Communicating with Your Healthcare Team

Information for people living with cancer and their family caregivers

The EPEC Project

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Introduction

As a person living with cancer or family caregiver, you will have many visits with your healthcare team. During these visits, your healthcare team will tell you important information about your cancer treatment. They should also address your concerns and answer your questions.

A medical visit can be stressful and overwhelming. You may have many questions and concerns that you want to ask your doctor while also having to absorb critical information about your condition or treatments. If you have interacted with physicians who appeared to be too busy and did not have time to listen to you, you may feel reluctant to share important information or even ask questions.

Good healthcare depends on clear communication between you and your healthcare team. This brochure gives important steps to take before, during and after a medical visit to ensure your needs are communicated and addressed.

Before your visit

There are some important ways you can prepare for a medical appointment. Below you can find steps to make sure your questions are answered, you have important information recorded and you feel comfortable communicating with your healthcare team.

► American Cancer Society
Toll-free: 1-800-ACS-2345
www.cancer.org
An information specialist can answer your questions 24 hours a day, seven days a week. They can also help you find support groups in your area. The website also has information on talking with your doctor.

► National Coalition for Cancer Survivorship (NCCS)
Toll-free: 1-877-622-7937
www.canceradvocacy.org
As the oldest survivor-led advocacy organization, NCCS is a highly respected authentic voice at the Federal level, advocating for quality cancer care for all Americans and empowering cancer survivors. You can also find information about communicating with your doctor and building a healthcare team on the NCCS website.

Additional Resources
Here are some ways you can prepare for your visit:

► **Write down all of your questions and concerns**
Thinking about your questions and concerns before you meet with your healthcare team can help you communicate better. Use the LIVESTRONG™ Guidebook or other health journal to check in with yourself and to record any symptoms, signs or changes you experience. Be sure to note physical, emotional and practical concerns.

► **Research your condition**
Contact the cancer organizations listed in this brochure to find more information about your cancer type. Learn about treatments, medications, side effects, symptoms and clinical trial options. You can also search on the Internet or at the library. This information will help you ask better questions. You can also ask a friend or family member to help with research.

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**Resources**

The following resources can help you when talking with your healthcare team:

► **National Cancer Institute – Cancer Information Service**
Toll-free: 1-800-4-CANCER or 1-800-422-6237
www.cancer.gov
You can speak with staff who can explain medical information in easy-to-understand terms. The website also includes multiple resources on coping with cancer.

► **Lance Armstrong Foundation (LAF)**
Toll-free: 1-866-235-7205
www.livestrong.org/cancersupport
At the LAF website you can read topics about talking to your doctor and order a free LIVESTRONG™ Guidebook. You can also call LIVESTRONG™ SurvivorCare, which can provide you, your family, friends and caregiver with information, education, counseling services and referrals to other resources. They will also help with financial, employment or insurance issues. You can also speak to a case manager Monday - Friday from 9am – 5pm EST.
▶ Determine your goals for the visit
It may be helpful to list your questions and concerns in order of importance to you. You can also mail, email, or fax a copy of your questions or health journal to your healthcare team in advance.

▶ Bring a friend or family member to doctor’s visits
It is hard to remember all of the information that your doctor tells you. Friends and family can help you take notes and ask questions during your visit. The role they play is up to you—emotional support, asking questions or just note-taking; staying or leaving during the physical exam. Discuss their role before the visit.

## During your visit

▶ Tell your doctor what you do and do not want to know
Some people living with cancer may want to know as much as they can about their diagnosis and treatment. Others may want only general information. Your doctor should ask how much you want to know about your health. It is your decision how much or how little you would like your physician to share with you. It is important that you tell your family and doctor the amount of information you want to know.

▶ Find emotional support
When you feel sad or overwhelmed, talk to your family, friends, or others living with cancer about your feelings. Here are other people to whom you and your family or loved ones can talk:

- **Counselor**
  Ask your healthcare team to help you find a counselor who can meet your needs.

- **Chaplain or other spiritual advisors**
  Get support from churches or other faith groups. Your doctor or social worker can also refer you to a chaplain or spiritual advisor.

- **Cancer support groups**
  Many survivors find support groups helpful. You can hear other survivors' stories and learn ways to deal with your concerns. Hospitals or cancer treatment centers may have support groups that you can join. Ask your doctor or social worker or call LIVESTRONG™ SurvivorCare for help finding a support group in your community. You may also consider joining an online support group. Support groups are also available for family and friends of people living with cancer.
that your doctor answer all of your questions. Ask the doctor or nurse for anything that would make you feel more comfortable. You may want your friends or family to join you. Again, it is your decision how much information you would like your physician to share with you.

**After your visit**

Review the notes from your healthcare visit and follow through on any next steps. Talk to your family, friends or loved ones about the notes from the doctor’s visit and any changes in your treatment plan or medical history. Ask for help in sharing the news with your other family and friends. If your family has questions, either write them down in your health journal to ask during your next visit or contact a member of your healthcare team.

The following tips may also help you and your family deal with upsetting news:

► **Do things that you enjoy**

Take time for things that you enjoy such as hobbies, movies, and exercise. If possible, plan a vacation or visit people you love. Doing things you can enjoy may take your mind off of your cancer and how overwhelmed you are feeling.

► **Share your Health Journal with your doctor**

It is important to tell your doctor what concerns you have even if he or she does not ask. Show your doctor your health journal and talk about each of your physical, emotional and day-to-day concerns. Although a doctor may not have a lot of time, you have the right to talk about all of your concerns.

This may include information about:

- Your condition
- Your treatment, side effects, and how well it might work
- Experimental drugs and treatment options

With your permission, your healthcare team can also help you to tell your family and friends.
► **Ask questions about things you do not understand**

It is important that you understand your treatment plan. If you do not understand something, ask your healthcare team member to explain what it means in a way that you understand. You can say something, such as:

"You just mentioned __________. Could you help me understand what you mean?"

"You said that you would recommend ____ treatment. Could you tell me more about how that will affect me?"

You should not leave until your questions are answered clearly. Do not be afraid to ask questions until you are comfortable with the information. If needed, ask your doctor if an interpreter is available.

► **Talk about your feelings and emotions**

It is normal to have many emotions when dealing with cancer or when told upsetting news. It is important to tell your doctor the feelings and worries you have.

Your doctor should listen to your feelings. She or he may also give you the names of other healthcare team members who can offer emotional support, such as a social worker, counselor, or chaplain.

► **Ask your doctor what to expect**

Your doctor will work with you to decide what next steps to take. You should know what to expect with your treatment.

Your next steps may include:
- Returning for a future visit with the doctor
- More treatment
- Seeing another doctor
- Asking for a second opinion
- Getting more tests
- Talking to your family, friends and loved ones
- Talking to a social worker or counselor

► **Have a family member or friend record important information.**

An alternative is to use a tape recorder during the visit. You may be worried that your healthcare provider will be uncomfortable if you tape record what is said. One way to bring this matter up is to say something, such as:

"I am worried that I might forget some of the things that we discuss. I hope it is okay if I record our conversation."

During each visit, you may receive news about changes in your condition. The information your doctor may tell you can be upsetting.

► **Ask for a quiet place to talk**

Your doctor should take you to a private room when talking about your cancer. It is important