

Taking an active role in the treatment of your loved one can help ensure that he or she gets high-quality care. Your participation is vital, because you are an important member of the health care team.

You know the patient better than anyone on the medical team. You care for your loved one daily, and you can tell the medical team about changes you have noticed, such as when the patient's appetite is poor, when a medication's side effects are burdensome, or when a mood is low.

To make the most of each visit with your health care team, try these tips:

- **Be prepared.** Come to appointments with a list of questions. (*For questions to help get you started, see the **Addendum** at the end of this document.*)
- **Take notes.** This can help you remember what the doctor says.
- **Record it for later.** Ask the nurse or doctor if it's OK to use a tape or digital recorder to record the discussion for later review.
- **Get the answers you need.** Ask the doctor to explain anything you don't understand. Ask yourself, "How much do I want to know?" Don't be afraid to tell the doctor how much, or how little, information you want. And don't worry about changing your mind over time.

*"I used a big notebook to keep things organized."
—Gail, caregiver of a patient with myeloma*

How to Problem-Solve with the Health Care Team

During cancer treatment, members of the health care team can become like family. You'll spend a lot of time with them and share some of the most intense experiences of your life. But, as with any family relationship, discord can arise. When this happens, speak up – even if you're uncomfortable doing so.

Most health care professionals want to meet the needs of their patients and their families. If something is wrong, they welcome the opportunity to fix it. Here are some steps to help solve difficult issues:

- **Define the problem.** Is it an issue with the oncologist, a member of the health care team, or the doctor's office? Figure out exactly what's bothering you to ensure you're directed to someone who can help.
- **Take your problem to the person who can solve it.** If you want more information from the oncologist, approach the doctor. If the problem is with the

doctor's office, speak to the manager. If you're not sure who can fix the problem, ask your nurse for suggestions.

- **State your concern clearly.** Consider sandwiching your concern between compliments if you're worried you might sound angry (e.g., "You're a great oncologist, Dr. Smith, but I can't always wait an extra 30 minutes for you to see Jim; I need to get to work. What suggestions can you make to help reduce our wait time?") If you think you have a solution, suggest it ("Could we get the earliest appointment in the morning?").
- **Ask for help.** Voice your concerns to a nurse, social worker, or chaplain who can help you evaluate the issue and make suggestions.

If the situation doesn't improve:

- Call Dana-Farber's Patient/Family Relations Department (617-632-3417) or Ethics Consult Service (617-632-5713). These master problem-solvers will listen to your concerns and work with you and the health care team to find a solution.
- Sometimes you may choose to switch team members. Perhaps you can be assigned to another infusion nurse, for example.
- You might choose to live with the trade-offs. For example, you may find that a certain doctor's expertise is worth waiting for appointments. Deciding what is critical to the care of your loved one may help shift expectations.

Get Help from an Ethics Consult

When you face a difficult issue, Dana-Farber's Ethics Consult Service may be able to help. The service can help everyone involved in a patient's care talk about, understand, and come to agreement about ethical issues concerns or issues such as:

- Resolving conflicts with caregivers or loved ones
- Deciding whether to stop anticancer treatment
- Making decisions about cardiopulmonary resuscitation (CPR)
- Planning for a time when a patient may no longer be able make medical decisions (advance directives or surrogate decision-making)

To request a consult, call the ethics hotline and voicemail at **617-632-5713**. Learn more online at www.dana-farber.org/pat/support/ethics-consultation-service.

Privacy and the Doctor-Patient Relationship

It's important to remember that *patients* have control over information that is shared about them. Caregivers are usually included in conversations with the doctor unless the patient objects. In most cases, the patient's wishes will be honored. Consider the following situations:

When you and the patient have the same desire for information: If you're someone who likes to read the "fine print," and your loved one does too, it should be easy for the medical team to convey the information you want.

When you want more information than the patient wants: Your loved one may be satisfied with the oncologist’s observation that “everything looks stable,” but you may want to understand exactly what “stable” means. How do you get *your* needs met? Try these tips:

- Educate yourself about your loved one’s disease and its treatment, so that when the oncologist says that “everything looks stable,” you understand what that means.
- Ask to speak to the oncologist if you have general questions about cancer.
- Ask another member of the health care team to explain things to you while your loved one is busy having blood drawn or undergoing a procedure.

When the patient wants more information than you: If you’re satisfied with the oncologist’s observation that “everything looks stable,” but your loved one wants to know exactly what that means, consider leaving the consulting room to allow for private time between oncologist and patient.

When you’d prefer information be kept secret:

There may be times when you learn information about the patient’s condition that you don’t want shared with him or her. Maybe “cancer” is a death knell in your culture and you don’t want that word used around the patient. Or perhaps the patient’s condition isn’t improving, and you’re worried that he or she will lose hope and refuse treatment. What can you do?

- **Express your concerns to the health care team.** Be prepared: There may be times when they can’t follow your wishes.
- **Ask a hospital chaplain, social worker, or therapist to learn what support is available to your loved one,** particularly if the doctor has bad news to convey. Problem-solve together about how to discuss difficult subjects.
- **Talk with other patients or a social worker.** Consider getting help for yourself, so that you feel as prepared as possible to manage whatever comes your way.

Getting Started

Talk with your loved one about his or her needs for information. Decide how much detail you both want to know. How will this information be conveyed? Do you plan to talk with the doctor together, or does your loved one prefer to keep those discussions private? Start talking – and keep talking. People’s needs change over time.

If you feel others may be keeping secrets: There may be times when you feel the medical team is sharing more information with the patient than with you. You don’t fully understand what’s going on, and you feel something is wrong. It may be that your loved one has requested that the medical team

“George feels his doctor knows best, and doesn’t ask many questions. I usually go ahead and just ask.”

— Gail, caregiver of patient with myeloma

not share health information with you. In this case, the patient's request will likely be honored.

If you feel the health care team isn't giving you information you feel is important, first talk with your loved one. Ask whether he or she has asked the health care team to avoid providing you with information on his or her condition.

If you want the full story, let your loved one know. While you may not be eager to hear bad news, you may prefer to know and prepare for it than to be surprised. And you may prefer to share the roller coaster of cancer treatment with a person you love, rather than have each of you ride alone.

To view Dana-Farber's full privacy policy, visit www.dana-farber.org/privacy.

If your loved one tells you he or she has given the team permission to share information about your condition and you still feel that information is being kept from you, ask the doctor for a meeting, so that you can clear the lines of communication.

Managing Pain

The Pain and Palliative Care Program at Dana-Farber/Brigham Women's Cancer Center helps patients live as well as possible while facing a serious or life-threatening illness. Palliative care can be helpful through all stages of illness. Early on, it can help make medical treatments more tolerable; at later stages, it can reduce suffering, help you carry on with your daily life, assist in planning for future medical care, and provide support for living with a life-threatening illness. To learn more, visit us online at www.dana-farber.org/pat/adult/pain.

Put Your Values in Writing

Making sure that a patient's beliefs and values can be upheld even when he or she can't communicate is the purpose of advance care directives, which include health care proxies and living wills. Get a free copy of the Massachusetts health care proxy form by calling a patient representative at **617-632-3417**. If you have questions about the document or want to discuss the decisions involved in signing it, please call a Dana-Farber social worker at **617-632-3301**.

The National Hospice and Palliative Care Organization offers health care proxy and living will forms for each state on its Caring Connections Web site. Find documents for your state online at www.caringinfo.org/stateaddownload.

Addendum: Helpful questions about cancer diagnosis and treatment

Asking questions can help you and your loved one get the most appropriate care. Be persistent until you understand the answers. Don't be afraid to ask for clarification.

The Leukemia & Lymphoma Society recommends the following questions to learn more about any type of cancer diagnosis and potential treatment options. Print these out and have them handy at your loved one's health care appointment.

Physician's name _____ Date _____

1. What do the blood tests show? How do the results compare to "normal"?
2. When will these tests need to be repeated?
3. What are the goals of treatment?
4. Is there a standard treatment?
5. Is there one option that you recommend over the others? Why or why not?
6. What is the risk versus benefit of each option?
7. What are the chances for a remission or a recurrence?
8. What are the risks if the disease isn't treated? Should we "watch and wait"?
9. When do you think treatment will begin?
10. Does the patient have a choice about when to begin treatment?
11. Does the patient have a choice about which days or time of day to have treatment?
12. Where will treatment take place?
13. How many treatments will be involved?
14. What drug or drugs will the patient need to take?
15. How will the drugs be given?
16. How long will each treatment last?
17. Will the patient need help on the day of treatment?
18. Are there any signs or symptoms I should watch for after the patient finishes treatment? For how long?
19. Will the patient be able to work or go to school while on treatment?
20. Will the treatment be paid for by the patient's health insurance (or Medicare)?
21. Should the patient be enrolled in a cancer clinical trial?
22. How often and how long will the patient need treatment or follow-up visits?
23. What type of follow-up tests will be needed?
24. Will we need to change our daily routine?

Questions about side effects

1. What are common side effects of this treatment?
2. What are less common side effects of this treatment?
3. When are side effects likely to happen?
4. Are there any side effects we should tell the doctor about right away?
5. What can I do to help ease side effects?
6. What are the long-term and late effects of my treatment?
7. Will this treatment affect fertility, pregnancy, or breast-feeding?

Addendum: Questions about surgery

If surgery is recommended, find out all you can about the benefits, risks, and side effects of the operation. The American Cancer Society recommends the following questions to help you feel more comfortable with the decision.

1. Why is the patient having this operation? What are the chances of its success?
2. Is there any other way to treat this cancer?
3. Other than cancer, is the patient healthy enough to go through the stress of surgery and anesthesia?
4. Are you certified by the American Board of Surgery and/or Specialty Surgery Board?
5. How many operations like this have you done? What is your success rate? Are you experienced in operating on this kind of cancer?
6. Exactly what will you do in this operation? What will you be taking out? Why?
7. How long will the surgery take?
8. What can we expect after the operation? Will the patient be in a lot of pain? Will the patient have drains or catheters? How long will the patient be in the hospital after surgery?
9. Will the patient need blood transfusions?
10. How will my loved one's body be affected by the surgery? Will it work or look different? Will any of the effects be permanent?
11. How long will recovery take?
12. What are the possible risks and side effects of this operation? What is the risk of death or disability with this surgery?
13. What will happen if the patient chooses not to have the operation?
14. What are the chances that the surgery will cure the cancer?
15. Do we have time to think about options or get a second opinion?

Addendum: Questions about radiation treatment

The American Cancer Society recommends these questions to help you learn more about radiation treatment and why it may be needed.

1. What is the purpose of radiation treatment for this type of cancer?
2. How will radiation therapy be administered? Will it be external beam or brachytherapy? Can you explain the difference?
3. Will the treatments hurt?
4. For how many weeks will the patient receive radiation? How many treatments will be needed per week?
5. What are the chances that radiation therapy will work? What is the chance that the cancer will spread or come back if the patient doesn't have radiation therapy?
6. Will the patient need chemotherapy, surgery, or other treatments? If so, in what order will treatments occur, and how soon after radiation therapy will they start? How can I expect the patient to feel during treatment and in the weeks following radiation therapy?
7. Can the patient drive alone to and from the treatment facility?
8. Will my loved one be able to continue normal activities, including exercise?
9. What side effects may occur from radiation, and how are they managed?
10. Will radiation therapy affect our sex life or the ability to have children?
11. Does the patient need to take any special precautions, like staying out of the sun or avoiding people with infectious diseases?
12. Do I need to prepare a special diet during or after treatment?
13. Will side effects change the patient's appearance? If so, will the changes be permanent or temporary? If temporary, how long will they last?
14. How often does the patient need to return for checkups?
15. How soon can the patient go back to regular activities? Work? Sexual activity? Aerobic exercise?
16. Do you accept the patient's health insurance?