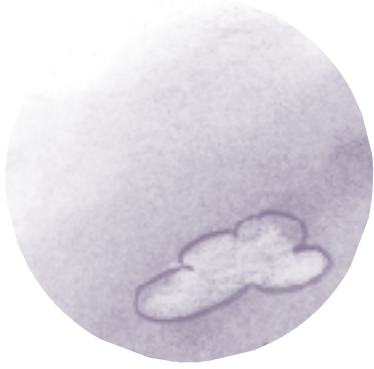


"Taking notes has always helped me control panic, and taking notes shows doctors that you are paying attention, that their time is not wasted in explanation. The prime reason for taking notes, however, is simply to have an accurate record of what was said during what is so often a tense and hurried meeting. You will want to think about what was said, you will want to discuss it with others, perhaps including other doctors. You will be hearing words you don't understand, that you may want to look up later in a medical dictionary. Those notes will be the foundation on which you will build your own understanding of what is happening, that basis on which your decisions about your life, or the life of the person you are caring for, will be made. Some people even tape-record medical conversations, which is even better."

- Adapted from *In The Country of Illness*  
by Robert Lipsyte

# NAVIGATING "THE SYSTEM"





As a family caregiver, you play a major role in your loved one's medical care. This means that you may be involved in making serious medical decisions, performing medical procedures, managing medication, monitoring the patient's health status, and reporting symptoms or health concerns to the health care team. These are important responsibilities, which can seem overwhelming if you feel as if you are managing things on your own. This chapter is about communicating more effectively with health care professionals. Effective communication can help you to:

- n Understand the patient's illness/disability
- n Know what needs to be done to attend to the patient's medical needs at home
- n Get the most out of your office visits/appointments with health care professionals
- n Recognize when to call the doctor/health care professional

## Who Do I Call?

At any given time, there may be a variety of people involved in your loved one's medical care. Depending upon the diagnosis, there may even be a number of doctors from different areas of medicine (specialists) working with you and the patient. With so many people, you may feel confused and unsure about who to ask for help. Some health care professionals may be better equipped than others to give you information or answers to your questions. It is important for you to know the appropriate person to speak to, depending upon the help you need. At the time of the office visit or hospital discharge, ask the doctor who to call if you have questions. Also make sure that you are familiar with each member of the health care team involved in the patient's care.

## Questions to Ask the Doctor:

- s What days/hours is the office open?
- s How are medical emergencies handled?
- s When is the best time to reach the doctor by phone, fax, or email?
- s Which method of communication does the doctor prefer?
- s Who can answer questions if the doctor is not available?
- s Who can you call after hours or when the doctor is away?
- s Who will have an up-to-date copy of the patient's file, including information about his/her condition, treatment plan, and medications?

## Members Of The Health Care Team

### Attending Physician (MD)

The supervising doctor who dictates the patient's care. The attending may be the patient's general practitioner, or he/she may be a specialist in areas such as cancer, pain, or cardiology (heart disease).

### Fellow (MD)

A doctor who has finished residency training, but is continuing training in a subspecialty. These doctors are assigned to work closely with the attending physician.

### Resident (MD)

A doctor who is training in a specialized area of medicine for 3 to 5 years. These are the doctors whom you will see most on the hospital floors.

### Medical Student

An individual who is still in the process of completing 4 years of medical school to become a doctor.

### Physician Assistant (PA)

A professional with special training that allows him/her to assist the doctor by performing medical procedures, ordering medications and tests, and communicating with patients.

### Registered Nurse (RN)

A member of the health care team who assists physicians by doing health assessments and advising patients on such things as diet and lifestyle. Nurses also perform clinical procedures, such as wound dressings and injections, administering medications and treatments, and teaching patients and caregivers how to continue medical care at home.

### Nurse Practitioner (RN, NP)

A nurse with 2 to 4 more years of education and training than an RN, which enables him/her to diagnose complaints, order tests, plan treatments, and prescribe medications (in some states).

### Social Worker (MSW, CSW, ACSW)

A member of the health care team who is trained to assess patient/caregiver needs and resources, produce a care plan, give guidance, help coordinate services, and provide counseling.

### Physical Therapist (PT)

An individual who is licensed by the state and is educated in identifying, preventing, and correcting problems with the muscles, bones, and nerves by physically manipulating affected areas.

### Occupational Therapist (OT)

An individual who is educated in helping patients retrain their bodies or minds, and modify living/working arrangements to perform tasks in new ways when recovering from an injury or illness.

### Psychologist (PhD)

An individual with specialized training in the psychological, emotional, and behavioral aspects of illness and patient care. Psychologists can specialize in different areas.

### Chaplain

An individual who is trained to provide religious and/or spiritual support to patients, their families and their loved ones.

### Patient Representative/Advocate

A staff member of the hospital who tries to resolve patient complaints about the quality of hospital care, or hospital policies and procedures.

### Hospital Administrator

A staff member of the hospital who knows the hospital policies and standards, and resolves financial, operational, and personnel issues.

On the next page, list all the members of the patient's health care team and their specialties. Make sure to write down their phone numbers and attach any business cards you have.





### **What to do if you have a complaint:**

If you are not satisfied with your loved one's care or have a complaint, there are strategies for resolving the situation. Though your feelings of anger or frustration may be warranted, it will not help matters for you to vent these emotions to the wrong person or in an improper way. You should try to go through the appropriate channels and allow the hospital and staff to take care of the problem.

In order to most effectively lodge a complaint, follow the **hospital chain of command**:

- 1 Speak to **the person you are dissatisfied with** and give him/her a chance to respond. Many times problems arise out of miscommunications that can easily be cleared up.
- 2 If that result is not satisfactory, you should contact **the primary nurse or doctor** of the patient and make them aware of the situation.

3 If the situation is still not improved or you are not satisfied with the result, the **patient representative** should be notified.

4 Finally, if the problem is still not corrected, you can report the problem to the **hospital administrator**.

(adapted from McFarlane & Bashe, 1998)

### **When Do I Call?**

You can call any member of the health care team at any point in your loved one's illness, treatment, and its aftermath. Doctors are very busy and often do not have a lot of time for answering questions over the phone. If you have basic questions about the care of your loved one, it may be best to call the nurse or physician assistant. They usually have more time to help you and can look up information in the patient's chart or consult with the doctor. However, if you have concerns about larger issues, you should not hesitate to ask for the doctor. For example, you should speak to the doctor when:

- n You would like to discuss the patient's diagnosis
- n There is a change in the patient's prognosis
- n You are concerned about a new symptom
- n A new medication is not working or is causing negative side effects
- n You want to find out about or discuss test results
- n You think you need a referral for home nursing care



### Timing is everything

- n Call in the morning and ask the secretary when the best time is to reach the doctor, then call back at that time.
- n Leave a message with the secretary in the morning for the doctor to return your call. Provide the secretary or answering service with all numbers where you can be reached at certain times, and make sure you are there at those times. This includes home, work, car phone, beeper or cellular phone.
- n Some doctors have specific hours when they take calls. Find out when this is, and call during those times.

#### Other options:

- s If you have basic questions, and have access to e-mail, ask if you can send the doctor an e-mail.
- s Write down your questions and concerns and ask the doctor at the patient's next appointment.
- s See if you can get answers to your questions through other means, such as books, pamphlets, or the Internet.

### What Do I Say?

#### Tips for good communication with health care professionals

- n Be prepared before calling.
- n Write down your questions.
- n Know exactly what information you need to know and why.
- n Make sure that your questions are clear and specific.
- n Be concise and stick to the issues.
- n If you don't understand something, don't be embarrassed to ask for a second explanation.
- n Repeat what was said to make sure that you understand what he/she told you.
- n Take notes or tape record doctor appointments so that you remember what was said.

#### Troubleshooting: What to do if...

##### There is a situation that you think might be an emergency:

- n Call 911 immediately if you are sure that the situation is an emergency.
- n If you are not sure, call the doctor or the emergency room until you reach someone you can talk to.
- n Make sure you tell the person that you think the situation might be an emergency.
- n Use the word "emergency" when explaining the situation.
- n Do not hang up until you have the information you need to help your loved one.

##### What you might say:

"I may have an emergency and need to speak to a doctor."

"I am concerned about [patient] and am not sure if this is an emergency. Can you help me?"



### A nurse/physician assistant returns your call but you would like to talk to the doctor:

- n Thank the nurse for getting back to you.
- n If you are certain that the nurse cannot answer your question, explain that you would like to speak to the doctor.
- n Explain why you would like to speak directly with the doctor.

### The doctor does not return your call:

- n Do not assume the worst. The doctor may be out of town or unavailable at the time.
- n Call the office secretary and ask when the doctor will be available so you can call back.
- n Leave a message with the office secretary stating that you really must speak with the doctor as soon as possible.
- n Be clear about what the problem is and why you need to talk to the doctor

#### What you might say:

"I am worried about [patient]'s condition and would really like to discuss the diagnosis with the doctor."

"Will he/she be available to talk to me today?"

"What time do you think he/she will be able to talk to me?"

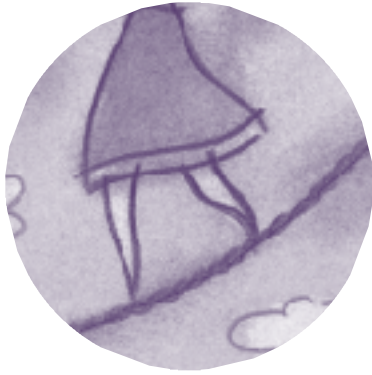
"May I leave a message for him/her to call me back at that time?"

-OR-

"Thank you, I will call back then."

#### What you might say:

"I really appreciate your getting back to me. However, I am very concerned about [patient] and need/want to speak to the doctor directly. When will he/she be available to speak to me?"



## Medical Emergencies

When caring for someone who is ill, it is vital to know how to handle a medical emergency. Though it is possible to avoid many medical emergencies by closely observing the patient for health changes, calling the doctor for advice, and keeping the home safe, emergencies can still arise. Having a plan to follow will help you remain calm if an emergency does occur. It can also aid those who assist you in caring for the patient when you are not at home.

### Post emergency information:

To start, fill out the Emergency Information form at the end of this section to organize and consolidate important emergency information.

Make sure that you list contact numbers, including the patient's doctors and other members of the health care team. This information should be photocopied and put in places that are easily accessible, such as next to the telephone and on the refrigerator.

### Know when to call for an ambulance

There are certain instances in which recognizing an emergency and calling 911 can save a person's life. However, since ambulance service can be extremely expensive when not covered by insurance, it is important to know exactly when it is necessary. Always call for an ambulance if a person...

- n is unconscious
- n has chest pain or pressure
- n has trouble breathing or is not breathing
- n has no pulse
- n is bleeding severely
- n is vomiting blood or is bleeding from the rectum
- n has fallen and may have broken bones
- n has had a seizure
- n has a severe headache and slurred speech
- n has pressure or severe pain in the abdomen that does not go away
  - OR –
- n moving the person could cause further injury
- n traffic or distance would cause a life-threatening delay in getting to the hospital
- n the person is too heavy for you to lift or help

If you know CPR or other emergency procedures, you should call for an ambulance before doing anything else. Once you make the call, you can care for the patient until help arrives.

(Adapted from Meyer, et al., 1998)

## **Going to the Emergency Room (ER)**

Most people try to avoid going to the ER at all costs. This is usually based on past negative experiences with the ER. However, there are times when the patient's need for care is urgent, and you must take him/her to the emergency room. Though such a visit is rarely a pleasant experience, there are some things that you can do to make going the ER more satisfying.

- n If you think that the patient's condition may lead you to the ER, pack a bag in advance so that you are ready to go if/when the time comes.
- n Make sure you are familiar with the patient's medical history, in case the patient cannot speak for him/herself. Keep a list of important information, such as past health problems, allergies, and current medications and dosages (a "Medication Schedule" is provided at the end of this section).
- n Be able to describe exactly what the patient's problem is, when it started, what may have caused it, and if the patient was given any medication or other treatments.
- n Know the patient's legal rights and responsibilities while in the hospital. "A Patient's Bill of Rights" is a document developed by the American Hospital Association outlining the patient's rights regarding health care and appropriate treatment from staff within the hospital (see page 17 for a copy of "A Patient's Bill of Rights").
- n Use good communication skills. Though the ER can be a frustrating place, it will not serve you well to take your anger out on the staff. Try to be understanding and patient, while being assertive. To do this, follow these tips for better communication:
  - Don't be afraid to speak up if you feel that the patient's rights are being violated or if you are not satisfied with the patient's care.
  - Tell the health care professional about your dissatisfaction with care in a direct way that is not demanding or disrespectful.
  - Speak in a way that does not put the health care professional on the defensive. When talking, use "I" statements, such as, "I don't like that my mother is in so much pain," rather than, "Why won't you do something about my mother's pain?" This sounds less accusatory, and expresses how you are feeling to the other person.
  - Be clear about what you and/or the patient need in order to feel comfortable and content with the care.
  - Listen carefully to what the health care professional has to say and ask for clarification to make sure that you fully understand what is being said before responding.
  - Be sensitive to the health care professional's limitations in his/her ability to help you and the patient. ER staff members are usually very busy, over-worked and tired. Don't assume that they are just unpleasant or unwilling to help.
- n For patients who go to the ER frequently (e.g. sufferers of sickle cell disease), try to develop good relationships with familiar ER staff members. If you are friendly and treat them with respect, you are more likely to receive the same treatment in return.

n Know the ER chain of command. If you are not happy with the care the patient is receiving or if there is a problem with a particular staff member, identify the appropriate person to speak to. There is a nurse manager who oversees the nurses and a chief physician who supervises the residents and other physicians. You should speak to one of these two people for problems with staff on the floor. If you still are not satisfied with the patient's care, you can always make a complaint to the hospital patient representative or administrator (see page 8 for a list of hospital staff).

### **Learn first aid and basic emergency procedures**

If you are not familiar with CPR or other emergency procedures, and would like to learn, you can take a course from the American Red Cross. The following are some basic tips about first aid and emergencies. You should always call 911 or an ambulance before performing CPR or first aid.

To locate a Red Cross near you, contact:

#### **American Red Cross**

431 18th Street, NW

Washington, DC 20006

(703) 206-7090

[www.redcross.org](http://www.redcross.org)

[www.nyredcross.org](http://www.nyredcross.org) (for the New York area)

**Check if the patient is conscious** – Ask the person a question and gently shake his/her shoulders. If there is no response, the person is unconscious.

**Open the airway** – Place two fingers under the point of the patient's chin and lift the jaw. At the same time, place your other hand on the patient's forehead and tilt the head back.

**Check if the patient is breathing** – Listen and look at the chest to check for breathing. Feel for breath coming out of the mouth on your cheek for 5 seconds. If you do not hear, see, or feel anything, the patient is not breathing.

**Check for a pulse** – Place two fingers over the patient's Adam's apple and slide the fingers toward you in the groove of the neck. Feel for the pulse for 5-10 seconds.

**Give "Rescue Breathing"** – Remove any material from the patient's mouth or throat. Tilt the head back (see opening the airway), rest your hand on the patient's forehead and pinch their nose closed with your thumb and index finger. Take a full breath, place your lips around the patient's mouth and blow into his/her mouth until the chest rises. Remove your mouth and allow the chest to fall fully. Continue providing 1 breath every 5-6 seconds.

**Give CPR** – Place the heel of one hand over the lower 1/3 of the breastbone (where the ribs meet the breastbone). Place the heel of the other hand on top of the hand on the breastbone and intertwine your fingers. Lean over the patient with your arms straight and begin press down on the chest about 1-1/2 to 2 inches. Complete 15 chest compressions, at a rate of about 80-100 per minute. Give 2 rescue breaths (see "Give Rescue Breathing" above). Continue alternating 15 chest compressions with 2 rescue breaths.



**Treat choking** – Ask the patient if he/she can speak or cough. If the person cannot speak, give the Heimlich Maneuver. Stand behind the patient, place your fist just above the navel, clasp your fist with the other hand, and give quick, upward thrusts until the object is removed or the person becomes unconscious.

If the person becomes unconscious, give two rescue breaths. If they do not go in, sweep the mouth with your finger, then give abdominal thrusts by straddling the person's legs, placing the heel of your hand (one on top of the other) directly above the navel and give inward, upward thrusts. If breathing starts, lay the person on his/her side with the head tilted back and the top knee bent to prevent rolling forward.

**Treat burns** – Pour cold water on the burned area for 2-3 minutes. Remove any clothing or jewelry that are on or around the burned area, unless they are sticking to the burned area. Cover the burn with a sterile dressing. Do not apply lotions, ointments, or fat (e.g. butter) to the burn. Do not touch the burned area or burst any blisters. Do not cover a facial burn.

**Treat severe bleeding** – If you have latex gloves, these should be worn at all times while in contact with blood. If not, you can use plastic wrap or layers of cloth. Using a clean pad or dressing, apply direct pressure to the wound for 10 minutes. If no bones are broken, raise an injured limb to above the level of the patient's heart. Lay the patient down to reduce the chance of shock and minimize blood flow. Apply a bandage over the original pad or dressing. Wash your hands thoroughly with soap and water after providing care.

(Adapted from VNAA, 1998 and Meyer, et al., 1998)



### **Troubleshooting: What to do if...**

#### **The person is injured, but conscious**

1. Assess injuries
2. Call an ambulance (if necessary)
3. Treat injuries (see First Aid)

#### **The person is unconscious**

1. Call an ambulance
2. Open airway and check breathing

#### **The person is breathing**

1. Place the patient on his side or stomach  
(only if spinal injury is not suspected)
2. Wait for the ambulance to arrive

#### **The person is NOT breathing**

1. Give "Rescue Breathing"
2. Check pulse

#### **There is a pulse present**

Continue "Rescue Breathing"  
and keep checking the pulse  
until the ambulance arrives

#### **There is NO pulse present**

Perform CPR until the ambulance  
arrives

#### **Reminder**

If the patient has a signed Do Not Resuscitate (DNR) Order, you must show it to the paramedics immediately. Otherwise, they are required to perform CPR and other life-saving procedures. The DNR Order must be kept with the patient at all times in the ambulance, emergency room, and hospital.

(Adapted from VNAA, 1998)

## A Patient's Bill of Rights

These rights can be exercised on the patient's behalf by a designated surrogate or proxy decision-maker if the patient lacks decision-making capacity, is legally incompetent, or is a minor.

### 1. Quality of Care

The patient has the right to considerate and respectful care.

### 2. Information Regarding Treatment and Medical Team

The patient has the right to and is encouraged to obtain from physicians and other direct caregivers relevant, current, and understandable information concerning diagnosis, treatment, and prognosis.

Except in emergencies when the patient lacks decision-making capacity and the need for treatment is urgent, the patient is entitled to the opportunity to discuss and request information related to the specific procedures and/or treatments, the risks involved, the possible length of recuperation, and the medically reasonable alternatives and their accompanying risks and benefits.

Patients have the right to know the identity of physicians, nurses, and others involved in their care, as well as when those involved are students, residents, or other trainees. The patient also has the right to know the immediate and long-term financial implications of treatment choices, insofar as they are known.

### 3. Patient Choice

The patient has the right to make decisions about the plan of care prior to and during the course of treatment and to refuse a recommended treatment or plan of care to the extent permitted by law and hospital policy and to be informed of the medical consequences of this action. In case of such refusal, the patient is entitled to other appropriate care and services that the hospital provides or transfer to another hospital. The hospital should notify patients of any policy that might affect patient choice within the institution.

### 4. Living Wills and Other Advance Directives

The patient has the right to have an advance directive (such as a living will, health care proxy, or durable power of attorney for health care) concerning treatment or designating a surrogate decision maker with the expectation that the hospital will honor the intent of that directive to the extent permitted by law and hospital policy.

Health care institutions must advise patients of their rights under state law and hospital policy to make informed medical choices, ask if the patient has an advance directive, and include that information in patient records. The patient has the right to timely information about hospital policy that may limit its ability to implement fully a legally valid advance directive.

### 5. Privacy and Confidentiality

The patient has the right to every consideration of privacy. Case discussion, consultation, examination, and treatment should be conducted so as to protect each patient's privacy.

The patient has the right to expect that all communications and records pertaining to his/her care will be treated as confidential by the hospital, except in cases such as suspected abuse and public health hazards when reporting is permitted or required by law. The patient has the right to expect that the hospital will emphasize the confidentiality of this information when it releases it to any other parties entitled to review information in these records.

### 6. Right to Information

The patient has the right to review the records pertaining to his/her medical care and to have the information explained or interpreted as necessary, except when restricted by law.

### 7. Appropriate Treatment

The patient has the right to expect that, within its capacity and policies, a hospital will make reasonable response to the request of a patient for appropriate and medically indicated care and services. The hospital must provide evaluation, service, and/or referral as indicated by the urgency of the case. When medically appropriate and legally permissible, or when a patient has so requested, a patient may be transferred to another facility. The institution to which the patient is to be transferred must first have accepted the patient for transfer. The patient must also have the benefit of complete information and explanation concerning the need for, risks, benefits, and alternatives to such a transfer.

### 8. Possible Conflict of Interest

The patient has the right to ask and be informed of the existence of business relationships among the hospital, educational institutions, other health care providers, or payers that may influence the patient's treatment and care.

### 9. Research

The patient has the right to consent to or decline to participate in proposed research studies or human experimentation affecting care and treatment or requiring direct patient involvement, and to have those studies fully explained prior to consent. A patient who declines to participate in research or experimentation is entitled to the most effective care that the hospital can otherwise provide.



### **10. Continuity of Care**

The patient has the right to expect reasonable continuity of care when appropriate and to be informed by physicians and other caregivers of available and realistic patient care options when hospital care is no longer appropriate.

### **11. Knowledge of Hospital Policies**

The patient has the right to be informed of hospital policies and practices that relate to patient care, treatment, and responsibilities. The patient has the right to be informed of available resources for resolving disputes, grievances, and conflicts, such as ethics committees, patient representatives, or other mechanisms available in the institution. The patient has the right to be informed of the hospital's charges for services and available payment methods.

### **Patient Responsibilities**

The effectiveness of care and patient satisfaction with the course of treatment depend, in part, on the patient fulfilling certain responsibilities. Patients are responsible for providing information about past illnesses, hospitalizations, medications, and other matters related to health status. To participate effectively in decision making, patients must be encouraged to take responsibility for requesting additional information or clarification about their health status or treatment when they do not fully understand information and instructions. Patients are also responsible for ensuring that the health care institution has a copy of their written advance directive if they have one. Patients are responsible for informing their physicians and other caregivers if they anticipate problems in following prescribed treatment.

Patients should also be aware of the hospital's obligation to be reasonably efficient and equitable in providing care to other patients and the community. The hospital's rules and regulations are designed to help the hospital meet this obligation. Patients and their families are responsible for making reasonable accommodations to the needs of the hospital, other patients, medical staff, and hospital employees. Patients are responsible for providing necessary information for insurance claims and for working with the hospital to make payment arrangements, when necessary.

A person's health depends on much more than health care services. Patients are responsible for recognizing the impact of their life-style on their personal health.

Hospitals have many functions to perform, including the enhancement of health status, health promotion, and the prevention and treatment of injury and disease; the immediate and ongoing care and rehabilitation of patients; the education of health professionals, patients, and the community; and research. All these activities must be conducted with an overriding concern for the values and dignity of patients.

## Coping With Home Care

Some of the duties required in caring for your ill loved one can be difficult for you to handle on your own. The patient may require technical medical care for his/her illness, disability, or injury, which you may not feel prepared to handle. In certain cases, home care services are covered by the patient's insurance. Other times, it is necessary to hire a home care nurse or health aide privately to help with medical and/or personal care of the patient. While these people can help to reduce much of the nervousness that you may feel, they can also add a certain amount of stress. Having a stranger in your home takes some getting used to. It takes time to get to know the home care worker and to feel comfortable with him/her. There are some things that you can do to help make the transition as smooth as possible.

### Consider home care when the patient needs:

- n Home assessments for an unstable physical illness, such as cardiac, respiratory, or kidney diseases
- n Wound care
- n Incontinence care, including Foley catheters and ostomy care
- n Diabetic instruction
- n Home rehabilitation
- n Medication monitoring or education

### What to expect from the home care nurse:

- n On the first visit the nurse will:
  - Review the patient's medical history and medications
  - Perform a physical assessment of the patient
  - Identify patient needs
  - Develop a plan of care with you, the patient, and the patient's doctor
- n During return visits, the nurse will:
  - Review the patient's plan of care
  - Coordinate services that the patient may need
  - Educate you and the patient as needed
  - Report to the patient's physician about health status

### Tips for Preparing for Home Care:

- n Participate in making the care plan with the hospital staff and home care agency.
- n Familiarize yourself with the home care plan and know what to expect, when the nurse or aide will be in the home, for how long, and what services will be provided.
- n Determine how the home care nurse, aide, or others will be paid. If this service is not covered by insurance, make sure you discuss and agree on the fee for each home care team member.
- n Know who to call if you need help when the home care worker is not scheduled to be there. There should be someone from the home care team/agency available for you to contact 24 hours per day.
- n Have all medications, insurance cards, and hospital discharge information available at the first visit from the visiting nurse.
- n Ask to be educated about the patient's needs and anything you can do to help when the home care worker is not in the house.

- n Keep important patient information handy for the home health care worker. This includes emergency information, as well as current medications and advance directives (e.g. home DNR order, living will, or written information about the health care proxy).

**Making the relationship work:**

- n Be friendly and polite when first meeting the home care nurse or aide.
- n Introduce yourself and tell the nurse or aide how you would like to be addressed.
- n Introduce the aide or nurse to the patient and to others who are frequently in the house.
- n Refer to the nurse or aide as Ms. or Mr. \_\_\_\_\_ unless he/she tells you otherwise.
- n Give him/her a tour of the house and point out where important things are kept.
- n Inform the visiting nurse or aide of any changes since the last visit.
- n Ask if you can help the nurse or aide with anything periodically.
- n Unless assisting the nurse or aide with something, try to stay out of the way.
- n Be patient. Being in your home is a new experience for the home care worker. It will take some time for him/her to get adjusted to the situation.

(Adapted from McFarlane & Bashe, 1998)

**Troubleshooting:**

Many issues can arise when you are dependent on someone else for the care of the patient. You may find that you do not like the way the home care worker is doing something or that the person does not show up at his/her scheduled time. You need to know the proper way to handle and resolve these and other problems with home care professionals in order to make the care plan work.

- n Find out who is the target person/supervisor you should speak to about any complaints or problems. This is usually a nurse who is assigned to the patient’s case. Write down these important contact numbers below.
- n If there is a problem, tactfully raise it with the home care worker. If you do not feel comfortable with this, or the problem persists, discuss it with the supervising nurse who can tell you how to handle the problem or take care of it for you.
- n Do not hesitate to speak to the home care agency if you feel that you need more help in the home. There may be other resources available to you through your insurance or other means that can be of help.

See Appendix F for how to find home health care services in your area.

**Contact numbers:**

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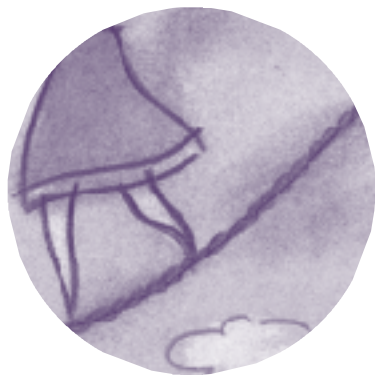
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# JUGGLING FINANCIAL EXPENSES

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Whether or not you share finances with the patient, as a caregiver you will likely find yourself involved in financial matters. Even if the patient is not your spouse or partner, you may find that you want or have to contribute your own money to the care of the patient. This can be an expensive commitment, especially if you and/or the patient have had to cut down on hours at work or take leave from your jobs. Medical bills and prescriptions can become very costly, leaving you wondering how you and/or the patient will make ends meet. Although financial problems can become overwhelming, it is important not to panic. There are ways to better manage money, receive financial assistance, and get the most coverage possible from the patient's health care benefits.

## Budgeting Money

The best way to get a handle on the patient's finances is to work out a budget. Start by writing down all regular monthly expenses, including:

- n rent or mortgage payments
- n phone and utility bills
- n transportation (car payments, gas, public transportation, tolls, parking)
- n insurance premiums
- n food
- n clothing
- n child-care or elder-care costs
- n medical expenses (prescriptions, medical supplies, other medical costs)
- n monthly loan payments
- n taxes
- n tuition
- n legal and accounting fees
- n other household expenses
- n any other monthly expenses

Once you have written down all of these expenses, add up the total, deduct this from your monthly income, and review the amount left. If you find that cash is low, you may want to try some of the following options:

- n Prioritize bills. First pay for essential expenses, such as food, shelter, and medication. If possible, postpone payment of larger medical or credit card bills.
- n Ask your utility companies (gas, electric, phone) about assistance programs they may offer to help people who cannot meet payment.
- n Find out whether the pharmaceutical companies that produce your family member's medication offer prescription medicine assistance programs.
- n Make sure your family member is receiving his/her Social Security benefits (Retirement, Disability, Survivor, Supplemental Security Income (SSI), or Black Lung benefits).
- n Look into dependent-care tax exemptions or credits for family caregivers.
- n See if there are family caregiver assistance programs offered at your local agencies on aging.
- n Consider other ways to bring in income, such as working from home, asking family members for a loan, or requesting help with bill payment from other household members.

**Appendix C lists agencies that can assist you in obtaining these and other financial options.**

## **Handling Health Insurance**

Receiving huge medical bills from the hospital or doctor can cause a lot of anxiety. Reading the bill, figuring out how it will be paid, and determining which services should be covered by the patient's insurance company are some of the problems you may face. Understanding the patient's health care benefits can be confusing. Dealing with health insurance companies can be frustrating. However, there are some things that you can do to help minimize the stress associated with these activities.

### **Read the insurance policy thoroughly**

Whether the patient has private health insurance, Medicare, or Medicaid, there are certain services that the plan will and will not pay for. It is important for you to know what is covered by insurance in order to follow procedures that will maximize coverage, such as getting a referral before seeing a doctor. It will also help to ensure that the patient is getting all benefits to which he/she is entitled. If you have trouble understanding the insurance contract, ask someone with more experience to help you or call the insurance company with specific questions about what is covered.

### **Check medical bills**

It is not uncommon to be billed incorrectly by the hospital or doctor. Look over each bill carefully and make sure that the patient is not being billed for services that were not received. If you find charges that are doubtful, call the billing department of the hospital or doctor's office for clarification.

### **Don't panic about big medical bills**

If a huge medical bill arrives asking for payment of the "amount due," don't panic. Many times, bills are sent out before payments are received from the insurance company. This makes it look like the patient owes the hospital or doctor more than they really do. It can take up to 2 months or more for insurance companies to process claims and send out reimbursement payments. Therefore, bills that are received may not reflect what is really owed. If you are concerned about the balance on the patient's bill, you can call the billing office at the hospital or doctor's office and ask if there are any insurance claims pending on the patient's account. If so, you can wait until all payments are received from the insurer before paying the bill. If there are no claims pending, you can review the health insurance benefits to ensure that all of the billed services are not covered by the patient's insurance. If you find that there are services on the bill that should be covered by the patient's insurance, you can either tell the hospital or doctor's billing office, or submit a claim to the insurance company yourself (see below).

### **Submit claims properly**

Some doctor's offices or insurance companies require the insured person to submit claims, rather than the billing office. If you have to fill out claim forms and submit them, be sure to:

- n Submit a claim as soon as you receive a medical bill.
- n Double check your work to make sure the information on the claim form is correct.
- n Make sure to attach all supporting documents (e.g. copies of bills, receipts).
- n Keep photocopies of bills, submitted claims, payment stubs from the insurance company, explanations of benefits, and insurance company findings.
- n Call the insurance company if you have any questions or are unsure about anything to do with making a claim.
- n Keep notes on your phone conversations, including the name of the insurance agent, the date of the call, and the information you were given.

### **Be persistent**

Claims may be denied for any number of reasons, including mistakes on claim forms, missing documents, or varying practices of claims adjusters. If the patient's claim is denied, you can always send it again and try for a different result. It may also help to ask the patient's doctor to write a letter to the insurance company, explaining the need for certain procedures. Sometimes, this will lead the insurance company to re-examine a claim. If you have tried these suggestions, and are still not happy with the result, you can ask the insurance company about their procedure for resolving disputed claims. You can also contact a lawyer or your state insurance regulator.

(Adapted from McFarlane & Bashe, 1998)

## About health insurance

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### MEDICARE:

- n Health insurance program funded by the federal government.
- n Offers health care benefits to people 65 or older, and to anyone under 65 who has been collecting Social Security disability for at least 2 years or has a serious disability, such as kidney failure.
- n Medicare has two parts.
  - Part A covers institutional care, such as hospital costs, rehabilitation, home health care, and hospice.
  - Part B covers medical expenses including doctor's bills, outpatient tests, lab services, and home health care. There is a monthly charge to the patient for coverage from Part B, and a deductible is also applied.

### MEDIGAP:

- n Private health insurance policy offered to people who are eligible for Medicare.
- n Pays for those services that are not covered by Medicare, such as deductibles, co-payments, and prescriptions.

### MEDICAID:

- n Health insurance program funded by federal and state governments.
- n Offers health care benefits to those with low income, such as those who are collecting SSI, welfare, or public assistance.
- n Eligibility depends on monthly income, personal assets, and state regulations.
- n Covers most medical care and nursing home costs, but is not accepted by all hospitals/doctors.

### PRIVATE INSURANCE:

- n Insurance that is covered under a group plan from an employer or purchased by an individual.
- n There are basically two types of private insurance:
  - Fee for Service Plans require you to pay premiums and a deductible, then you (or the doctor's billing office) submit a claim to obtain reimbursement for the cost of care.
  - Managed Care Plans (HMO/PPO) are prepaid health insurance plans that cover the cost of services within a network of health care providers. Patients choose a primary care physician who they must see for referrals to other specialists. These plans do not usually have a deductible for in-network visits, but do charge a small co-payment for doctor's visits and prescriptions.

### For More Information:

Medicare Hotline: (800) MEDICARE (633-4227)

Medicare Rights Center: (800) 333-4114 or  
(212) 869-3850 (in New York City)

American Association of Retired Persons (AARP):  
(800) 424-3410

Federal Hill – Burton Free Care Program:  
(800) 638-0742; (800) 492-0359

National Insurance Consumer Help Line: (800) 942-4242