



Family
Caregiver
Guide



Some patient stay in the hospital for a day or more to be “observed” but are not admitted. This can affect how much of the bill Medicare pays and eligibility for skilled nursing facility rehabilitation services later. See page 9 for details.

Hospital Admission: How to Plan and What to Expect During the Stay

Admission to the hospital can happen in various ways. You family member may be treated in the Emergency Room (ER) and need additional treatment requiring a hospital stay. Other times you may know that your family member will be staying in the hospital for at least one night. This planned admission could be for elective (non-emergency) surgery, tests, or special procedures.

Whether it starts as an emergency or as a planned admission, a hospital stay is often the first stage in a series of transitions, or moves to different health care settings. You and your family member will feel more prepared and perhaps less anxious when you know what to expect.

If you are helping your family member plan for a hospital admission, start by reading the first section of this guide.

If your family member is already in the hospital, you can skip this part and go directly to page 5.

Getting Ready and the Admission Process

Pre-Admission Packet



Your family member's doctor may give a list of what to do before admission. This can include: tests, medications (to take or not take), and food (whether or not to eat or drink before admission). Make sure your family member follows all these instructions.



Remember that not all these questions can be answered ahead of time, and that some things may change during the hospital stay.

Your family member will likely get a packet of pre-admission papers. Ask for this packet if the hospital does not offer it. The packet will have basic information about:

- ▶ Tests your family member needs before admission.
- ▶ Where to go on the day of admission and what time to arrive.
- ▶ Hospital policies, such as visiting hours.
- ▶ Information about paying for this hospital admission.

Make sure to read all the papers in this packet. You might also want to make a list of questions to ask. Most hospitals have websites where you can find additional information.

Questions to Ask Before Hospital Admission

You and your family member should know ahead of time what tests or procedures he or she is likely to have and why they are needed. Here are some questions you might want to ask:

- ▶ Where is the best place to have this test or procedure done? Your choice may depend on location, insurance, and where your doctor can admit patients. A hospital checklist to help you in this process can be found at http://hospitalcompare.hhs.gov/Hospital/Static/SupportingInformation_tabset.asp
- ▶ How much time should it take for this test or procedure?
- ▶ How long will my family member be in the hospital?
- ▶ Will my family member be able to go home from the hospital? Or will he or she need rehabilitation (rehab) after the hospital?
- ▶ What type of care will my family member need at home?
- ▶ What possible problems or side effects should I be aware of?



Keep your Hospital Kit nearby so you can quickly find it. Make sure to always have a notebook and pen to write down information and questions.



Don't forget to bring items for your own comfort. You might be waiting for your family member to return from tests or just being there while he or she rests. Bring books, magazines or a newspaper for yourself. Snacks and drinks are also a good idea.

Hospital Kit for Your Family Member

You and your family member can create a kit to take to the hospital. Here are some items to include in your hospital kit:

- ▶ Your family member's insurance information and identification card.
- ▶ List of doctors treating your family member. Make sure to include each doctor's phone number and other contact information.
- ▶ Telephone numbers of people to call in an emergency.
- ▶ Test reports, lab results, and copies of recent X-rays. If you do not have these reports then at least write down where these tests were done.
- ▶ Names and dose of all your family member's medications. This includes prescription drugs as well as vitamins, herbals, laxatives, and other over-the-counter products. You can keep track of all these by using the Medication Form.
- ▶ List of any allergies your family member has to medicine and food.
- ▶ *Health Care Proxy and Advance Directives.* These papers may be in the pre-admission packet or given to your family member at admission. To learn read our guide to Advance Directives.

Other Items to Bring to the Hospital

- ▶ Eyeglasses, dentures, and hearing aids.
- ▶ Personal items such as toothbrush, toothpaste, comb, hairbrush, shampoo, battery-operated shaver, and deodorant.

The suggested items below can provide your family member some comfort:

- ▶ robe, slippers, and a nightgown a favorite pillow,
- ▶ Newspapers, snacks, Magazines or books.
- ▶ Cell phone and charger. (Some hospitals only allow you to use cell phones in certain places, such as waiting rooms. Ask before you use your cell phone.)



Your family member's medications will be provided by the hospital.

The hospital cannot provide you with any medications. Be sure to bring any medications YOU are taking.

Items NOT to Bring to the Hospital

- ▶ Some items are best left at home. These include:
- ▶ Medications (unless the doctor asks you to bring them). At some point you may be asked to bring in certain medications you cannot get at the hospital
- ▶ Valuables such as your family member's wallet and jewelry.
- ▶ Electric razors, hair dryers, or medical equipment used at home. These items may cause problems when used near hospital equipment.

Patient Rights and Responsibilities

There are a lot of papers to sign when your family member goes to the hospital. These include:

- ▶ **General consent agreement.** This is for routine treatment. Your family member will be asked to sign this. You may be the one to sign if you are the "legally responsible person" for your family member.
- ▶ **Consent for surgery or other special procedure.** The doctor will talk with you about risks and benefits of this surgery or procedure. Your family member (or you) will then be asked to sign a separate consent form. Ask the doctor for more information if you do not fully understand or have questions.
- ▶ **Agreement to pay for services not covered (paid for) by Medicare, Medicaid, or private health insurance.** Your family member (or you) will need to sign this.
- ▶ **HIPAA (pronounced HIP-paa) form.** The Health Insurance Portability and Accountability Act (HIPAA) is designed to protect the security and privacy of each patient's health care information. As a family caregiver you have a right to be informed about your family member's medical condition and care needs. To learn more, go to "[HIPAA: Questions and Answers for Family Caregivers](#)."

When Your Family Member is in the Hospital



Some units, for example, Intensive Care Units or Cardiac Care Units, may have strict guidelines regarding visits. These can include how many people can visit at a time, when and for how long.

You will need basic facts such as to how you can get to the hospital by car or mass transit, what times you can visit. Call the hospital's main phone number or go online to the hospital website to get specific information.

Visiting Hours

Most people want to know about visiting hours – times they can and cannot be with patients. There likely will be signs about this. Ask a hospital staff member if you do not see the sign or want to know more.

Private-Duty Nurse or Aide

Some families hire a private-duty nurse or aide to stay with their family member. This can be helpful when patients are having complex medical procedures or need extra attention. Here are other facts to know:

- ▶ This cost is usually not covered (paid for) by health insurance and can be expensive. Ask the nurse on your family member's unit where to find out the details. There will likely be an office that handles these requests. Most hospital do not allow nurses or aides from outside agencies to provide this service. If your family member is already being cared for by a private nurse or aide, you will need to find out if that person can stay with him or her during the hospital stay. You will also need to know what your family member's private nurse or aide can and cannot do while at the hospital.

Meals and Snacks

Most patients can choose their meals from the hospital menu. Talk with the doctor or nurse if your family member asks for certain food from home. This may not be allowed because of your family member's medical condition.



It can be hard to keep track of who each person is and how he or she helps in your family member's care. You can often learn more by reading each person's name badge.

Health Care Team Members

There likely will be many doctors as well as other health professionals caring for your family member. They are sometimes referred to as "health care team members."

Below are some facts about many types of health care team members.

Doctors (Physicians)

If your family member is a patient at a "teaching" hospital then you are likely to meet many doctors and medical students. Feel free to ask each doctor his or her name and level of training. You should also ask who is in charge of your family member's care.

Doctors can include:

- ▶ **Attending Physician ("Attending").** This is an experienced doctor who is in charge of your family member's treatment plan. He or she works with and supervises other doctors treating your family member.
- ▶ **Hospitalist.** The attending physician may be a hospitalist, an experienced doctor who takes care of patients throughout the hospital admission but does not see patients outside the hospital. The patient's primary care ("regular") doctor will probably not come to the hospital. You should ask the hospitalist or other attending physician to be in contact with the primary care doctor. For more, see the Next Step in Care guide "[What Is a Hospitalist?](#)"
- ▶ **Fellow.** This is a doctor who is getting advanced training in a special area of medicine.
- ▶ **Resident.** This refers to a doctor who graduated from medical school two to three years ago. Residents are being trained in special areas of medicine. A "senior" resident is in charge of "junior" residents and interns. They are supervised by the attending physician.
- ▶ **Intern.** This is a new doctor working under the guidance of residents and the attending physician.
- ▶ **Consultants or specialists.** The attending physician may ask other doctors to help diagnose or treat your family member. For instance, your family member may be seen by a cardiologist who is a specialist in heart disease or a neurologist who knows a lot about strokes.

Other health care team members (not doctors)

It is likely that there will be many other health care professionals on the health care team. Nearly every hospital will have the following professionals on staff:

- ▶ **Registered Nurse (RN):** Nurses perform health assessments, give medications, monitor (check) vital signs, change wound dressings, provide wound care, and teach family caregivers basic skills to care for the patient at home. You may see new nurses each day as most work in 8- or 12-hour shifts. The nurse is often the best person to talk with if you need something or have a question.
- ▶ **Nurses' aide or nursing assistant (NA):** These team members work under the supervision of RNs. Their job is to take blood pressure, change bedding, assist patients going to the bathroom, give baths, and help make sure patients are clean and comfortable. They work in shifts (like nurses) and you may not see the same aide each day.
- ▶ **Social worker:** The social worker assesses the needs of each patient and family. He or she helps with health insurance problems and, as needed, plans for social or psychological services. The social worker is often the person that helps with discharge planning. This includes transportation home or to another facility as well as referrals for care after discharge. You can learn more by reading, [Family Caregivers' Guide to Hospital-to-Home Discharge Planning](#).
- ▶ **Medical technologists, radiographers, and nuclear medicine technicians.** These technicians take blood and perform X-rays and other tests.
- ▶ **Dietitians (Nutritionists).** They provide counseling and assessment about nutrition (food and diets).
- ▶ **Patient Representative:** This person helps resolve complaints from patients and caregivers. These complaints may be about the quality of care, hospital policies and procedures, or conflicts with hospital staff. Patients and family members can ask to meet with the Patient Representative.
- ▶ **Chaplain:** Hospitals have specially-trained clergy (religious leaders) who provide pastoral care and talk with patients and their family members. You do not need to belong to an organized religion or be religious to speak with a chaplain.

- ▶ **Escorts/Transport:** These workers take patients for tests and procedures within the hospital. Sometimes it takes a while for escorts to arrive as they can be very busy. You may want to go with your family member to all tests and procedures.

Depending on your family member's condition and care, other staff members may be involved:

- ▶ **Nurse practitioner (NP):** This is a registered nurse who holds a master's degree and received advanced training. He or she is certified to treat many common illnesses, take a patient's medical history, order tests and prescribe therapy and medication (in most states).
- ▶ **Physician's assistant (PA):** This person is supervised by a doctor. PAs can take a patient's medical history, order tests and prescribe therapy and medication (in most states).
- ▶ **Therapists.** They include: physical therapists (PT) who help patients with walking and regaining strength; occupational therapists (OT) who help patients with skills like eating, getting dressed, and using assistive devices; speech therapists (SLP) who provide specialized care as needed.

Family Caregivers are Health Care Team Members, Too.

Here are some ways you can help:

- ▶ **Help make sure that your family member gets the treatments needed.** You can do this by checking with the nurse going off duty and asking what needs to happen during the next shift. This includes medications, tests and procedures. You can make sure the nurse coming on duty next has the same information.
- ▶ **Ask questions about your family member's medical condition, treatment, and follow-up plan of care.** It is a good idea to write questions as you think of them. This way, you will be prepared when meeting with the doctor, nurse, or other health care professional.
- ▶ **Keep track of all instructions and plans for discharge.** A good way is to write this information in a notebook and keep it by the bedside.

- ▶ **Tell the doctor or nurse if you do not understand something or want to learn more about a certain topic.**
- ▶ **Let the doctor or nurse know if you do not feel ready to care for your family member after discharge.**
- ▶ **Use good communication skills.** This means listening carefully, speaking clearly, and using a friendly tone.
- ▶ **Ask to speak with the doctor, nurse, social worker, or patient representative if you feel there are communication problems with the staff or you or your family member are not being treated fairly.**

Problems that can Happen and Ways to Solve Them

Hospital Admission or Observation Status?

Just because your family member is in a hospital bed, on a hospital unit, eating hospital food, and undergoing hospital tests does not automatically mean that he or she has been admitted to a hospital. Sometimes doctors want to watch a patient for a few hours or a day to see whether there is really a need to be admitted to the hospital. This is called "observation." More patients are now in hospitals being observed rather than admitted. This is largely because of Medicare's efforts to reduce expensive hospital admissions and possible readmissions.

Does it matter if your family member is admitted to the hospital or is just being observed? Yes, because Medicare pays for hospital admissions and observation differently. As a result, your family member's part of the bill is likely to be higher if he or she is only being observed than if he or she were actually admitted.

Admission vs. Observation

Hospital admissions are covered under Medicare Part A. Under Medicare Part A, after a one-time deductible fee, all hospital costs are covered when a person is admitted as an inpatient.	Observation status and emergency room care (without admission) are considered outpatient care, and are covered only by Medicare Part B. Medicare Part B treats each lab test, X-ray, and other service as individual items, each with a copay. Prescription drugs are not covered and may be a separate charge.
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There's more. To be eligible for Medicare-covered skilled nursing facility services, your family member must have been a hospital inpatient for at least three days. The observation days do not count.

The result? After 72 hours of observation, your family member will have a higher hospital bill and will not be eligible for Medicare-paid rehabilitation services in a skilled nursing facility. Note that these rules apply to regular (that is, fee-for-service) Medicare; if your family member belongs to a Medicare Advantage (HMO) plan, check with the plan for its requirements.

What can you do?

- ▶ In addition to all your other questions, ask repeatedly, **"Has my family member been officially admitted to the hospital, or is he or she under observation status?"** Your family member's primary care doctor will probably not be involved in this decision.
- ▶ Make a note of each staff person's response, including the name and date.
- ▶ The hospital can retroactively (after the fact) change the patient's status from inpatient to outpatient. This change is supposed to be made while the patient is still in the hospital, with a written notification to the patient.
- ▶ If you do not receive this notification, or if you want to appeal the decision, you can contact your state Quality Improvement Office at
http://www.qualitynet.org/dcs/ContentServer?c=Page&page_name=QnetPublic%2FPage%2FQnetTier2&cid=1144767874793

Medicare has issued a brochure that explains observation status.

<http://www.medicare.gov/publications/pubs/pdf/11435.pdf>

Also see the Center for Medicare Advocacy website.

www.medicareadvocacy.org

Financial (Money) Issues

For a planned hospital admission, contact your family member's insurance company before the hospital stay. You need to do this because most insurance plans require "prior approval" - when the insurance company agrees to pay for the hospitalization before your family member is admitted.

For an emergency hospital admission, call your family member's insurance company as soon as you can. If the hospital admission has been planned with a doctor's office, someone there will help make sure approval has been granted. Let this person know if you have any insurance problems.

Learn about your family member's insurance. This includes what it will and will not cover (pay for). This helps you prepare for any additional costs. Speak with the hospital account representative if your family member does not have insurance or if insurance does not cover all the costs. Also let the account representative know if your family member cannot pay the costs. The hospital may be able to get you financial assistance or arrange a payment plan.

Delays

There may be times when your family member's tests or procedures are delayed (late). This happens because hospitals can be very busy. Be patient and ask the nurse to tell you when this test or procedure might take place. Remember that the nurse may not be able to control the schedule.

Quality of Care

You may have concerns about the quality of your family member's care. Perhaps you think that there is too much care (such as too many tests, too many consultants, or too many medicines). Or maybe you are concerned about too little care (such as few doctor visits, unclear plans, or information that changes from person to person).

Here are some common quality concerns along with what you can do:

- ▶ If you feel your family member is being discharged before he or she is ready, you have the right to ask for a review of this

decision. Let the nurse or case manager know about your concern and your wish to have the decision reviewed.

- ▶ If you are concerned that your family member is getting care that is of poor quality, not well coordinated, or unsafe, tell the doctor or nurse.
- ▶ If problems are not solved, you can make a formal complaint through the Patient Representative or Senior Administrator "On Call."
- ▶ If problems are still not resolved, you can contact your state's Quality Improvement Organization (QIO). This is an independent review board that will investigate your complaint. You can find the QIO in your state by going to the QIO Locator on the American Health Quality Association website www.ahqa.org.

If Your Family Member is Confused

Many patients become confused when in the hospital. This happens even more when patients are older, have had a stroke or brain injury, or are in the ICU. Even though it is common for patients to be confused, do not ignore it.

Family members are often less confused when caregivers stay with them. Caregivers can help explain what is going on and offer comfort. Let staff know if your family member seems more confused. They likely can find ways to help.

If Your Family Member has Alzheimer's or Other Form of Dementia

A hospital stay may be especially difficult for people who suffer from Alzheimer's or other forms of dementia. These patients are likely to feel disoriented, confused and anxious in an often chaotic environment such as the hospital. They may be upset by an unfamiliar routine and care by strangers. Be sure to let hospital staff know any helpful tips about feeding or bathing your family member. Also let them know if your family member has problems such as wandering, shouting or other aggressive behaviors and how best to cope with such behaviors. It might help to remind staff that looking directly at your family member, and talking in a calm and reassuring voice will help reduce anxiety. For your part, make sure you orient your family member to the hospital surroundings as often as you can.



Even though you may be able to interpret for your family member, it is best to have a trained interpreter when talking about complex medical information. Children under 16 should not be asked to interpret for family members



Most hospital admissions are very short. Be prepared for the next step in care -- whether that is home, a rehab unit, or long-term care placement. To learn more, go to *Next Step in Care* to explore the various transitions.

Words You Do Not Understand

Health care professionals often use special language ("jargon") when talking to each other. This may save time but can be very confusing for patients and family caregivers. This includes terms as "PEG" (a feeding tube inserted in the stomach) and words like "febrile" (having a fever).

Ask what these words and terms mean. Don't be embarrassed. Many people have trouble with jargon. Here is a way to learn about common medical terms, click here.

<http://www.nlm.nih.gov/medlineplus/mplusdictionary.html>

When You Need an Interpreter

It can be very hard to talk with the health care team when English is not the first language for you or your family member. You have a right to ask for an interpreter when important information is being discussed. The hospital may offer help by bringing in a hospital employee who speaks both the patient's language and English, or using an outside telephone service. You can request a sign-language interpreter if your family member is deaf or hard of hearing.

If You Do Not Agree With the Treatment Plan

There may be times when you do not agree with your family member's treatment plan, perhaps around end-of-life care or a risky procedure. You can ask to speak to a member of the hospital "ethics committee" when there are major disagreements between you and the healthcare team or family members. An ethics committee member works at the hospital but is not involved in your family member's direct care. He or she can offer an objective (fair) point of view. You can ask to speak with the whole ethics committee if you still need help with problems like these.

Take Care of Yourself

As a family caregiver, you are a very important member of the health care team. You can help your family member prepare for a planned hospital stay. You can also help make the time in the hospital less confusing and scary.

While you are there to support your family member, make sure to also take care of yourself. Think about your own needs. Eat when you have a chance. Take a book or magazine to read while waiting. Ask others to take over so you can have a break. And of course, rest when you can.