

Questions to Ask

Whether you are just beginning treatment, are a long term survivor, or somewhere in between, you probably have some unasked or unanswered questions. You might be concerned about your symptoms or want to ask about treatment options. You may have obtained copies of your medical records and read something you don't understand. Or perhaps you would like guidance about resuming your routine activities.

We encourage you to take these questions to your health-care team. Your doctors and nurses can respond with personalized answers which cannot — and often should not — be provided by outside sources. By asking questions you're participating in your healthcare. By gathering information, you'll feel more comfortable making decisions about your treatment plan.

In this chapter, we offer some sample questions you may want to ask at various times during your illness. Feel free to modify this list based on your particular concerns and situation.

Talking to Your Healthcare Team

Make a list of your questions and bring them with you when you visit your doctor. Be sure the questions that concern you the most are at the top of the list. If you think of other questions after you return home, begin a list for the next visit.

If you want to bring family or friends with you when you visit your doctor, make an appointment for a conference. Let the receptionist know the purpose of your visit — that way, a block of time can be set aside for you.

Your First Visit

Many people don't remember much when their doctor first tells them they have a serious disease. Try to come away with some basic information:

- Where is the tumor located?
- Based on the scans, do you have an idea of the type of tumor?
- What is the next step? Do I need more tests? Do I need to see any specialists?
- Until we know more, should I continue my daily routine? Can I work? Should I drive?
- Do I need to take any medication? If so, what is it for? What are the side-effects?

About Insurance

After your first visit, you'll need to verify your healthcare insurance coverage. The answers to most of your insurance questions can be found in the insurance policy itself or the policy manual. If you don't have a copy, now is the time to obtain one.

For employer-provided health insurance, contact your employer's Human Resources office or your benefits manager and ask for the manual. For individual policies, call your insurance agent. For Medicare/Medicaid coverage, call the Medicare Hotline at 800-633-4227. For CHIP coverage (Comprehensive Health Insurance Programs) through your state, call your state Department of Insurance.

If you are uninsured, please begin by contacting the social worker at the hospital at which you will be treated. You can reach the social work department by calling the general hospital number and asking for the social work office. The social worker can outline federal assistance programs, local and national funding organizations, and ways to help you obtain alternate forms of healthcare coverage.

QUESTIONS FOR YOUR INSURANCE PROVIDER

Be sure you know the answers to these questions:

- Do you need to obtain pre-certification for hospitalization or treatment? If so, who do you call? Most insurers include the pre-certification telephone number on the back of the insurance card. When you call, be sure to record the name of the person you speak with, the date, and the "case number" assigned to your claim.
- Do you need to obtain a second opinion before non-emergency surgery? If so, are there any limitations on who provides the second opinion?
- Do you need to stay within a particular network of hospitals or physicians to receive your benefits? Do you have a current list of those providers? What will happen if you are treated "outside the network?"
- Does your policy have a deductible? If so, how much of that deductible have you paid for the year? Knowing this will help avoid "surprise" bills for which you are responsible.
- Will your insurance cover investigational treatment if you choose it?

Seeing a Specialist

One of your next visits will likely be to a specialist. Regardless of whether the next step is a consultation regarding surgery, radiation, chemotherapy or another treatment, the basic questions are very much the same.

QUESTIONS FOR A SPECIALIST

You'll want to know:

- What treatment is recommended?
- What is the goal of that treatment? To cure the tumor, to control the tumor, or to control symptoms?
- What are the potential benefits of the treatment?
- What are the risks and side-effects of the treatment?
- What will happen if I don't have this treatment, or if I postpone it?
- Are there other options beside this treatment?
- Is this an experimental treatment?
- Will I need any more tests before the treatment begins?
- How will we know if the treatment was effective?
- What type of follow-up will I need, and when?

Following Treatment... A Next Step

Eventually, the frequent appointments for therapy stop, and the dates for follow-up care become further apart. The pace slows, and another period of adjustment begins. Now is the time to begin re-defining "normal" in your life. It's a time to slow down and be good to yourself.

QUESTIONS FOLLOWING TREATMENT

When you finish your last treatment, be sure you know:

- When is my next doctor visit? Which doctor(s) do I see, and how often?
- When is my next scan? Do I need a doctor's order? How will it be scheduled?

- Do I need any medications? If so, are there any potential side-effects?
- Can I work? If so, do I have any restrictions on my activities? Will I need any work site accommodations?
- Can I drive?
- Can I exercise? If so, do I have any limitations?
- What type of diet should I follow? Is there a registered dietician I can consult to provide me with healthful eating guidelines?

Living with a Brain Tumor

As time goes on, you and your family may have questions about concerns common to all people living with a brain tumor — patients and family members alike. Those concerns may involve:

- financial assistance
- employment interests
- vocational re-training
- obtaining new health insurance
- sexuality
- forming new relationships
- starting or adding to your family
- parenting
- counseling or support groups
- rehabilitative services
- cosmetic and image interests

As more brain tumor patients become survivors, there are increasing resources for people living with a brain tumor. Tap into these services and learn how they can help enrich your life. Our social work program can help you explore these, and other, opportunities. Please feel free to call us at 800-886-2282.