Navigating the Health Care System

What to know and do to ensure effective care
THE METLIFE MATURE MARKET INSTITUTE®
The MetLife Mature Market Institute is MetLife’s center of expertise in aging, longevity and the generations and is a recognized thought leader by business, the media, opinion leaders and the public. The Institute’s groundbreaking research, insights, strategic partnerships and consumer education expand the knowledge and choices for those in, approaching or working with the mature market.

The Institute supports MetLife’s long-standing commitment to identifying emerging issues and innovative solutions for the challenges of life. MetLife, Inc. is a leading global provider of insurance, annuities and employee benefit programs, serving 90 million customers in over 50 countries. Through its subsidiaries and affiliates, MetLife holds leading market positions in the United States, Japan, Latin America, Asia Pacific, Europe and the Middle East.


200 Park Avenue
New York, NY 10166
MatureMarketInstitute@MetLife.com

NATIONAL ALLIANCE FOR CAREGIVING
Established in 1996, The National Alliance for Caregiving is a non-profit coalition of national organizations focusing on issues of family caregiving. The Alliance was created to conduct research, do policy analysis, develop national programs, and increase public awareness of family caregiving issues. Recognizing that family caregivers make important societal and financial contributions toward maintaining the well-being of those for whom they care, the Alliance’s mission is to be the objective national resource on family caregiving with the goal of improving the quality of life for families and care recipients.

www.caregiving.org
This guide will help IF you or a loved one:

- Experience a serious illness, accident, or hospital stay.
- Have a chronic condition that requires frequent or ongoing care.
- Must understand how to best pay for health care, including the role insurance plays in protecting against high out-of-pocket costs.
- Must regularly communicate with physicians, nurses, insurance companies, and other health care professionals in a hospital, at home, or in another care environment.

NAVIGATING THE COMPLEX WORLD OF HEALTH CARE

When you or a loved one are seriously ill, it can feel like uncharted territory. The health care system has become increasingly complex and fragmented. Medical professionals are pressed for time. Patient loads have increased. And the parties involved — clinics, hospitals, nursing staff, and after-care facilities — do not always have mechanisms in place to effectively communicate with each other regarding your care.

You are the consistent link in the chain of communication, and it is up to you to stay on top of changing circumstances to ensure quality care and effective recovery. To navigate the health care system effectively, you must equip yourself with information: which documents and resources to gather, how best to communicate with medical and insurance professionals, and what to watch for as you or your loved one move through the stages of care. You must be empowered with information so that, together with your health care providers, you and your family can make informed health-related decisions and make certain that any questions or concerns related to your care are addressed.
Assess the Situation

GETTING THE BEST HEALTH CARE
Now more than ever, you are the most important member of your health care team. Today’s health care system is complex, fragmented, and often frustrating. As you move through the system from physicians to hospitals to care after your discharge, you must ensure that information regarding your condition and care is communicated along the way. You can no longer expect to get information regarding your health insurance plan from those providing your care. Insurance policies are varied and complicated. It is up to you to understand how your insurance policy works and how it can assist you.

Assessing your health care situation is the first step toward getting effective care. It helps you to understand your options, put together a plan for your care, and monitor and adapt to circumstances as they unfold. To assess your care options, it is important to understand:

- How the health care system works
- Which information you will need to communicate to your care team
- What will be required of you as a patient or as an advocate for a loved one who needs care

THE BASICS OF THE HEALTH CARE SYSTEM
The health care system is made up of many separate entities. These entities employ a wide range of medical and health-related professionals and care providers—from physicians to surgeons to nurses to therapists to home health aides—as well as administrative personnel. You will interact with many different professionals in many different roles during the course of your care.

Most individuals seeking care are covered by some form of health insurance, either private or government-provided. Insurance company personnel will interact with you and with your medical providers during the course of your care. Your health insurance may dictate where you can seek care and what type of care will be provided to you. It will also be a primary factor in what you will pay for your care.

As you move through your care, bear in mind that specialists, emergency rooms, primary care physicians, and hospitals have no easy way to communicate with each other, so it will fall to you to ask necessary questions, monitor your care, and pass on critical information regarding your medical condition and medications.
INFORMATION YOU SHOULD GATHER

You will be a key source of information during your care. Gather needed documents regarding your medical condition, legal circumstances, insurance policies, and any other information that will be useful to those providing your care.

Information to Gather When You Need Care

<table>
<thead>
<tr>
<th>Medical</th>
<th>Legal</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Medical records</td>
<td>• Contact information for your attorney</td>
</tr>
<tr>
<td>• Information on current medications</td>
<td>• Durable power of attorney for finances</td>
</tr>
<tr>
<td>• Past diagnoses</td>
<td>• Advance directives</td>
</tr>
<tr>
<td>• List of allergies</td>
<td>– Living Will</td>
</tr>
<tr>
<td></td>
<td>– Durable power of attorney for health care</td>
</tr>
<tr>
<td></td>
<td>Insurance</td>
</tr>
<tr>
<td></td>
<td>• Health insurance policies</td>
</tr>
<tr>
<td></td>
<td>• Disability income insurance policies</td>
</tr>
<tr>
<td></td>
<td>• Long-term care insurance policies</td>
</tr>
<tr>
<td></td>
<td>• Insurance wallet cards with policy information</td>
</tr>
</tbody>
</table>

For your own use, you may also want to gather information required for longer term care, for instance, community resources available to assist you in your recovery, options available for home care, and names and addresses of housing or after-care options.

See The Essentials: Legal Matters, The Essentials: Adult Day Services, The Essentials: Assisted Living Communities, The Essentials: Choosing a Nursing Home, and The Essentials: Receiving Care at Home, as well as the Personal Health Information tool.
WHAT IS AN ADVOCATE?

If a loved one is unable to navigate the health care system alone, because of illness, dementia, advancing age, or some other factor, you may need to become an advocate. Advocates act on their loved ones’ behalf to assure that they receive the best possible care. They make decisions that reflect what their loved ones would want if they could speak for themselves.

Stepping in as an advocate is one of the most important steps you can take to ensure that your loved one receives quality care. While it can be a rewarding role, it may also be frustrating and challenging:

- Advocating often becomes necessary during a stressful time such as during a hospital stay or a major health event, giving you little time to prepare yourself from either an emotional or practical standpoint.
- You may encounter ambiguous situations such as when health care professionals don’t agree or you require information that is not immediately available.
- If you are caring for a loved one, you will be experiencing your own emotional stress, which can affect your ability to focus and make decisions.
- You may have little or no time to prepare or practice. You will likely have to learn along the way.

What an Advocate Might Do

- Communicate with the care team.
- Assess options for treatment.
- Investigate side effects and risks.
- Identify alternatives.
- Assist with billing issues.
- Monitor medications.
- Identify options for ongoing care following a hospitalization or to assist someone with a chronic health condition.
Advocating is not a single event. Rather, it is a series of events that occur over time. Because it is difficult to separate yourself from the stress and emotion, it is important to carefully assess the situation, understand the options, develop a plan for needed care, and continually monitor the situation, adapting to changes along the way. If you are advocating for a loved one, always remember to involve your loved one in the decisions and discussions at each point along the way to the extent that he or she is able to participate.

WHEN TO STEP IN AS AN ADVOCATE
It may be a sign that you need to step in as an advocate for a loved one’s care if he or she is experiencing any of the following:

- Can no longer make health decisions on his or her own.
- Has asked for help in making decisions.
- Has had a recent hospitalization.
- Has recently been diagnosed with a serious or terminal condition.
- Has a chronic condition such as diabetes or heart disease that requires frequent or ongoing care.
- Needs care services that are not easy to find or access.
- Needs medical information — from medical personnel, the insurance company, or other sources — that is not readily available or is unable to be gathered by your loved one alone.
- Is confused by conflicting instructions and opinions from health care professionals.
- Has limited information with which to make health care decisions.
- Is frustrated with his or her medical situation and ability to get care.

ADVOCATING ON YOUR OWN BEHALF
Always bear in mind that you are the best advocate for your own health as long as you have the capacity to make decisions on your own. Make sure you gather all the information needed to get the best health care. Assess your options, seek care alternatives, and get second opinions. Communicate openly with physicians, nurses, therapists, and other members of your care team. Taking charge of your care is the best way to ensure that you get what you require.
Understand the Options

WHAT TO KNOW BEFORE YOUR CARE
During the course of your treatment, you will be asked to make numerous decisions regarding your care. Part of selecting the best options is knowing what to expect from your insurance coverage and understanding the costs of care. If you are advocating for another, it is important to understand legal considerations and privacy regulations that might impact your ability to make decisions or get information from the care team.

The Health Insurance Policy
In exchange for your premium dollars, health insurance policies commonly pay for all or a portion of the following:

- Hospitalization
- Medical tests and x-rays
- Surgery
- Physician office visits

Read the insurance policy carefully. Policies vary widely as to what they will cover and the conditions under which benefits will be paid. Be sure you know exactly what illnesses and conditions are covered. Call the insurance company to clarify any provisions that you do not understand. Create a summary of policy provisions, which includes limitations, that you can share with physicians and other providers. The type of coverage you carry will affect how and which treatments and costs are covered. Your insurance policy will likely fall into one of the following categories:

- Traditional health insurance (also called a fee-for-service or indemnity plan). Traditional insurance allows you to use any physician or hospital you choose and submit your medical bills as a claim to your insurer for reimbursement. You will typically have an annual deductible and coinsurance payments for services received. Plans may not cover certain preventive care services such as annual physicals.

- Health maintenance organizations (HMOs). HMOs are prepaid health plans for comprehensive care. Most HMOs emphasize preventive care. They usually cost you the least amount of money out of your pocket, but they do restrict your choice of physicians, hospitals, and other providers. A primary care physician in the network will manage your care and make referrals to specialists if needed.

- Preferred provider organizations (PPOs). PPOs let you see physicians from inside or outside of their networks. It generally will cost less to see network physicians, who have agreed to a discounted fee from the insurance company. Preventive care is sometimes provided.
Point of service plans (POS plans). Point of service plans combine the managed care features of an HMO with a traditional plan, allowing you to go both in-network and out-of-network. Each time you require medical services you have the option of seeing your in-network primary care physician and receiving coverage under HMO guidelines, or seeing another physician who is not in the network. A visit to an out-of-network physician is covered by a deductible like a traditional plan. After your deductible has been satisfied, the insurer pays a certain percentage of the expenses.

How Will I Pay for My Care?
There are several elements of your insurance policy that impact what you will pay for your care.

<table>
<thead>
<tr>
<th>Basic Components of Your Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Copayments</strong></td>
</tr>
<tr>
<td>Typically paid each time you visit the physician. The copay is a small part of the total cost of a physician office visit. Copays can change if you see a specialist or a physician outside your network.</td>
</tr>
<tr>
<td><strong>Coinsurance</strong></td>
</tr>
<tr>
<td>The way that you and the insurer split the cost of care after a deductible has been reached.</td>
</tr>
<tr>
<td><strong>Deductible</strong></td>
</tr>
<tr>
<td>Your part of medical costs before your health insurance starts paying. Deductibles span a one-year time period.</td>
</tr>
<tr>
<td><strong>Network providers</strong></td>
</tr>
<tr>
<td>Providers (hospitals, physicians, labs, and medical professionals) who have entered into an agreement with the health insurer to provide negotiated rates that are typically discounted.</td>
</tr>
<tr>
<td><strong>Non-network providers</strong></td>
</tr>
<tr>
<td>All other physicians, hospitals, labs, and other medical professionals who are not part of a contracted network. Use of a non-network provider will typically cost you more.</td>
</tr>
<tr>
<td><strong>Out-of-pocket annual maximum</strong></td>
</tr>
<tr>
<td>The maximum costs for covered health care services that you would have to pay in one year under the terms of your insurance plan.</td>
</tr>
</tbody>
</table>

You may also find it helpful to answer the following questions:

- **Am I covered by more than one policy?** If you and your spouse both work and get health care benefits, you will need to coordinate the costs of care with both insurers.

- **Will I be eligible for any tax allowances?** If your out-of-pocket medical costs exceed a certain percentage of your adjusted gross income, you may be entitled to a deduction on your federal income tax return. Track all expenses incurred and consult the IRS, your accountant, or tax planner on how to claim these expenses.

- **Am I contributing to a flexible spending account?** Some employers offer flexible spending accounts (FSAs), which allow you to set aside pre-tax dollars through payroll deduction to pay eligible medical expenses.
- **Do I need a referral to see a health care specialist?** Some health insurance plans require a referral to a specialist from your primary care physician before you seek care. Failure to get a referral may result in reduced payment or denial of payment.

- **Will I need to file claim forms or will that be done on my behalf?** A requirement to file claim forms might impact the time it takes for your bills to be paid or for you to be reimbursed.

- **Does my plan require pre-authorization?** Some health insurance plans require pre-authorization for certain tests, procedures, surgeries, or hospitalizations. Failure to get approval in advance may result in reduced payment or denial of payment.

- **Are there limits as to the amount of service I can receive?** There could be limitations to the amount of care you can receive in a particular service category such as chiropractic care or mental health services.

- **If I require care following a hospitalization, what will be covered and for how long?** If you receive additional care at home or in a facility, you may need to receive prior authorization, meet certain criteria, or use particular providers.

- **Does my plan have provisions for prescription drug coverage?** Prescription drugs can be very costly. It is important to understand how your policy provides reimbursement for these costs.

- **Does my plan have a care coordinator?** Some plans have nurses or other professionals who can provide support and assistance if you have a complex medical condition or require specialized care following an accident or sudden event such as a stroke.

---

**What Might Help You Pay for Care**

- Health insurance
- Dental insurance
- Flexible spending accounts (FSAs)
- Medicare and Medicaid
- Long-term care insurance
- Critical illness insurance

*See also The Essentials: Medicare and Medicaid.*
LEGAL CONSIDERATIONS

If you have any advance directives, gather them before your care or entrust them to a family member or other trusted individual. Advance directives are designed to convey your wishes about future medical care to your family members and physicians should there be a time when you can no longer communicate on your own. There are two types of advance directives: a living will and a durable power of attorney for health care.

■ **Living will.** A living will is a legal document that allows you to specify your wishes about future medical treatment should you be unable to convey them when care decisions need to be made. Living wills, sometimes called health care declarations or health care directives, spell out both the types of treatment and life-sustaining measures you would want as well as those you would not want such as cardiopulmonary resuscitation (CPR) or use of a mechanical ventilator for breathing.

■ **Durable power of attorney.** A durable power of attorney for health care, also called a health care proxy or appointment of a health care agent, allows you to appoint an individual, called an agent or proxy, to make medical decisions for you if you are incapacitated and unable to make decisions on your own. This person may make decisions applying to your medical condition, such as providing medical consents, selecting facilities for care, hiring and firing of caregivers or health care providers, and authorizing access to medical records. They may not, however, make decisions that contradict your desires as outlined in a living will. They also may not make decisions regarding your finances unless they have also been identified as your agent in a durable power of attorney for finances.

If you are advocating on behalf of a family member or loved one, advance directives can assist you in making decisions or taking action on your loved one’s behalf. If the documents already exist, make copies for yourself. If not, have your family member speak with an attorney to execute these documents. As an advocate or caregiver, it is crucial for you to ask your loved one about the legal affairs related to health care decisions. Ideally, these discussions should take place before a crisis occurs.

*See also The Essentials: Legal Matters.*
PRIVACY REQUIREMENTS

One of the reasons that health organizations do not share information on your medical care is the concern for privacy. Privacy regulations restrict them from sharing information without your permission. This is for your benefit in that it helps to protect your personal health data, but it can also impede the flow of needed information among members of your care team.

You will always have access to information regarding your own care but should take steps to make sure others have what they need. Here are some ways you can facilitate the flow of needed information.

- **To members of your health care team.** Most medical offices and hospitals will have release forms for you to sign that allow them to release your medical records to your insurance company and other health professionals. Your insurance company may also have release forms it requires. Make sure you have authorized the various organizations providing you care to share pertinent information regarding your medical condition.

- **To family members, caregivers, or trusted advisors.** The best way to ensure your family members, caregivers, or advisors have access to needed information is by using the legal avenues already discussed: advance directives including a living will and durable power of attorney for health care. These documents let you indicate who gets what information and will help others to honor your wishes regarding health care decisions in the event that you are unable to express them yourself.
COMMUNICATION IS KEY TO GOOD CARE

One of the keys to good care is learning how to communicate with all the parties involved in your treatment — physicians, insurance company personnel, hospital staff, and others. Good communication takes preparation, an ability to remain calm in stressful situations, and the ability to be both considerate and assertive in your communications.

Before you contact any health care or other professional, be sure you have done your homework, are in the right frame of mind for a calm and persuasive discussion, and are prepared to record and share the information you learn. Remember your objectives and the reason you are calling.

GENERAL GUIDELINES FOR COMMUNICATING

These simple steps can help you prepare for and effectively conduct communications with your care team:

- Determine what information you need and explore one topic at a time.
- Try to remain calm in all conversations.
- Be prepared. Learn what questions to ask and write them down.
- Organize information in advance, starting at the beginning of the health care problem, but just convey the high points.
- Ask what is most important to you first.
- Be concise, stating what you need to know and why.
- Be persistent and follow up.
- Make multiple contacts via phone calls, letter, or e-mail if needed to get results.
- Pay attention to facts and details.
- Keep a log of contacts, phone numbers, names, dates, and information obtained.
- Never lose sight of your reason for advocating no matter how frustrated you may feel at times.

These general guidelines can help you get the information you need from physicians, insurance companies, hospital staff, and other medical personnel before, during, and after your care.
TALKING WITH THE PHYSICIAN

Talking with a physician about your condition or the condition of someone you care for can be difficult. Elderly patients, in particular, might hesitate to question physicians, nurses, or other health care providers because they were raised in a generation where medical professionals were considered to be above reproach. Physicians may use language that is unfamiliar or approach the patient’s condition from a different perspective than friends and family.

Compounding this is today’s harried health care environment. Physicians are caring for many patients simultaneously. Because of the many demands on their time, they are often forced to limit time with each patient when what most family caregivers and patients need is more time to understand the nature of their illnesses, treatments, and care options.

All these factors make it critical to prepare for a discussion with a physician. Whether you are communicating in person or on the phone, some simple preparation can help you get the most out of your conversation.

Before a call or visit with the physician:

- Make a list of your concerns and specific questions so you do not forget anything.
- Plan ahead to write things down during the meeting.
- If the meeting might be stressful or upsetting, bring along a family member or another person you trust to provide a second ear or record information that you might be too distracted to remember.

During a call or visit with the physician:

- Share your point of view. The physician will not know what you want or think unless you share it.
- Stick to the point. Focus the conversation on what you need to know now.
- If you do not understand something, ask for clarification.
- Do not assume. Ask questions even if the answers seem obvious.
- Do not jump to conclusions. Let the physician speak first and listen to what is being said.
- Write down the answers to your questions. If you cannot write down answers during the conversation, do so immediately after the visit or take along a trusted individual to write them down for you.
- Ask the physician to provide any important or complex instructions in writing, particularly those relating to medications.
- Ask for and record additional resources you can consult on what you are facing.
TALKING WITH THE INSURANCE COMPANY

During the course of your care you may need to contact specific individuals at your insurance company beyond those in the customer service center. The two most likely contacts are a claims supervisor or case manager.

1. **Consulting a claims supervisor.** A claims supervisor can help you resolve claim payment issues. Because of the complexity of health insurance plans, it is no longer possible to rely on the physician, hospital discharge planner, nurse, or hospital admission department to tell you whether specific costs are covered by your health insurance plan. Plan in advance for your call. Have any bills in question, your policy, and your specific questions at hand.

2. **Consulting a case manager.** A case manager, sometimes called a care manager or clinical care coordinator, is usually assigned to you by the insurance company if you have complex medical needs, a chronic condition, or an extended hospital stay that may include a subsequent need for follow-up services. Your case manager can help you understand your treatment options and access the right resources for your specific needs. If you feel you need a case manager and have not been assigned one, you can request one.
GETTING RESULTS WHEN YOU CALL THE INSURANCE COMPANY

- Make calls when you are not pressed for time.
- Be patient. Calls may require time, navigating through phone menus, or transferring from one person to another.
- Have in front of you the name, date of birth, and insurance policy numbers for the insured person, and any bills or explanation of benefits forms in question.
- Speak with a case manager or claims supervisor if possible. Try to speak with the same person each time. Ask for the name and number of the person you are speaking with in case you get disconnected.
- Ask your questions clearly. State what you need to know and what you expect from the person answering the call.
- Keep good notes including the date of the conversation.
- Remain considerate and polite but remember that you are the customer. Be assertive if it is necessary to get results.

STAYING AT THE HOSPITAL

Communication is critical at every stage of your hospitalization — at admittance, during the course of your stay, and as you prepare to be discharged. There is information you need to gather and information you need to convey to your care team. Follow the guidelines on page 15 for a more effective hospital stay.

CARE AFTER HOSPITALIZATION

When you or your loved one is released from the hospital, you may find it necessary to receive care either at home, in a nursing home, or in an assisted living community. For those who are terminally ill, hospice care may be needed. As with other aspects of care, communication is a critical component in making the health care system work for you.

COMMUNICATING AT HOME

Typically, the main contact for home care is a home care nurse who is responsible for coordinating a team of agency personnel and establishing a care plan. Keep an open line of communication with the home care nurse. Find out what information the home care team needs from you to provide the most effective care. Communicate crucial information such as location of advance directives, allergies, medications, physician information, and family contacts. Make certain you provide the agency with a minimum of two emergency contacts.
Navigating Your Hospital Stay

| On Admittance | • Tell the treatment team about allergies or dietary requirements.  
|               | • Communicate any medical problems or medications taken that are not directly related to your hospital stay.  
|               | • Make staff aware of hearing loss, vision problems, confusion, and other medical conditions that might affect care. |

| During the Stay | • Understand medications in use and any possible side effects. Monitor any medication changes.  
|                | • Know what complications might result and how to recognize them.  
|                | • Learn hospital routines. Know when the physician typically makes rounds so that you can get medical updates. Understand shift times so you know when nursing staff changes.  
|                | • Learn the language of care. Ask for the definition of terms you do not understand.  
|                | • Ask who to call for information during your stay.  
|                | • Stay actively involved in your care while at the hospital. This can help you be more attuned to your needs and speed your recovery.  
|                | • If you have concerns or problems you cannot resolve on your own, see if the hospital has a defined patient advocate who can assist you. |

| For Discharge | • Do not wait until the day of discharge to look into the next steps. Hospital stays are typically short.  
|              | • Determine who the discharge planner is as soon as possible during your stay and schedule an appointment if you think you may need any follow-up services or equipment upon discharge.  
|              | • If you have had previous care at home and you want to use the same agency, let the discharge planner know.  
|              | • Determine how you will pay for your care. Check with your insurance provider as necessary.  
|              | • Find out if follow-up care is required and whether it will be at home or in a residential facility. The discharge planner should make arrangements for needed services.  
|              | • Request copies of medical records to share with your primary care physician.  
|              | • Get a written list of all medications needed after you leave the hospital and the directions for taking them. Confirm with the physician that the list is correct and complete.  
|              | • Make sure all post-discharge questions are addressed.  
|              | • Make a post-hospital follow-up appointment with your physician before you leave. |
If you are advocating for someone else, ask to be part of the periodic planning conferences that are an essential part of quality care (and often required by regulations). Do not hesitate to ask questions or consult a supervisor if you feel care needs are not being met.

See also The Essentials: Receiving Care at Home and Emergency Information for Family Caregivers, Important Information for Caregiving and Personal Health Information tools.

COMMUNICATING WITH THE NURSING HOME OR ASSISTED LIVING COMMUNITY
Develop good communication with the staff. Do not assume that information regarding your health or a loved one’s health has been passed on to the new site. Get to know the head nurse, evening shift nurse, social worker, therapists, nursing assistants, and others on the care team. Be sure to praise good work and show appreciation to the staff. If caring for another, visit on a regular basis and at different times of the day to assess the quality of care.

Find out the procedure for sharing concerns. If you are concerned about your care or the care a loved one is receiving, do not be afraid to speak up. Let the staff know if you see changes in your loved one that concern you. It is best to discuss issues as early as possible so they can be addressed before they become a larger problem. If you do not get the results you want, consider contacting the long-term care ombudsman in your area for assistance.

See also The Essentials: Assisted Living Communities, The Essentials: Choosing a Nursing Home, and The Essentials: Preventing Elder Abuse.

COMMUNICATING ABOUT HOSPICE CARE
Hospice care is designed to assist both the individual in need of care and his or her family. End-of-life decisions related to treatment and care are rarely clear cut and are often made in the midst of multiple emotions and opinions. Physicians, nurses, social workers, and clergy can help clarify your options. Whether you are considering hospice care for yourself or assisting a loved one with the decision, it is important to openly explore all of your questions and concerns so that you can make an informed decision. Decisions about hospice care are best done through conversations and dialogue with all the people involved, especially the individual facing a terminal illness.
Monitor and Adapt

HOW TO MONITOR CARE

Your needs will change as your health conditions change. At every step of the way, remember that you are in charge of your own care. As your health care changes, your care team may change, too. You are the consistent link in the chain of communication, and it is up to you to stay on top of changing circumstances to ensure quality care and effective recovery.

Actions you can take to adapt to changing care:

- Ensure safe use of medications, particularly as they are modified.
- Keep your primary care physician in the loop about everything related to your health and let the physician help you to manage your care.
- Keep a record — forever — of procedures, medications, and treatments received so it is available as needed for future care.
- Make sure all financial issues relating to your care are resolved so they do not cause additional stress later.
- Share your findings along the way with the rest of the family and care team. It is important to keep all members of the care team updated on any changes to your medical history, condition, or medications.

During and after care, stay alert for signs that something may be wrong. No one knows better than you how your recovery is progressing, and you should communicate any concerns you have to family members and your care team.

What to Monitor

- Changes to medication
- New or changing symptoms
- Signs that needed care is not being received
- Changes to therapies or treatments
- Changes to the care team
- Medical test results
- Inconsistencies in care
- Dietary changes or changes in eating habits
- Mood swings or signs of depression
- Changes in sleeping patterns
If something about your care concerns you, immediately raise the issue with the members of your care team. If something seems unusual or inconsistent, ask about it. Remember that you are a critical link in the communication of those who provide your care. Do not assume that everyone has the same information.

At all stages of your care, pay close attention to your medications. When admitted to a hospital, communicate information on any medications taken prior to your hospital stay. Monitor medications given during your stay, paying particular attention to medication changes. Get written instructions for any medication you will be taking at home, including possible side effects to watch for.

See also The Essentials: Safe Use of Medications.

ADVOCATING FOR EFFECTIVE CARE

Advocating for the health of another requires the same attention to facts and details that your own care requires — and perhaps more. If your loved one is confused, disoriented, or too ill or tired to monitor his or her care, it is up to you to do so. How you advocate and who you have contact with will change as the health care situation changes. Here are some tips for staying on top of the situation:

- Keep good notes of all discussions with medical personnel, including the date of the discussion, name of the people involved, and the topics discussed.
- If you have items to follow up, do so as soon as possible after the meeting.
- Keep copies of all written correspondence and notes from all phone calls.
- Do whatever it takes to resolve the issue to your satisfaction. This may require multiple calls, letters, or e-mails. Persistence pays off.
- Share your findings with the rest of the family and care team. It is important to keep all members of the care team updated on any changes in medical history, medications, and other pertinent data.

See the tools Family Caregiver Emergency Information, Important Information for Caregiving and Personal Health Information.
ADAPTING TO CHANGE

Your care experience may restore you to your previous health or may require you to adapt to new circumstances. As you adapt after your care, stay mindful of what it takes to manage your ongoing health care needs. Keep apprised of changes to the health care system and to your health care team. Keep your documents and resources current and available. Continue to monitor your health and communicate with medical and insurance professionals. If you are acting as an advocate for another, stay alert to changes in his or her medical condition or signs that additional resources may be needed.

While managing your health care may seem daunting, knowledge and persistence pay off. You will receive better quality care, become more attuned to what you need to do, and have better information if you stay in charge. Become an informed advocate for yourself and those you love as you face future health challenges.
Resources for You

American Bar Association Commission on Law and Aging  
www.abanet.org/aging / 202-662-8690  
A group that seeks to support and maintain the quality of life for elders. Its Web site contains information on a variety of topics including health care decision-making tools, state-specific contact numbers, and resources for legal assistance for older adults.

American Board of Medical Specialties  
www.abms.org / 312-436-2600  
A non-profit organization that assists a variety of approved medical specialty boards in the development and use of standards for the ongoing evaluation and certification of physicians. Its Web site can help verify the specialty in which a doctor has been certified.

The American Geriatric Society Foundation for Health and Aging (FHA)  
www.healthinaging.org  
A national non-profit that advocates on behalf of older adults and their special health care needs. The Web site contains comprehensive resources such as the online guide ElderCare at Home and the “What to Ask” series for communicating with health care providers.

The Assisted Living Federation of America  
www.alfa.org / 703-894-1805  
A national association exclusively dedicated to professionally operated assisted living communities. Its Web site contains a searchable assisted-living facility provider directory, state rules, regulation changes, and new developments in the industry.

Eldercare Locator  
www.eldercare.gov / 800-677-1116  
The Eldercare Locator, a public service of the Administration on Aging (AOA), U.S. Department of Health and Human Services provides older individuals and family caregivers with information on state and community resources in their local area.

Family Caregiver Alliance (FCA)  
www.caregiver.org / 800-445-8106  
Provides information, education, services, research, and advocacy for caregivers. The Web site is a resource for informational fact sheets including one on Alzheimer’s disease, online support groups for caregivers, and the “Family Care NavigatorSM,” which allows you to search for resources on a state-by-state basis.

Federation of State Medical Boards  
www.fsmb.org / 817-868-4000  
A national non-profit organization that promotes excellence in medical practice, licensure, and regulation. Its Web site has contact information for each state’s medical board.