Information for the Asking

Questions to Help You Get the Information You Need from Your Healthcare Providers

Provided by

The **Alliance for Lung Cancer Advocacy, Support, and Education** developed this booklet of questions to help you work as effectively as possible with your healthcare providers and to get the information you need to make informed choices.

We hope you find it helpful.

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Facing the diagnosis and treatment of cancer is difficult at best. However, with some planning and forethought, finding your way through what may seem like an endless maze of tests, doctors, other healthcare providers, and medical jargon can become easier. We hope the following information will be helpful to you as you proceed on your lung cancer journey.

Personal Decision-Making Style

Each of us has a different personal decision-making style. It is especially important for you to identify your style so that your specific information needs can be met in the best possible manner. Read through the following statements and determine which one best fits your own personal style for making medical decisions:

- I prefer to make the final selection of my treatment(s) after seriously considering my doctor's opinion.
- I prefer that my doctor make the final decision about which treatment(s) will be used, after seriously considering my opinion.
- I prefer to make the final selection about which treatment(s) I will receive.
- I prefer to leave all decisions regarding my treatment(s) to my doctor.

It is important to understand that there are no right or wrong answers, and remember, your style may change as you proceed through diagnosis and treatment. It will be important to find healthcare providers who respect and understand your personal decision-making style, so give some serious thought to your needs when choosing healthcare providers. Studies have shown that the relationship between patient and physician is extremely important. If you are in a managed care program, though, your choices may be limited.

We have also added tips in this booklet to help you develop better communication, even with someone whose style differs significantly from yours. And, often, you may find that the person who becomes your best teacher and advocate is some member of your healthcare team other than your physician. The bottom line is: if your physician can't fill all the roles you need, find someone else in the system who can!

Finding an Advocate

As you progress along your journey with lung cancer, you will find it is very helpful to have someone in your healthcare system with whom you can really communicate. This may be your primary-care doctor, your surgeon, your medical or radiation oncologist, or your pulmonologist. But there are others who you will see regularly, such as a nurse or social worker. Be sure to find at least one of these people to whom you can relate. Talk to this person openly about being your advocate to help you get what you need and what you want.

Personal Information Needs

After determining what your personal decision-making style is, it is also important to think about how much information you need to make yourself comfortable with your diagnosis and treatment options. Some people need as much information as they can possibly gather. Others find that less information, or information with a specific focus, is best for them. Some cancer survivors find it helpful to hear only the good news. Others want the whole picture, including the negative possibilities. Again, let your doctors and healthcare team know what your needs are. They may be able to provide you with print or other information, as well as point you toward other resources that can help you gather whatever information you find necessary.

The Bottom Line

It is important to remember that the questions that follow are designed to help you feel comfortable with your all of your healthcare options. You have a right to be at ease with your decision-making style, your treatment decisions, and your healthcare team. Your doctor should help you to achieve your optimum comfort level. All members of your healthcare team can do this best if you are willing to work with them in an honest, straightforward manner. Use what you know about yourself as a person to help yourself as a patient.

When you think of a question that isn't on the following lists, write it down. It is best to have your list typed, if at all possible, so that it can be easily read. Or you can copy these lists and add your own questions to them. Either way, printed lists can save your physician, or others to whom you go for information, a lot of time. And, they will all be grateful for this consideration. You may want to submit your questions to your doctor or nurse sometime before your scheduled appointment so that they will be able to prepare answers and/or do any necessary research.

Ask your doctor if you can take notes or audiotape your appointments, or if you can bring a friend or family member to your appointment to take notes for you. Appointments can be stressful, and you cannot be expected to remember every detail, which is why written or recorded notes will be helpful for you to refer to at a later time. Or, if you take a list to your appointment, check those questions you are most concerned about. Ask your physician to review all of the questions and then decide which ones he or she is most concerned about. First discuss the questions you both think are most important. That way, if you run out of time, the less important questions can be answered by one of the nurses, or your physician, at a later time.

One Final Note

Remember that the following questions are intended as a starting point only, not as an exhaustive list of necessary questions. You may only feel comfortable with some of the questions, some may not be appropriate, and you may come up with others you need answered. Again, add these questions to the list, or start your own. Keep copies of your questions and answers easily accessible, since you may want to refer back to them in the future.

Questions to Ask New Providers and When Getting Second Opinions

If you are looking for another healthcare provider, some simple questions will help you to evaluate their expertise. For example, your lung cancer may have been diagnosed by your primary-care physician or a pulmonologist and now you must find a surgeon, or a medical or radiation oncologist.

Take the time to interview a number of physicians to be sure that you will be comfortable under the care of the one you choose. If one provider doesn't offer the experience you are looking for, ask your referring physician for other names.

Since it is always a good idea to get a second opinion, these suggestions will also help you to find physicians who will meet your specific needs. Some questions to ask a healthcare provider you are considering include:

- Are you board certified in your specialty area(s)?
- How do you keep up-to-date on current treatments?
- How many times have you performed this particular surgery (if you are having surgery)?
- Do you do this surgery routinely?
- Can I talk to other patients who have had the same or similar surgery? (treatment?)
- Are you willing to answer my questions?
- Will you answer my questions directly?
- Will you return my phone calls in a timely manner?
- Are you willing to honor my personal decision-making style?
- How do you feel when patients don't take your advice?
- Are you willing to help me seek other opinions?
- Do you accept my insurance?
- What hospitals, etc., do you work with? Are these facilities convenient for me?
- Who provides backup care if you are out of town or unavailable?
- Do you participate in clinical trials?

Questions to Ask to Evaluate Your Physician's "Bedside Manner"

Your doctor's personality and style are important aspects of his or her ability to care for you. These next questions are designed to help you find healthcare providers whose personalities and styles will complement your own. Ask yourself these questions after your initial consultation.

- Are you comfortable with this person?
- Do you feel that your personalities are a good fit?
- Were all of your questions answered in a way that was acceptable to you?
- Do you feel you can talk with this person about any topic?
- Do you feel you can tell this person if you don't understand what he or she is telling you?
- Do you think this person will listen to you and respect your concerns?

Questions to Ask Prior to Testing

If you are in need of diagnostic procedures and/or are preparing for tests, be sure to discuss your fears about any tests your doctor may want to perform, such as a fear of discomfort or pain. Some tests may lead to a diagnosis, while others will be done in order to determine what treatments might be best for you. And some may be done because they are considered necessary to monitor your health status.

In every instance, if your doctor uses terminology you are not familiar with or do not understand, ask for a simplified or "nonmedical" explanation. The following questions may be helpful.

- What tests do I need?
- Why do I need these tests? What are you trying to find?
- What is involved in these tests?
- Who will perform the tests? Where will they be performed?
- How long does it take to perform each test?
- Are there any possible complications from these tests? If so, what should I look for that will alert me to any complications?

- Do I need to follow any restrictions before these tests?
- How will I feel after the test(s)? Do the tests hurt?
- What will each test determine specifically?
- How will these test results be helpful?
- When will I get the results? How will you notify me of my results?

Questions to Ask After Testing

After undergoing testing, you will receive the results. Again, ask for an explanation of anything you do not understand. These questions should help you to learn more about what your doctor has discovered.

- What have my tests shown?
- What do these test results indicate?

Your doctor may, after testing is completed, discover that you have a disease. At this point some appropriate questions would be:

- What is the name of my disease?
- What stage is my disease?
- Are all of my symptoms caused by this disease?
- Is this a disease you specialize in? If not, can you recommend someone who does?

Questions to Ask About Your Treatment Options

After choosing a physician who can help you with your health needs, it is time to look more closely at your treatment options. Several options may be available to you. Remember to think back to your personal decision-making style.

Please note that just because you ask for your treatment options, you do not and probably should not make any treatment decisions right away. Give yourself time to digest and think about the options before making a decision. A second, or even third, opinion may be in order, as well.

Ask your physician as many questions as necessary until you feel comfortable that you understand your treatment options. Besides asking what kinds of treatments are available, it is important to get as much information about each treatment and its side effects as possible.

- What are my treatment options?
- What is the specific goal of each of the treatments?
- How will each of the treatments affect the disease?
- What are the benefits of each the treatments?
- What are the possible side effects of each of the treatments?
- How long will the entire course of treatment or treatments take?
- Who will perform the treatments?
- Where will I go for treatments?
- Are there precautions I need to take during treatments (diet, etc.)?
- Can I drive myself home after a treatment?
- What kind of body changes will take place during treatment, if any?
- How else will my life change during treatment? Is my current lifestyle compatible with the treatments? If not, what kinds of changes will I need to make?
- Do I need to schedule regular appointments with you during the treatment cycle?
- Will you support my decision to use complementary therapies, as well as conventional therapies?
- If I do choose a complementary therapy, how will it affect my conventional treatments?
- What will happen if I choose no treatment at this time?

Questions to Ask About Clinical Trials

Your doctor may recommend that you participate in a clinical trial. Clinical trials are studies designed to answer specific questions about new treatments and/or new ways of using standard treatments. By participating in a clinical trial, you will make a contribution to our knowledge about the best ways to treat lung cancer and you may receive a new treatment that may be more effective than the standard treatment.

Before you enroll in a clinical trial, your doctor will explain all aspects of the study. You will then sign an informed consent form. This form states that you know and understand what is involved in the study including the type of treatment, possible problems, and what costs are covered by the study.

It is important that you understand exactly what the study is about and what is required of you. The following questions will help you to make the best decision about participating in a clinical trial.

- What is the purpose of the study?
- What does the study involve?
- What kinds of tests and treatments are involved?
- What is likely to happen in my case with, or without, this new research treatment?
- What are my other choices and what are their advantages and disadvantages?
- How could the study affect my daily life?
- How long will the study last?
- Will I have to be hospitalized? If so, how often and for how long?
- Will I have any costs? Will any of the treatment be free?
- If I am harmed as a result of the research, what treatment would I receive?
- What type of long-term follow-up care is part of the study?

Your Questions

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