



Coping with Lung Cancer:
The Emotional Journey



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Introduction

How this booklet can help

Learning more about coping with lung cancer is a positive step.

The focus of this booklet is on your feelings and emotional well being. You will find practical tips and basic facts, as well as ideas about how you can take good care of yourself.



You might want to share it with those close to you. You can ask your doctors and nurses for advice and more details on what support is available. Patient support groups can give you information and support, and you can find more details on page 19.

Feelings you may have

People react to having lung cancer with many different emotions.

Some common emotions include:

- Fear
- Anger
- Grief
- Guilt
- Anxiety
- Depression
- Loneliness
- Hopelessness

On the other hand, some people find themselves feeling confident and hopeful about the future. Remember that your emotions will continue to change. On some days, you may feel very positive, and on more difficult days, you may feel very down.

Dealing with Your Diagnosis

Coping with shock and worry

“You have lung cancer.” Hearing these words from your doctor may be a shock.

You may have many mixed feelings and emotions, or just feel numb. You may find it hard to believe this diagnosis. You may have fears about the future or feel angry that this is happening to you.

All of these reactions are normal when people find out they have cancer. Doctors and nurses are aware of this and they recognize that helping you cope with your feelings is an important part of your care.

During this period, just after your diagnosis, it may help if you can ***gather information at a pace you can deal with***. People often feel, at this stage, they ***can only take one day at a time***. However, if you know what to expect, this can help to reduce uncertainty and anxiety.

You, and those close to you, ***can talk about what you need to know*** and ***then plan how to find out this information***.

It can take a few days or a few weeks for the feelings of shock and fear to subside. Try to put ***aside anything that is not urgent*** during this time so you can focus on getting through what is often a difficult time emotionally.

Having cancer is often compared to going on a difficult journey, but you don't have to make it alone.



Many people are ready to help you, each step of the way. **Find out** who these people are, and think about what help you want from them and how you will get it.

Difficult emotions

People with lung cancer can sometimes think that they caused their disease and feel guilty. Awareness of the link between certain types of lung cancer and smoking can make this feeling even stronger in those who were smokers. Worrying about what other people may think can make it hard for you to talk about your cancer or ask for help, contributing to a sense of isolation. However, sharing your thoughts and emotions will help you to manage feelings of guilt, isolation and loneliness.

Your family may also be struggling with similar ideas and emotions. It helps to keep this in mind, as there may be tensions that increase the stress on everyone close to you.

This is a difficult period, which demands patience and tolerance by all those affected.

Facts about lung cancer

You may want a lot of information about lung cancer – or none at all. Both of these reactions are normal.

When you're ready, here are a few facts to get you started:

Types of lung cancer

There are two main types of lung cancer:

- Non-small cell lung cancer (75% of cases)
- Small cell lung cancer

Depending on which type of lung cancer you have, treatment options will be different.

Who gets lung cancer?

- Lung cancer is one of the most common kinds of cancer that people get
- Each year, 1.4 million people are diagnosed with lung cancer worldwide
- Lung cancer accounts for about one in ten cancer cases

Thinking ahead

If you can organize everyday life so that it's easier, you will have more time and energy to look after yourself during treatment.

If others want to help – let them! You can build your own support team from family and friends. You don't have to rely on just one person. Think of how others can help you to manage:



- Your job
- Your finances
- Care for your children or other dependants
- Pet care
- Your home
- Shopping, meals and cooking
- Visits to medical appointments
- Staying fit, both physically and emotionally. Even if you may not feel up to it, having a friend take you out for a walk can really help to lift your spirits

It's a good idea to talk to your cancer team, too. You could discuss where you want to be treated, your fears or worries, and what kind of treatment you are hoping for.

Well being tip: Make sure that caring for yourself is at the top of your list.

Thinking about relationships

Cancer affects everyone who is close to you. They are probably experiencing strong emotions and feeling worried and afraid about what will happen to you.

One of the hardest things about having cancer is telling your loved ones about your diagnosis. Some people don't find it easy to talk about cancer.

A cancer diagnosis can change relationships, too. It can be difficult to accept that someone you love suddenly has to take care of you while you are ill. Maybe the roles are reversed now and you are relying more on your children.

Anyone who helps look after you will need a regular break. It's important that they also look after themselves.

Having cancer – or treatment – can also affect your body image. You may feel less confident or afraid of rejection.

The good news is that there are many ways to stay close to your partner. It all depends on your personal situation and feelings as a couple.



Quick tip: Whatever your perspective, a kiss or a loving touch is one of nature's best medicines.

If you want to talk to your family or loved ones about cancer or your relationship, but can't find the right way, you could ask for advice from your doctor, nurse, or any member of the health care team working in your clinic. They can refer you to someone else who can help you. Joining a cancer support group is another option (see page 21 of this booklet).

Well being tip: Negative feelings from the past create stress. You may feel better if you resolve old quarrels and emotional injuries. Now can be a good time to let go of the past and heal relationships.

Understanding and Coping with Your Treatment

Facts about treatment

Agreeing on a treatment plan with your doctor is an important decision. The best treatment for you will depend on the type of lung cancer you have, how far it has progressed and your overall state of health.

Cancer treatment is a complex field and there's a lot to learn. As treatments are often changing, it is important to talk to your doctors and nurses about what can be expected and achieved through your treatment, and how it is tailored to your individual needs.

As a starting point, here is an overview of the main options.

Treatment	How it works	When it might be used
Surgery	Operation to remove some or the entire tumor	<ul style="list-style-type: none">· For patients in general good health· At the earlier stages of lung cancer
Radiation	High-energy x-ray beams with the aim of shrinking the tumor or destroying cancer cells. May also destroy non-cancerous cells	<ul style="list-style-type: none">· For patients not undergoing any form of surgery· Occasionally before or after surgery· Throughout various stages of lung cancer· For the relief of some symptoms (i.e. pain, coughing up blood)
Chemotherapy	Drugs used to destroy growing cancer cells. Treatment may cause side effects such as nausea, vomiting and hair loss	<ul style="list-style-type: none">· As a stand alone treatment to shrink tumor· Alongside radiation to shrink the tumour (occasionally before surgery)· After surgery or radiation to destroy any cancer cells left behind
Targeted therapy	New class of drugs intended to kill only cancer cells. The majority of side effects are not life-threatening and are manageable	<ul style="list-style-type: none">· As a stand alone therapy to control your disease

Talking to your health care team

Good communication with your care team is very important. You should meet a lung cancer specialist nurse (your key worker) who will be able to advise and support you through your illness. Many patients are happy to let the doctors make most of the decisions about treatment and just want to know what to do and when. Others feel more comfortable having lots of information. Do what feels right for you and your family.

Questions:

- What is the name of your nurse?
- How do you contact this nurse?

Have this information close by and share it with your loved ones so they know who to contact.

If you feel you do not have the information you need, talk to your doctor or nurse and explain what it is you want to know. If you feel that you do not want any more information, let your doctor or nurse know that you have about as much information as you can handle right now. Doctors and nurses will find it helpful if you make your information needs clear to them.

It might be hard to ask questions or speak up when you disagree with professionals. However, it's *your* treatment and it's okay to say what you think. Your doctors and nurses need to know what's on your mind, too, so they can give you the best care or guide you to the best professional to provide the support you may need.

If you're nervous during a consultation, you might forget what you wanted to say, and the information you've heard. Why not:

- Take a friend or relative along to help with this
- Take notes, make a recording or ask for written information
- Make sure you know which healthcare professional to contact when you have a problem, especially at nights, weekends and holidays

Talking tip: Doctors might not ask about your feelings, but that does not mean they don't care. Doctors will often wait for you to take the lead with expressing feelings and emotions in your discussions. Because doctors are concerned about your emotional health as well as your physical health, talk to them if you are struggling with emotions. Tell them how you feel.

Questions to ask

If you are meeting with a healthcare professional, think ahead of time about what you want to ask, and write your questions down. Here are a few suggested questions:

- You've told me about my cancer's 'stage.' What does this mean?
- How will my cancer affect my everyday life?
- I'm troubled by some of the emotions I'm having. Is this normal? Can someone help me with this?
- What cancer treatments should I have? What are the side effects?
- What other treatment options do I have?
- Can I keep taking my other medicines during my treatment?
- Who do I contact if there are problems?
- Are there special dietary consideration to keep in mind (foods to avoid, alcohol consumption, special foods to incorporate into my diet)?

Well being tip: Feeling in control of your care will reduce your stress levels. Some people feel better if they share medical information and decision-making with their key workers or significant others. In any case, talking with your doctors, nurses and therapists about your treatment is always important.

Take your emotional temperature

This distress thermometer was designed to help doctors and nurses talk to their patients about upsetting feelings. It also gauges how intense the feelings of distress are. You can also use it to take your own emotional temperature. Doing this gives you a chance to reflect on your feelings and how they might be affecting your life.

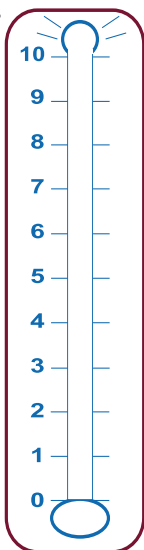
Think about how you are feeling and mark the levels on the diagram. A higher score means higher feelings of distress.



If you like, show this thermometer to your doctor or nurse and discuss ways to manage your feelings of distress.

Screening Tool for Measuring Distress

Extreme distress



No distress

Yes	No	Practical Problems	Yes	No	Physical problems
<input type="checkbox"/>	<input type="checkbox"/>	Child care	<input type="checkbox"/>	<input type="checkbox"/>	Appearance
<input type="checkbox"/>	<input type="checkbox"/>	Housing	<input type="checkbox"/>	<input type="checkbox"/>	Bathing/dressing
<input type="checkbox"/>	<input type="checkbox"/>	Insurance/financial	<input type="checkbox"/>	<input type="checkbox"/>	Breathing
<input type="checkbox"/>	<input type="checkbox"/>	Transportation	<input type="checkbox"/>	<input type="checkbox"/>	Changes in urination
<input type="checkbox"/>	<input type="checkbox"/>	Work/school	<input type="checkbox"/>	<input type="checkbox"/>	Constipation
<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	Diarrhea
Yes	No	Practical Problems	<input type="checkbox"/>	<input type="checkbox"/>	Eating
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with children	<input type="checkbox"/>	<input type="checkbox"/>	Fatigue
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with partner	<input type="checkbox"/>	<input type="checkbox"/>	Feeling swollen
Yes	No	Emotional problems	<input type="checkbox"/>	<input type="checkbox"/>	Fevers
<input type="checkbox"/>	<input type="checkbox"/>	Depression	<input type="checkbox"/>	<input type="checkbox"/>	Getting around
<input type="checkbox"/>	<input type="checkbox"/>	Fears	<input type="checkbox"/>	<input type="checkbox"/>	Indigestion
<input type="checkbox"/>	<input type="checkbox"/>	Nervousness	<input type="checkbox"/>	<input type="checkbox"/>	Memory/concentration
<input type="checkbox"/>	<input type="checkbox"/>	Sadness	<input type="checkbox"/>	<input type="checkbox"/>	Mouth sores
<input type="checkbox"/>	<input type="checkbox"/>	Worry	<input type="checkbox"/>	<input type="checkbox"/>	Nausea
<input type="checkbox"/>	<input type="checkbox"/>	Loss of interest in usual activities	<input type="checkbox"/>	<input type="checkbox"/>	Nose dry/congested
Yes	No	Spiritual/religious concerns	<input type="checkbox"/>	<input type="checkbox"/>	Pain
<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	Sexual
			<input type="checkbox"/>	<input type="checkbox"/>	Skin dry/itchy
			<input type="checkbox"/>	<input type="checkbox"/>	Sleep
			<input type="checkbox"/>	<input type="checkbox"/>	Tingling in hands/feet

Other problems:

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Emotions and treatment

It's normal to have strong emotions about cancer treatment. You might be afraid of the side effects or angry that you have to go through treatment.

It can also be tough to not know what will happen next.

It might help to:

- Talk to your cancer team, your family, or a counselor who specializes in helping cancer patients and their families with the fears, depression, anxiety or other challenges of cancer
- Talk to people in cancer support groups
- Write a diary to express your feelings
- Keep your treatment goals in mind
- Use a pill box to make it easier for you to manage your treatment

Quick tip: Distraction can be a good coping technique. Try to find something that takes your mind off your health problems; even if just for a while.

Sometimes chemotherapy, other medicines or the disease itself can cause confusion or emotional problems.

Make sure that you talk to your medical team about any feelings you have about treatment or any problems that you are experiencing.

Managing symptoms

Pain

It's normal to be afraid that you may experience pain associated with lung cancer or your treatment. However, if pain is a problem talk to the doctor or lung specialist nurse as it is possible for it to be kept under control.

Tell your doctor or lung specialist nurse if you are having trouble with pain or any other physical symptoms. It's better to control pain before it gets worse. Your doctor also needs to know about pain because it might mean your treatment should be adjusted. Do not suffer in silence, pain can be controlled.

Self help tip: It is important to tell your doctor if your treatment or medication is causing pain. Getting the dose right can take careful fine-tuning.

Breathing problems

Breathlessness may be a symptom of lung cancer and it can be very frightening and distressing. Again, make sure you ask your doctor or nurse for help. You can also help yourself by doing breathing exercises (see page 17).

Side effects from treatment

You might be worried about side effects from your treatment. For example, chemotherapy can sometimes make you feel nauseous. Your doctor can give you medicines and advice to help you with the side effects.

Coping tip: Avoid strong smells and spices to reduce the effects of nausea. Eat and drink slowly, don't mix hot and cold foods and avoid fried or fatty foods and caffeine. Eat small amounts of food throughout the day, rather than eating three large meals.

People react differently to treatment. Some individuals may find they have few problems or side effects.

Ideas for Coping

Worries you may have

It's natural that you should have concerns or worries about what's going to happen with your treatment. You might be thinking:

- Am I getting the best treatment?
- Will the treatment work?
- Will it be painful?
- Will it make me feel sick?
- Will my hair fall out?

You might even be wondering what would happen if you did not have treatment at all.



Quick tip: You could write down your fears or questions about treatment and talk to your doctor about them.

Be kind to yourself

There will be times when you feel low and very tired. It's important to be extra kind to yourself as you prepare for and go through treatment.

Well being tip: Although it can be difficult, try to enjoy everyday life. Give yourself treats – see a film, visit a café, meet with friends.

A healthy lifestyle is important, too:

- Eat a healthy diet, including plenty of fresh fruit and vegetables, whole grains, and protein (some sources include meat, fish, nuts and dairy products)
- Drink plenty of fluids
- Get enough rest and sleep
- Do gentle exercise

Good nutrition is really important for keeping your strength up. If you don't have much appetite or if side effects of treatment make it hard for you to eat well, a dietitian can help you get the right nutrition and more enjoyment from meals.

It can be hard to do some of these things when you have lung cancer, so ask your care team for support. If you smoke, and wish to stop, they can help you to do so, which may have real benefits for you.



Learning to relax

Thinking about your lung cancer diagnosis can be a stressful time for you.

There are techniques to calm the mind and body, which can help with anxiety, pain and the side effects of treatment. Some of these methods include progressive relaxation, meditation and visualization (creating positive pictures in your mind).

If you want to try these methods, you should find a professional to teach you how. Some cancer centers provide classes. Your doctor, nurse or therapist might also be able to recommend a professional.

If you're not comfortable with finding professional help, there are also books and other resources available for you to utilize.

To get an idea of what it might feel like, you can try this basic 20- to 30-minute relaxation exercise:

- Sit comfortably, somewhere quiet
- Close your eyes and decide to “let go of any thoughts”
- Breathe deeply and slowly
- Mentally go through each part of your body, and release all muscle tension. Start with your head and work all the way down to your toes
- When all of the tension is gone, continue to breathe slowly with your eyes closed

Once you get used to this, you will be able to relax more easily and quickly.

Relaxation tip: Close your eyes tightly and release all the tension from your eyes and then open them again.



Ways to breathe easier

Feeling breathless is common for people with lung cancer. It can make you panic – and that just makes your breathing worse.

If you have breathing problems, tell your doctor or nurse. Oxygen or medicines may help you. Ask to see an occupational therapist, who can suggest small changes in your everyday life so your lungs won't have to work so hard.

Useful tips:

- Sitting up helps you breathe more easily
- Try sleeping in a reclining position rather than lying flat
- Try using a fan – this helps to keep the air moving through the room
- If you have oxygen, make sure that you have it close to hand
- Anxiety can make breathing worse – try using relaxation exercises. You can also ask your doctor about medications that relieve anxiety
- If dry mouth makes you feel worse, try sucking on a sweet to encourage saliva
- Speaking takes more breath – try speaking more slowly and pause often

All of these things will help you to feel more in control of breathlessness if it occurs. This reduces the chance that you will feel anxious.

Breathing exercises

A physiotherapist can teach you helpful breathing exercises. You could try the following exercise to start with:

- Fast, shallow breaths will make you tired. Aim for gentle breaths, at a normal rate, from your lower chest
- Pursing your lips when you breathe (as if you're about to kiss someone) often helps
- Sit comfortably, put your hands on your thighs, and breathe out to relax your shoulders
- Put your hand on your belly and cough. You will feel your diaphragm (main breathing muscle)
- Keep your hand there so you can feel if you are breathing correctly and deeply
- Breathe in through your nose, and out through your mouth. Make your outward breath twice as long as your inward breath
- Practice by doing five to 10 breaths, several times a day

Well being tip: Aim for a home environment that's pleasant and healthy. Let the fresh air and the sunshine in. Hygiene is important but you won't always have energy for doing work around the house, so try to get help with some of these jobs. Little touches like pictures, photographs or candles can make a room relaxing.

How professionals can help

Your nurses and doctors know that you need emotional as well as medical support. You can turn to them if you are feeling frightened or depressed. They can:

- Explain what's happening with your cancer and treatment
- Tell you what to expect next
- Plan your care with you
- Help you with symptom control
- Refer you to other professionals:
 - Social workers for support with family, home or financial concerns
 - Counselors (see page 20)
 - Psychiatrists or psychologists for guidance and medication to help manage anxiety, depression, insomnia and fatigue
 - Complementary therapists who can provide alternative “feel good” treatments like massage, acupuncture and aromatherapy
- Give information on organizations outside the hospital that may provide this support and care



Don't worry that asking for help means giving up your independence. In fact, getting extra support should make it easier to live your life on your own terms.

Getting emotional support and help

It's very common for people with lung cancer to suffer from emotional distress. If you're feeling overwhelmed and afraid, don't hesitate to talk to your doctor or lung specialist nurse.

Sometimes your cancer or your treatment can be a physical cause of emotional problems, and your doctor can help to correct this. They might also prescribe medicines to help with emotional problems.

Often, what you really need is someone to talk to and give you support while you think things out.

Your doctor can refer you to a service which provides psychological care and support. This can happen one-to-one, as a family, or in a group of people. Another popular type of support is called Cognitive Behavioral Therapy. This approach helps you understand how the way you think can affect the way you feel. See the resource section at the end of this booklet for more details on Cognitive Behavioral Therapy.

Well being tip: Make time for the little things that give you pleasure in life. Chat with a friend, sit in the park, watch the sunset – whatever makes you smile.

Talking to children

Many people with dependent children wonder what to tell them about lung cancer and treatment.

What you say depends on their age, but ***try to avoid telling them anything that is not true.*** If and when they find out it is not true, it can shatter their confidence.

Like adults, children need only as much information as they can handle. ***Give them the opportunity to ask questions but check how much they want to know.***

Children often benefit by having routines at home continue as normally as possible.

If you want more information about talking to children, there is a resource list at the end of this booklet.

How patient groups can help

A support group can put you in touch with other people who have lived with lung cancer, or who are living with it now.



They can give you information and practical advice. Some groups can also help if you have a problem getting the care or support you need.

Sometimes, just talking to someone who is in a similar situation can make you feel better. Ask your care team how to contact local groups.

Key contacts

International Psycho-Oncology Society (IPOS)

www.ipos-society.org

This professional organization focuses on the emotional and interpersonal needs of people with cancer and their caregivers. On its website, you can find many useful links to patient support groups and information sources.

This booklet has been written with help from members of IPOS.

IPOS welcomes comments from patients and caregivers on programs they can develop in the future.

IPOS plays an important role in training professionals from all over the world and welcomes delegates from professional groups, patient advocacy and caregiver groups to attend annual congresses and training academies.

For more information on IPOS educational programs and publications, please visit www.ipos-society.org.

Global Lung Cancer Coalition (GLCC)

www.lungcancercoalition.org

The GLCC is the international voice of lung cancer patients. It provides lung cancer facts and links to patient groups around the world.



Information Sources

Selected information sources

Here are some of the information sources that were used to write this booklet. You can look at these websites, articles and books for more information.

Internet

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CancerBackup (2007) Breathlessness. Available at: www.cancerbackup.org.uk

CancerBackUp. Information on all types of questions and support services. Available at: www.cancerbackup.org.uk

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Parenting At a Challenging Time (PACT). Information available at: www.mghpact.org

Riprap: When a parent has cancer. Advice column and support information. Available at: www.riprap.org.uk

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