

- Question and clarify contradictory information. This will help you to understand your care better and assures that the team members are working together.
- Know your medications, the tests you have had and their results.
- Know your allergies, situations in which you have had complications or reactions to medications or treatments.
- Tell your care team about any over-the-counter or herbal medications you may be using. Often these can interact with or interfere with prescribed medications.

- Be alert to caregivers who are unfamiliar to you. If you encounter someone you don't know or weren't expecting, ask what their role is, do they know the others on your team, have they discussed your case with them.

Remember no question is insignificant. Ask about anything and everything you don't understand.



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ROLE OF THE PATIENT ADVOCATE



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Illness is a stressful time for patients as well as for their families. The best-laid plans can go awry, judgement is impaired, and put simply, you are not at your best when you are sick. Everyone who is sick needs someone who can look out for their best interests and help navigate the confusing healthcare system, in other words, an advocate. This may be a spouse, a child, another family member, or a close friend. Hospitals usually have professionals who play this role called Patient Representatives or Patient Advocates. Social workers, nurses and chaplains can also be helpful.

An advocate is a "supporter, believer, sponsor, promoter, campaigner, backer, or spokesperson." It is important to consider all of these aspects when choosing an advocate for yourself or someone in your family. It is important to choose someone willing to act on your behalf as well as someone you trust and can work well with other members of your healthcare team.

Choosing your advocate is just the beginning. Below are some tips to help you think through how you want to work with an advocate.

BASIC CONSIDERATIONS FOR ALL ADVOCATES

- Be clear about what you want help with and what you want to handle on your own.

You may want help with:

- Clarifying your options for hospitals, doctors, diagnostic tests and procedures or treatment choices;
- Getting information or asking specific questions; or,
- Assuring that your wishes are carried out when you may not be able to do that by yourself.
- Select a person you can communicate with and that you trust. It's important to pick someone who is assertive and who has good communication skills!

WHEN A FAMILY MEMBER IS YOUR ADVOCATE

- Let your physician and those caring for you know who your advocate is and how you want them involved in your care;
- Be very clear about what you would like the advocate to know and be involved in—Treatment decisions? Any change in your condition? Any new tests that are ordered for you? Test results? Medication lists?
- Arrange for your designated advocate to be the spokesperson for the rest of your family and make sure your other family members know this.

This will provide a consistent communication link for your caregivers and will minimize confusion and misunderstandings that can arise when many versions of a story get passed around a family.

- Family members often see more than patients—and indeed may view things differently. Select a trusted member of your family and rely on their judgement.
- Devise a list of questions together and make sure that they are all answered.
- Ask for all information in writing: medication list and directions, discharge instructions, explanations of tests and test results, appointment information.
- Make sure your doctor and nurses have your advocate's phone number and make sure your advocate has their numbers.
- Decide if you would like your advocate to accompany you to tests, appointments, treatments and procedures. If so, insist that your doctor and other caregivers allow this.

WHEN A PROFESSIONAL IS YOUR ADVOCATE

- Professional advocates can be very effective at cutting through red tape.
- Be very specific about what kind of help you do and don't want.
- Clarify what the advocate can do for you and when to expect follow-up.

- Let the professional advocate know if you have a family member or friend you would like them to communicate with.

Ensuring your safest care

The best strategy here is to be as informed as possible. Learn as much as possible about your illness, treatment alternatives, medications you are taking, and planned and expected tests and treatments. Get help searching Web sites, reading available information, and try to talk to other patients and their family members who have had the same condition or experience. Hospital librarians can be very helpful and many healthcare organizations have information about formal and informal networks of patients and support groups. Ask about what to expect, what was successful for them and what they would do differently. You can also contact disease-specific organizations such as the American Cancer Society or the Arthritis Foundation. An excellent place to start for good clinical information from the Internet is the National Library of Medicine Web site, www.medlineplus.gov.

Learn about your health-care providers, hospital, physicians, health plan, pharmacy, home care agency, and nursing home. Find out what services they offer, how they resolve disputes should they arise, and what their reputation is in their community.

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Two good sources of information about health plans and nursing homes are www.medicare.gov and www.ncqa.org.

Write down your questions and practice asking them! It is hard to question your caregivers or complain when you feel vulnerable or when you think it may get someone in trouble. It's important to remember that everyone taking care of you wants the best for you and they need to know when something goes wrong. That's the only way they can identify problems to make sure they never happen again. If you speak up about a problem and nothing happens, it's time to involve your family and professional advocate!

HERE ARE SOME TIPS TO ENSURE YOUR SAFETY:

- Ask questions, read labels, ask for explanations, take nothing for granted.
 - Insist on explanations and clarification if you feel you are receiving conflicting information from the people taking care of you.
 - Ask everyone who comes into your room to identify themselves, and tell you their name and why they are there.
 - Identify yourself—let the staff know what you would like to be called.
- Ask for written information about medications you are given in the hospital and when you go home.
- Don't be afraid to question some thing you don't understand—

never agree to a test you were not expecting, a medication you did not know you were taking, or any thing else that is a surprise.

- Insist staff check your armband before they take you for tests, give you oral medications, or put any thing in your intravenous fluids.
- Pay attention to symptoms—pain, nausea, drowsiness, dizziness—often these are side effects of medications or treatments. Don't ignore them. Make sure your nurses and doctors know how you are feeling.
- Always ask for help if something just doesn't "feel right".
- Ask what, when, why, and how about everything!

Discussing Safety with your Doctors and Nurses

Safety is everyone's responsibility. Your involvement and participation is the best way to ensure your own safety.

Let your caregivers know what is most important to you. Everyone has particular concerns, pet peeves, and past experiences—both good and bad—that impact the way we think and feel about our care and caregivers. Discuss these with your care team. They can then work to allay any fears or misunderstandings you may have, or to modify their care and treatments based on your needs.

Decide how you want to be involved in your care. Some people want to know about every option available for diagnosing and treating their problem and they want to make

all of the decisions. Some people only want to know about the diagnostic and treatment options their doctors recommend. Some people want to know everything about certain things and nothing about other things like prognosis. Some people want to leave everything up to the people taking care of them.

There are no best ways to be involved in decision-making other than making sure you do what's right for you and letting your doctors and nurses know what you want!

It is alright to change your mind. Any illness takes a toll on energy and emotions. You can change your mind about anything you have decided at any point. Just let your caregiver, family and/or advocate know what you've changed your mind about and why.

If you think a mistake has happened or something is not right, talk with your doctors and nurses about what to do and who to call. This is also something your advocate can do for you. If you are not comfortable talking about mistakes, consider writing a letter later or describing the problem in a patient satisfaction survey. This is important information to

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healthcare providers. If you are comfortable, indicate you would be willing to discuss it with someone at a convenient time. Your feedback is key to improving care for everyone.

Advocating patient safety—the role of the team

Teams of caregivers are the norm in our healthcare system, while each team member brings a specific talent and focus to enhance your care, the complexity of this process can lead to misunderstandings, inaccurate assumptions and miscommunication.

There are many things you can do to help:

- Include yourself as part of the team. You are involved in this case!
- Announce this frequently, if you feel others are forgetting about your role.
- Don't assume information about you is passed along. Information about your specific case, your care or how you want to be involved may not be passed from caregiver to caregiver. You may need to "remind" each one of what you need. It may even be helpful to write down how you want to be involved and make copies you can share with the people on your team.

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