

Advanced Lung Cancer: Issues To Consider

Patient Education Guide

When a person is diagnosed with lung cancer, the doctors do their best to provide treatments that can cure or slow the growth of the cancer. Cure is most probable when the cancer is diagnosed early, while it is still small. Early stage lung cancer is also called either stage I or stage II lung cancer.

When lung cancer is diagnosed in later stages (stage III or IV), the chance of cure is less likely. Then the doctors offer treatments that may help the person live longer. These treatments can also provide a better quality of life. However, the time may come when the treatments are not working as hoped. This is often a frightening time for the person living with lung cancer, as well as for their loved ones. It is also a difficult time for the doctors and nurses who have been giving the treatments. Often, everyone involved is afraid to bring up the idea that treatment to cure or extend life should end.

You may have been living with lung cancer for a few years. But, the cancer has progressed now, and you and your doctor have decided not to try any more treatments. You need to know what your options are now and what your life will be like.

Or, you may have just been diagnosed with late stage lung cancer. For one reason or another, treatment is not an option for you. The decision not to treat the cancer is a hard one for the person living with cancer, for his or her loved ones, and for the doctors.

This is the time when palliative care begins. This is comfort care to help ease your pain and suffering. This is the time when you, your family or other loved ones, and your health-care providers will probably talk about your death that will eventually happen. It may happen soon or it may happen many months in the future.

Quality of Life

Now you are concerned about quality of life. What will your life be like with cancer that is not being treated with the hope that it will either go away or not grow anymore?

For most people at this stage, the biggest fear is pain.

Another big fear for people with lung cancer is not being able to breathe easily. Dyspnea, or difficulty breathing, is a common problem with lung cancer. Well over half of the people living with lung cancer have dyspnea or trouble breathing. Not being able to get enough air is very scary for most people.

These do not need to be big problems. There are things that can be done to help and to keep quality of life good for as long as possible.

Managing Pain

Pain may be due to the cancer. It may also result from the treatments you have had. Pain control can be done safely. It can be done well. New medications and other methods have been developed so no one with cancer should be in unbearable pain. Your doctor or nurse will ask about pain every time you are together. It is important that you be very truthful about your level of pain. Sometimes, people with cancer don't want to complain about what their life is really like. This will not help you. Your doctors cannot provide the best care for you without this information.

Your pain will be related to where your cancer is located. Many people with lung cancer have little pain. This is most common when the cancer is just in the lungs. Often this pain can be treated with over-the-counter medicines, like acetaminophen or ibuprofen.

If the cancer is just in your lungs, a tumor could press on nerves in the spinal column and cause pain in your chest or back. This is true, as well, if the cancer has spread to the ribs or the spine. If the cancer has spread to the liver, the area on the right side under the lower ribs might hurt. Or, if the cancer has spread to the brain, you may have headaches.

The pain medicines that are prescribed will be based on the pain you have. There are many different types and levels of pain medication. Usually, the first pain control medicines will be acetaminophen or ibuprofen. If you need stronger medicines, drugs called opioids may be prescribed. There are also other medicines your doctor may suggest you try. Some of these work for some people and not for others. However, they are usually worth trying.

Many people worry about becoming addicted to pain medicines. That is not a concern. Many clinical studies have shown that people in pain because of cancer, rarely, if ever, become addicted. Good pain control is essential for good quality of life.

Sometimes, radiation is used to help reduce pain from cancer that has spread to the bones. Nerves can even be cut to help reduce pain.

If you are having pain that is not well controlled, ask your doctor to refer you to a doctor who specializes in pain control or to a pain clinic. These are available in most cities.

Managing Dyspnea

There are many things that can be done to help you breathe better. Medicines that are used to treat asthma work well. So do other medicines your doctor may prescribe. Listening to music or getting involved with other activities may also be helpful.

Many people with lung cancer, especially in late stage, use oxygen. Your doctor can request that you have oxygen in your home to use for a few hours a day or all the time. There are even very small, lightweight, portable units you wear on a belt so you can go out to a restaurant, visit your friends, or see your doctor.

Who Will Provide My Health Care?

The decision has been made that no further treatment will be used to control your cancer; this does not mean that your relationship with the doctors and nurses, who have been responsible for your care, will end. Often, they have become very important to you and your loved ones. Depending on your needs, they will probably continue to care for you or they may refer you to others who specialize in the care you need. You will probably see your primary care physician more often, instead of the oncology specialists who were treating you before. Your pulmonologist may also take a much greater part in your treatment.

Hospice Care

Hospice care is a good choice for many people. If you have made a decision not to have any more treatment, check with your local hospice. This is a time when you will want to have your family, other loved ones, and caregivers with you. Most hospices want to start working with a family or an individual as soon as it is clear that treatment to cure or to prolong life is no longer possible or is not wanted by the person with cancer. Hospice workers prefer to work with patients and families for a few months rather than becoming involved just before death. This way, they can provide the best care for everyone. Hospice care usually includes counseling and support for the patient and family. It also includes day-to-day medical care for the patient, such as pain and other symptom management. Hospice service will help to make sure that your care is the best for managing all the symptoms you might be having.

Legal Issues

This is also the time to make sure you have all your affairs in order. Do you have a will? Have you made decisions about whether you want to be resuscitated or placed on life support? Are there special conditions when you would want this, or would you not want it under any conditions? Do you have a living will? Have you given a copy of it to members of your family and your doctors? If you have a crisis at home, have you talked with your family about whether you want to be taken to the hospital or not? Your doctors and nurses, especially hospice staff, will want to discuss these issues with you.

Talking With Your Doctors and Other Caregivers

If you are living with late stage cancer, it is important for you to be able to talk openly with your doctors and nurses. If you don't talk about how the cancer is affecting you, they will not be able to give you the best care.

It is also important that you can talk openly with your family and other caregivers. Each of you will have lots of different feelings at this time. Fear is common. So are anger and grief. You and your loved ones may be very sad. You might have made special plans for the future. Now you are not sure if you will be able to carry out those plans. You and your loved ones may find that you disagree about your current care or the care you want in the future. You, the person with cancer, and those who care for you, need to be able to talk to one another and to others about what is going on. Open discussions with all those who are most important to you are very important. Hospice workers are trained to help these discussions take place.

But, this can also be a very special time. Many people with late-stage cancer say this is the most precious time for them. It allows them time to complete things with their family and friends. It is the time to have special conversations with those you love. It is the time to write special letters. It is the time, for many, to say those things they were not able to say before.

The most important thing is to use your time as wisely as possible. Decide what you most want to do. Plan your time and your energy so you can do those things. Maybe you want to attend a family wedding or a birthday party for a friend. Have some goals for the future, and, if you meet one, set another. Feel free to ask for help if you need it. Use the Resources section listed at the end of the brochure to help you find any services or assistance you might want.

Resources

Alliance for Lung Cancer Advocacy, Support, and Education (ALCASE)

Toll-free phone number: (800) 298-2436

Internet site: www.alcase.org

American College of Chest Physicians (ACCP)

Toll-free phone number: (800) 343-ACCP

Internet site: www.chestnet.org

American Cancer Society (ACS)

Toll-free phone number: (800) ACS-2345

Internet site: www.cancer.org

Cancer Care

Toll-free phone number: (800) 813-4673

Internet site: www.cancercare.org

Lungcancer.org

Toll-free phone number: (877) 646-LUNG

Internet site: www.lungcancer.org

National Cancer Institute (NCI)

Toll-free number: (800) 4-CANCER

Internet site: www.cancer.gov

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Patient Education
Guides Available**

Lung Cancer... Am I At Risk?

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Living With Lung Cancer

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