You should ask, for example, if the facility supplies continence supplies, basic toiletries such as shampoo and toothpaste, and a container to soak dentures, and if there is a separate charge for these supplies. (If your mother's care will be paid for by Medicaid, these items must be supplied by the nursing home at no additional charge to your mother.) If your mother needs a wheelchair or other special equipment, and is not bringing her own, make sure what she needs will be there for her, or is being ordered immediately.

The Director of Nursing in most nursing homes is an administrator who does little hands-on care. The people actually taking care of residents are professional nurses and **CNAs (certified nursing assistants)** assigned to each unit or floor. A "charge nurse" will be responsible for supervising the nursing staff on each shift, on each floor or unit. The person who will do most of your mother's daily care will be a CNA.

Try to meet the charge nurse and your mother's CNA before your mother moves in. If they have time to talk to you about your mother, do so. If they are too busy, at least you will know who you need to talk to on the day she enters. Ask the CNA what days (s)he usually works.

A note of caution about nursing home staffing:

Because nursing homes are increasingly understaffed and nursing home staff are overworked, you cannot be sure that your mother will have the same nurse or CNA from day to day. It is now common practice for nursing staff to be pulled from their usual assignment to work on another unit of the facility. Only "Alzheimer's units" or "dementia units" are required to have the same staff consistently assigned to care for their residents.

Many nursing homes rely on "agency staff" to fill their staffing needs. "Agency staff" work for a private nursing agency, not the nursing home. They usually are paid more than the regular staff, have no benefits, and get to pick their days and hours. Some agency staff work only part-time; others are employed full-time by one nursing home, and work additional hours elsewhere as agency staff. While agency staff get to pick their own shifts, the nursing home's own employees may not be able to choose the shifts they work, or may be working double shifts. Combined with low pay (rarely more than a few dollars over minimum wage, if that), and the physical and emotional stress, it is not surprising that the average CNA in Illinois stays in one job for less than a year.

Nursing homes in the Medicare or Medicaid programs are required to post the names of the staff who are actually taking care of their residents at any given time. They are also required to keep these records for two years, and show them to you if you ask.

It is dispiriting and confusing to residents to be cared for by people they do not know and who do not know them. It can also be dangerous. Residents may not get necessary care or may get the wrong care (including the wrong medication) if the staff do not know who they are or who is supposed to get what. Staff who are not familiar with their residents, may not recognize when a resident's condition deteriorates, or even know how to communicate with their residents. Even regular staff may be too tired or overworked to take proper care of their residents. **You must always be vigilant that your mother's health is monitored and her needs met. You can never assume that the staff will pay the kind of attention to your mother that she needs.**

3. Ask about filling prescriptions.

If you want the nursing home staff to fill your mother's prescriptions, ask the Director of Nursing how long it takes to get prescriptions filled, so you will know how much medication your mother should bring with her. If you want to fill her prescriptions yourself, tell this to the Director of Nursing; some nursing homes want residents to use a particular pharmacy. Some will not let families fill prescriptions.

It is becoming more common for nursing homes to require that drugs be bought in "single unit dosage." This is a kind of packaging in which the pharmacy wraps each dose of medication separately. Single unit dosage packaging is very expensive: you can pay more for the packaging than for the drug inside it. It is also probably safer, since it makes it harder for the staff to make mistakes in measuring how much medication your mother should be getting.

We don't know what effect the new Medicare prescription drug coverage will have on nursing home drug policies.

4. Get the residents' rights statement.

Nursing homes are required to give all new residents and their families a copy of a statement of residents' rights from the Illinois Department on Aging. If you do not already have a copy of the statement, ask the **administrator** for it. Read it.

5. Get "transfer orders" from your mother's doctor.

When your mother enters the nursing home, she will need orders from a doctor saying what kind of care she needs. Even if her current doctor will not continue to treat your mother after she enters the nursing home, this doctor should write "transfer orders." Transfer orders tell the nursing home staff how to take care of your mother until her doctor at the nursing home writes new orders.

Talk to her current doctor before (s)he writes the transfer orders. Make sure the list you have made of your mother's immediate needs matches the orders (s)he writes. A nursing home is required to follow any lawful doctor's orders, so having detailed orders makes it more likely your mother will get the care she needs. Detailed transfer orders are especially useful if your mother will be getting a new doctor who does not know her.

Nursing homes are required to give all new residents and their families a copy of a statement of residents' rights from the Illinois Department on Aging.

Transfer orders should include:

- your mother's medications and required medical treatments. This should include everything the staff needs to know about wound care, medication monitoring, monitoring of blood levels (such as blood sugar levels), and how often your mother should be turned to prevent skin breakdown. If she takes any over-the-counter medicines, vitamins, or dietary supplements which she needs the staff to give her, these should be included in the orders. (Even if she does not need the staff to help her with these, make sure the doctor knows she is taking them);
- any special dietary restrictions or requirements;
- therapies (physical, occupational, and speech) including what exercises she should be doing, how often, and what help she needs doing them. If your mother needs help walking, the orders should say what kind of help she needs, and how often she should practice walking;
- the extent to which she is able to participate in activities, even if she must stay in bed. The doctor can even order that she participate in certain activities right away;
- when she should return to the hospital or be seen by a particular medical professional for follow-up care.

It is important that your mother be as much a part of the decision-making process as possible.

Get a copy of the orders her doctor writes. Bring them with you when your mother moves in.

6. Talk to your mother.

Most nursing home residents these days enter the home directly from the hospital. Often the process for selecting the home is rushed — you may have been given only one or two days to find a facility — and the new nursing home resident will have taken no part in the selection process.

Whether she is going in for what you expect will be a relatively short period of physical rehabilitation, as a permanent move, or anything in between, it is important that your mother be as much a part of the decision-making process as possible. It is important that she understand as much as possible of what is happening. If she needs therapy to relearn certain skills (such as walking or eating) before she can go home, do your best to explain this to her. Wanting to go home can be the most powerful motivation your mother has to work hard at getting stronger and more independent.

If you do not know if your mother will be able to go home again, do not try to fool her by promising her otherwise. Of course you want to be optimistic and encouraging, but if you make promises you cannot keep, your mother may feel you have betrayed her, and not believe anything you tell her about her situation. You can emphasize the kinds of physical skills you hope she will be able to get back, the help with everyday tasks and the medical care that she cannot get where she lives now, and the possibility of increased social contact with other people. It may also reassure her to know particular details about the nursing home, such as that there are daily religious services, or a garden, or that you can bring the family pet for visits. It is possible to talk about this without denying the fear or sadness you both feel.

7. Your mother should consider making a “durable power-of-attorney for health care.”

If your mother is competent — that is, if she understands the meaning of her actions — she should consider creating a “durable power-of-attorney for health care.” This means she authorizes somebody to make health care decisions for her if she cannot. The health care power-of-attorney could make decisions about her health care if, for example, she becomes too confused to understand what her choices are, or is too physically sick to make her own decisions.

A health care power-of-attorney is not the same as a “regular” power-of-attorney, which gives authority to deal only with financial matters. It is not the same as a “living will,” which gives instructions only about what to do when someone is dying.

If your mother does not appoint a health care power-of-attorney, and her doctor certifies that she is not capable of directing her own medical care, Illinois law recognizes a list of people (beginning with parent or spouse, and ending with friend) who can legally make health care decisions for her as her “health care surrogate.” This list may not reflect what your mother wants. The law does not decide problems such as what happens if people with equal rights on the list — adult children or siblings, for example — cannot agree on a decision. And a health care surrogate has more limited authority than does a health care power-of-attorney. For these reasons, instead of relying on the list in the Illinois law, it is usually a good idea to formally appoint a health care power-of-attorney. (This means you should have one, too. But that’s not our subject here.)

You can get a simple health care power-of-attorney form from any hospital or nursing home, and in many office supply or stationery stores. ICBC publishes a version of the standard form in large print, with suggestions about how to fill it out to best reflect your mother’s wishes, and room for any special instructions she may want to include. No matter what form you use, you must take whatever time your mother needs to make sure she understands what her choices are, and what she is signing. If there is any doubt about her ability to understand what she is signing, either tape the procedure, or have somebody impartial witness it. The hospital social worker, her priest, her neighbor: any of these would be fine.

Because it may reinforce your mother’s fear that she is entering a nursing home to die, you may not want to bring up this subject now. Even if you don’t, however, the nursing home staff will: nursing homes in the **Medicaid** or **Medicare** programs are required to ask the new resident about whether she has a health care power-of-attorney, or wants to have one, as part of the admissions process. Depending on how your mother reacts to this discussion, it may be a good idea to create a durable power relatively soon, or to wait until she is less afraid.

But remember: you can’t predict a medical emergency, so the sooner the health care power-of-attorney form is signed, the better. If your mother changes her mind about what she wants, she can always change the document, so long as she understands what she is doing. If she changes her mind about who she wants to be her health care power-of-attorney, she can revoke the document even if she no longer is competent to make a new one.

You can get a simple health care power-of-attorney form from an hospital or nursing home and in many office supply or stationery stores.

8. Make sure you can get information about your mother's health and health care.

Legally, unless a court has said she is incompetent, or her doctor has certified in writing that she is not capable of directing her own care, all decisions about your mother's medical care are hers, not yours. But as a practical matter, even if she is competent, she is likely to need you to get information, explain things to her, and sometimes act for her. For this reason it would be a good idea for your mother to give you authority to get information from the nursing home staff about her health and her health care. You should also be able to review her nursing home records whenever you want. (If you are your mother's guardian, or are already acting as your mother's health care decision maker because she cannot make health care decisions for herself, you automatically have the right to get this information and see her records. You can also authorize other people to get information and see records.)

Every nursing home resident is required to have a doctor who is responsible for her care.

A federal privacy law (HIPAA, the Health Insurance Portability and Accountability Act) now tells nursing homes what a resident should sign to give someone permission to get health care information, and see and copy the resident's records.

APPENDIX FOUR to this guide is a form your mother can sign to give you permission to see and copy her nursing home records.

If your mother wants more than one person to have access to her medical records, you can handle it two ways. She can list every person she wants to have access to the information, on the authorization form. Or she can authorize you (and anybody else) to tell the nursing home who can get this information. To do it this way, add these sentences to the authorization:

I also authorize _(name)_ to give permission to any person(s) [s]he deems appropriate, to get information about my health and my health care, and to examine and copy records of my care at ___ Nursing Home. I instruct the nursing home and my other health care providers to provide this information when so instructed by _(name)_.

9. Choose a doctor.

Every nursing home resident is required to have a doctor who is responsible for her care. A resident may choose any doctor she wants who is willing to treat her, and who is willing to comply with such minimum requirements as being willing to examine her when necessary, communicate orders to the nursing staff, and provide a phone number to call both during regular working hours and in an emergency. If your mother's doctor is willing to meet these requirements, the nursing home must let your mother keep him/her as her doctor, even if the doctor has no other patients in the facility. If her current doctor does not make nursing home visits — and most do not — she will need to have a new doctor who is willing to visit and treat her.

Nursing homes have lists of doctors they recommend to residents and their families. Some of these doctors may have a financial relationship with the facility (such as being **medical director**, a paid member of the board of directors, or an owner), which may affect how insistent they are with facility staff that their patients get good

care. You can ask a doctor to whom the nursing home refers you, what his/her relationship is with the nursing home.

Get whatever information you can about your possible choices before picking one. See if the nursing home is willing to give you the names of some of each doctor's other patients in the facility, and talk to them. Or ask for the names and phone numbers of their relatives. Ask about how easy their doctor is to reach, how quickly (s)he responds in an emergency, and how willing (s)he is to listen, share information, and intervene with facility staff to correct problems. It is perfectly all right to discuss this subject with the families of other residents while you are visiting the nursing home. You can also ask the nursing staff about each doctor. Ask how quickly each returns phone calls, especially in an emergency.

If you can meet the doctor before your mother enters the facility, you should read **CHAPTER 5**. Discuss the issues we raise there with him or her before making a decision. Remember: you are not locked into keeping any doctor forever. Although it may be awkward, your mother can change doctors any time she wants to. If you are not satisfied with you mother's care and cannot find any other doctor, the medical director of the facility is required to be her doctor.

10. Start keeping a notebook.

Set aside a notebook to keep track of what happens while your mother is in the nursing home. So many things are likely to be happening, especially in the beginning, that you may forget what people have said or done, or what you want them to do, unless you write it down. Also, if your mother ever has problems with her care, you will want to have a written record of everything that happens.

***Bring your notebook
whenever you visit
your mother.***

Some things you should be writing down in the notebook:

- conversations in person or on the phone, that you have with her doctor and the nursing home staff;
- things you want to talk about with her doctor or the nursing home staff;
- conversations you have with your mother that indicate there are problems with her care;
- conversations you have with other people that indicate there are problems with her care;
- observations you make about your mother's physical or mental condition.

Bring your notebook whenever you visit your mother. Write down what you see or do or talk about as soon as possible after they happen. Write the date of every entry. You probably should not make entries in your notebook in front of the nursing home staff: it may make them uncomfortable and suspicious.

¹ **CHAPTER 6** describes the assessments nursing homes are required to do of their residents.