



COPING WITH

serious illness

For people with serious long-term illnesses, navigating America's health-care system can be daunting. Here's what patients and family members can do to increase the chances of getting the best, most humane treatment.

1 KNOW YOUR HOSPITAL

It pays to know what type of care to expect from hospitals in your area. Some are better than others at managing long-term conditions in a way that prevents the need for frequent hospitalizations and specialist visits, and the accompanying risks of infections and medical errors.

- If you have a choice, consider using a doctor attached to a hospital that practices conservative care.
- Work with your primary-care doctor, or the specialist in charge of your specific condition, on preventive measures that can help you avoid unneeded hospitalizations.
- When hospital stays are needed, try to ensure that a family member or friend is there whenever possible to monitor the patient's care.

2 ASK ABOUT PROS AND CONS

Just because a test or treatment can be done doesn't mean it should be done.

- For tests, ask: Will this test change the way you treat the disease? If not, what is the benefit of doing it? Is this test likely to lead to follow-up tests, biopsies, or other diagnostic procedures? How will this benefit my health?
- For treatments, ask: Is this likely to extend my life, and if so, for how long? How do its side effects and risks compare with the symptoms and risks of my disease itself? What will happen if I do not have the treatment?

3 PUSH FOR COORDINATION

Having many doctors involved in your care can lead to confusion and miscommunication.

- Develop a good, long-term relationship with a primary-care physician. When medical problems arise, ask this doctor or your main specialist to coordinate all of your treatment.
- Keep and update your own medical record. Whenever you get care from any other doctor, hospital, laboratory, or clinic, have a record of it sent to your primary-care doctor and to yourself.
- Keep an up-to-date list of all your medications, including prescription drugs, over-the-counter drugs, and dietary supplements. Include brand and generic name, dosage strength (such as 10 mg), and dosing schedule (such as once a day). Note any drugs that have caused bad side effects.

4 MIND THE TRANSITIONS

Many errors occur during transfers in the hospital, or to home, a rehab center, or a nursing home.

- Do not assume your primary-care doctor knows you have entered or left the hospital. Make a call yourself if necessary, and be sure to fill out forms authorizing the hospital to send your doctor records of your stay.
- Ask for “medication reconciliation” when moving from one health-care setting to another, including your home. Going over all medications, especially those prescribed in the most recent setting, helps you make sure you are getting all the medications you need without duplications or harmful interactions.
- Do not leave the hospital without completely understanding and signing off on the plan for follow-up care, who is going to arrange for and provide it, and how to get in touch with that person. And make sure you and your doctor receive the results of any tests taken in the hospital.

5 HAVE THE “TALK”

Families who have lost loved ones after strenuous courses of invasive treatments often say they regret not having recognized sooner that things were going downhill, and adjusting plans and expectations accordingly.

- If many doctors are involved in a case, try to get them together to discuss the patient’s overall condition and outlook. You might have to be insistent to get this to happen.
- Ask for a consultation with a palliative-care service for patients who are seriously ill and receiving aggressive care. Palliative specialists are trained to consider the patient’s entire medical and personal situation and to focus on symptom management and quality of life alongside any curative treatments that are still being tried.

6 THINK TWICE ABOUT DRASTIC MEASURES

More aggressive hospitals more often use treatments such as feeding tubes and cardiopulmonary resuscitation in patients nearing death. But those measures might not extend life for long, if at all, and can be uncomfortable.

- Every adult should have an “advance directive” (available at www.caringinfo.org). It gives your preferences for care in the event you are ill with no prospect of recovery and unable to express your wishes.
- Consider hospice care for a patient who, in the opinion of doctors, is likely to die within six months. Studies show that patients receiving hospice care on average live slightly longer than those with the same illnesses who are not in hospice.
- Don’t be pressured into agreeing to invasive life-support treatments, such as feeding tubes, without a thorough discussion of the patient’s prognosis, personal preferences (if known), and overall condition.