



**Coping with Lung Cancer:
Emotional Support and Help for Caregivers**



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Introduction

You are not alone

Learning that someone you love has lung cancer may have left you with many feelings including fear, shock and worry about the future. You may wonder what will happen and how you are going to cope.



Please don't face this alone. There are many people who are ready to help you, including the medical team looking after your loved one. The doctors and nurses know that you need assistance too, and your family and friends can also provide support and comfort.

You can gain support from cancer support groups, as many of the people attending such groups will have had experiences similar to the ones you are having right now. You may want to access psychological support to help you through these feelings and allow you to express your concerns. Remember that this support is available to you at all times.

How this booklet can help

This booklet may help you manage your feelings and emotions. You'll find facts and ideas about how you can take care of someone with lung cancer, while also taking good care of yourself.

There is a separate booklet especially for people with lung cancer, too. You could use it to start a conversation about lung cancer with the person for whom you are helping to care.

Common feelings

Now that you are caring for someone with lung cancer, you may experience one or more of the following – **they are all normal**:

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



Your loved one may also have some of these feelings and this is a normal response to their diagnosis. Their mood can be hard on you, and they may not realize it.

However your loved one's reactions may not be the same as yours and this needs to be respected. If they are naturally a private person, having cancer will not necessarily change that. They may find it difficult to express how they feel and may also worry about you and want to protect you.

It is important to recognize what you are feeling. Then give yourself full permission to have your feelings and emotions – it really is okay. It is normal to find that the more you talk about your feelings, the better you will feel. Having appropriate places to express your emotions can also help you to concentrate on getting the best treatment for your loved one. However, it is also okay to block out difficult thoughts, if it helps you to cope better.

Quick tip: If it is hard to talk to others about your feelings, why not start a personal journal and write your feelings and emotions each day? You can share your journal with your friends or your support group if it helps.

Changing relationships

Cancer changes relationships. You may now develop a new role within your relationship. Maybe you are looking after your parent, or maybe you are taking on more financial or household responsibilities because your spouse or partner is ill. Pride can make it hard for the person with cancer to accept your help. Sometimes it is a strain, and you can both find yourselves feeling lonely. Sometimes your relationship gets stronger with greater intimacy.

If you were used to your loved one being physically very capable, it can be shocking to see them struggle over simple things we take for granted, like climbing stairs or lifting objects.



Having cancer – or treatment – can also affect the way people feel about how they look (their body image). They may feel less confident or be afraid of rejection.

If you are caring for a partner, there are many ways for you both to stay close. It all depends on your personal situation and feelings as a couple. Whatever your outlook,

a kiss, gentle touch or just a warm smile can always help you to express your love and support. Caring for your loved one can be a very special time, one of great warmth and intimacy.

Touch is important for both you (as a caregiver) and your loved one. Whether people are private or open, they can respond to a hug or an arm around them when they feel low or afraid. It can be reassuring and soothing for them to be touched in the normal or usual way.

If you want to talk to your loved one about their cancer or your relationship but can't find the right way, you might find some of the talking tips in this booklet helpful. You could ask your doctor or nurse for advice or for a referral to a counselor. Joining a cancer support group is another option (see page 21 of this booklet).

Talking tip: Try to listen to your loved one without judging what they're saying. Sometimes they just need to express their feelings. You don't always need to solve their problems; just listen to what they are.

Dealing With The Diagnosis

Facts about lung cancer

Your loved one may want to know everything about lung cancer – or they may not. Both reactions are normal, and people require different amounts of information at different times throughout their illness.



Here are some basic facts for you and for your loved one, should they want to know, and when it is the right time.

Types of lung cancer

There are two main types of lung cancer:

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

Who gets lung cancer

- Lung cancer is one of the most common kind 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

As with every cancer, there are different stages of lung cancer. Your medical team can give you information and advice on the different stages.

Symptoms

When people have lung cancer, their symptoms can include:

- Persistent cough
- Coughing up blood
- Chest pain
- Breathlessness
- Wheezing
- Hoarse voice
- Repeated chest infections
- Neck or face swelling
- No appetite and loss of weight
- Fatigue
- Constipation or diarrhea
- Inability to sleep – having to sleep sitting up

Talking to each other

It's not always easy to talk about cancer. Every family, couple or set of friends has their own communication style. Some people talk about everything, while others leave a lot unsaid.

Your loved one may be acting as if everything is fine. This is a common reaction when people hear they have lung cancer. They may be trying to protect their loved ones.



Talking tip: Ensure that you find a private place to talk, where you will have no interruptions. Consistent eye contact helps to convey interest and readiness to listen.

If the person with cancer doesn't want to talk about it, you will need to be sensitive. Don't push too hard. Do remind them that psychological support is available and they may find it easier to talk to someone independent from you.

Some people find it easier to talk while doing something, like driving or walking together, instead of sitting face-to-face. Body language and gestures can be more powerful than words.

Once you do start talking, see if you can find out what your loved one wants in the future. What kind of treatment are they hoping to have? If you know their wishes, you'll be able to speak up for them. Make a note of their wishes; this can help later.

Listening is important, too. You can get so involved with caring that you can forget to really listen to what your loved one is saying.

Humor can also help you and your loved one deal with changes in your relationship. A laugh or smile can help you and your loved one communicate without words.

Talking tip: Check whether the person with cancer is in the mood to talk seriously. Sometimes they are too tired or it's just not the right time.

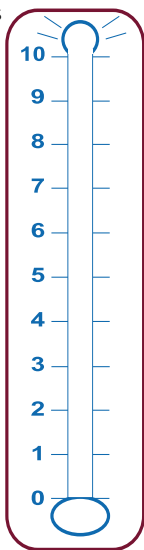
Take your emotional temperature

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 use it yourself, to take your own emotional temperature. Doing this gives you a chance to reflect on your feelings and how strongly they might be affecting your life.



Screening Tool for Measuring Distress

Extreme distress



No distress

Yes No Practical Problems

- Child care
- Housing
- Insurance/financial
- Transportation
- Work/school

Yes No Practical Problems

- Dealing with children
- Dealing with partner

Yes No Emotional problems

- Depression
- Fears
- Nervousness
- Sadness
- Worry
- Loss of interest in usual activities

Yes No Spiritual/religious concerns

-

Yes No Physical problems

- Appearance
- Bathing/dressing
- Breathing
- Changes in urination
- Constipation
- Diarrhea
- Eating
- Fatigue
- Feeling swollen
- Fevers
- Getting around
- Indigestion
- Memory/concentration
- Mouth sores
- Nausea
- Nose dry/congested
- Pain
- Sexual
- Skin dry/itchy
- Sleep
- Tingling in hands/feet

Other problems:

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Check how you are feeling and mark your level on the diagram. A higher score means higher feelings of distress.

If you like, show this thermometer to your doctor or someone on the cancer team and discuss ways to manage your feelings of distress.

Your loved one might want to try the thermometer, too. They may want to keep their answers private, though, especially if they are worried about hurting your feelings. You could encourage them to show it to their doctor or nurse as a way of starting a discussion about emotions.

Distress signals

There are ways to spot distress both in your loved one and in yourself. Look for signs like:

- Difficulty with sleeping
- Crying spells
- Restlessness
- Irritability
- Muddled thinking
- Not enjoying life's usual pleasures
- Abusing alcohol or drugs

Some problems, like loss of appetite, losing weight or fatigue signs in your loved one can be caused by the cancer or treatment. They can also be signs of depression or anxiety in yourself.

If you are worried by these signs in your loved one, tell their cancer team and get help. The same goes for you. You could also ask your own doctor for help if you are feeling distressed.

Self help tip: Be realistic about your personal limitations and how much you are actually able to do.

Caring for caregivers

Sometimes, caring for someone with lung cancer is not easy.

The strain can take a toll on both your physical and emotional health. Because caregivers are more likely to experience stress, you could become ill if you don't look after yourself. You must sleep and eat properly, but this is often neglected.

Health professionals are fully aware of this so don't be afraid to ask the cancer team for help if you feel overwhelmed. You could also talk to your own doctor.

The cancer team or your own doctor can also point you towards other professionals and support groups to help with:

- Balancing work and caregiving (employment rights)
- Finances – this can be a real concern, so do ask for support and information on available benefits or grants
- Running the home
- Family life
- Supportive care (having someone else provide caregiving so you can have a break, i.e a hospice) – remember to enlist the support of friends and family to help you do chores or run errands

On the positive side, caregiving can be a wonderful experience, very rewarding and fulfilling. It is a strong way to express your love for someone and can make you feel very proud.



Talking tip: When listening to your loved one's worries, don't try to offer a solution right away. Give them time to let it all out first.

Understanding and Coping with Treatment



Facts about treatment

You will want to know what treatment options your loved one has. The best treatment for them will depend on the type of lung cancer they have, how far it has progressed and their overall state of health.

Treatment options can be confusing and there's a lot to learn. 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

Asking for information

Talking to doctors, nurses and other professionals is a big part of your role as a caregiver. However, due to doctor-patient confidentiality there may be limitations to the amount of specific

information about your loved one's illness that they are able to share without your loved one's consent and/or presence. Talk to them about your involvement and participation during appointments and consultations.

You should have the telephone number of a doctor, nurse or other healthcare professional with whom you can talk comfortably about any questions you have.

If you are meeting with a healthcare professional, here are some tips to help you to be better prepared:

- Take notes or make a recording of the meeting, to help you to remember the details
- Request information that you can take home and read later
- Ask for the names and telephone numbers of people to contact for questions or help, especially outside of office hours

Questions to ask

You can also think ahead of time about what you want to ask, and write your questions down. Here are a few suggestions:

- What stage is the cancer? What does that mean?
- How will cancer affect our everyday life?
- What treatments do you recommend? What are the side effects?
- If chemotherapy doesn't work, what other treatment options do we have?
- During treatment, is it safe to continue taking other medicines?
- 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 the diet)?
- What about vitamins and supplements?

Talking tip: If you don't understand something the doctor says, keep asking questions until it's clear. Ask them to explain it a different way.

Treatment and emotions

It's normal for your loved one to have strong feelings about their cancer treatment. They might be hopeful and confident or afraid, angry, or just fed up and despairing. It can be tough not knowing what will happen next.

You might be feeling many of the same things. It is also hard to watch someone you love experiencing side effects from their treatment.

Sometimes treatment, other medicines or the cancer itself can cause confusion or emotional problems.

For these reasons, it's a good idea to talk to the doctor if you are worried about your loved one's emotions during treatment. Remember that you are not on your own.

You can also help your loved one by reminding them of their treatment goals.

Encourage them to eat well and rest. Try to take their mind off it by talking to them about ordinary life or helping them do things they enjoy.

Well being tip: Where possible, sit in a garden or park – nature can help to lift both of your spirits. You can also encourage your loved one to pursue their hobbies and interests, or start a new hobby.

Managing pain and symptoms

It's normal to be afraid of any pain associated with cancer or treatment. However, your loved one's pain can be kept under control. Understand the medication that helps your loved one. Keep a timetable and list of the different drugs they need to take.

The person with cancer may try to be brave and hide it. It's important to seek help from the doctor or nurse if you think your loved one is in pain, or having trouble with symptoms. It's better to control pain before it gets worse.



Quick tip: Try to spot pain on the face and body of your loved one. Frequent quivering of the chin or clenched jaw, kicking or drawing up of the legs are all signs of suffering.

Ideas for Coping

Breathing problems

Fear of not being able to breathe is a common worry for people with lung cancer. Breathlessness is a common symptom of lung cancer, which can be very frightening and distressing.

Some people can benefit from oxygen or medicines. Breathing exercises are useful and these are outlined in the INSPIRE booklet for patients.

Don't hesitate to ask for support from your loved one's medical team.

Side effects from treatment

You might be worried about side effects from treatment. For example, chemotherapy can trigger feelings of nausea. It's important to talk about any effects that treatment may have on your loved one. The doctor can provide medicines and advice to manage side effects.

Coping tip: Encourage your loved one to avoid strong smells and spices to reduce the feelings of nausea. It also helps to eat and drink slowly, not mix hot and cold foods, and avoid fried or fatty foods and caffeine.

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



As a caregiver, it can be shocking to see your loved one grow physically weaker. You may find that you have to get used to the need for oxygen tanks. It can be frightening to have this equipment around, but as a caregiver, it is important that you adapt as quickly as you can in order to give confidence to your loved one.

It is helpful for you to understand the medication your loved one has to use to assist with their symptoms. If your loved one thinks that you know about the medications and use of oxygen, it helps to take the pressure off them. If they are less anxious, then this takes the pressure off you, so you can worry less about how they are coping.

Talking tip: Ask your loved one how they feel about having cancer treatment. What are their hopes and fears?

Be kind to yourself

This is a difficult time and it is normal to feel stress. Be aware that caregivers can be at risk for emotional problems. It is, therefore, important to also take care of your own emotional health.

Sometimes even little things can give you a boost. Here are a few ideas:

- Find quiet times for yourself to reflect and relax
- Stay in contact with family and friends – you need their support and love to help you care for your loved one



- Have a day out, away from anything to do with hospitals and health problems.
- Enlist some help from family and friends so you can take time off
- Talk to your employer to see if you can take some time off from work and/or find a friend to take care of your other commitments
- Treat yourself. Get a massage, exercise, watch sports on TV – do whatever you enjoy
- Try to keep up at least one of your hobbies
- Ask for help

Simplify daily life while your loved one is having treatment. For now, focus your energy on the things that matter most. Try calling a help line or joining a support group if you want to talk to people who understand.



If you are ever worried about your own emotional well being, don't hesitate to ask for professional help (see pages 19 and 20). The cancer team or your own doctors are good people to start with.

A healthy lifestyle

While you are helping your loved one through treatment, it's important to maintain your own physical and emotional health. You can only support them if you are strong yourself.

If you follow a healthy lifestyle, it can encourage the person for whom you are caring to do the same. Here are some suggestions:

- Eat a healthy diet, with lots of fresh fruits and vegetables, whole grains and protein (some sources include meat, fish, nuts and dairy products)
- Keep it simple. Don't make extra work in the kitchen by cooking complicated meals, unless that is relaxing for you
- Drink plenty of fluids
- Get enough sleep and rest
- Exercise
- If you smoke, please try to stop. Everyone will benefit from stopping smoking

If you have any medical problems yourself, like asthma or diabetes, it's important to keep up with your own medical appointments, monitoring and treatment.

Talking tip: Make sure you have someone else to talk to (not the person with cancer) so you can express your feelings freely.

Caring for children

You may also have to help a child cope with a parent who has lung cancer.

They may feel anger, especially if their parent is a smoker. Children can have many complex and ambivalent feelings about their ill parent.



You may also find that you are doing more of the parenting now. Additional responsibilities may fall on your shoulders to keep your family's routine on track. Ask for help from your friends and family if this will help you to cope.

Keeping normal routines is important, and your children (no matter what age) should feel that they are still able to participate in activities along with their peers and carry on with their usual hobbies. Let them know that they can still laugh and have fun. If children are difficult, this may be their way of showing stress; try to take that into consideration.

Never lie to them or tell them more than they want to know. Your medical team can also help by talking to them and answering their questions where appropriate.

How professionals can help

The cancer team considers your loved one's emotional needs and medical needs. They also know that you need support. Tell them if you are worried about your loved one's emotional state or if you feel you need help yourself.



They can help you to feel better by:

- Explaining more details of what's happening with the cancer and the treatment
- Telling you what to expect next
- Discussing future care plans with you

They can also:

- Check to see if your loved one needs more treatment or medications
- Help you to arrange appointments with specialists
- Give you referrals to other professionals:
 - Social workers, who can help with family, financial or home-related problems
 - Psychologists, who can offer counseling (see next paragraph)
 - Complementary therapists, who can provide alternative treatments like acupuncture, massage and aromatherapy

Getting psychological help

If you're feeling overwhelmed or worried about your emotional health, don't hesitate to tell the cancer team and ask for help. You can also ask your own doctor for help.

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

You can go to a psychologist for counseling. This can happen one-to-one, as a couple or family, or in a group of people. Another popular type of counseling is called cognitive behavioral therapy. This approach helps you understand how your mind works. It gives you ways to calm yourself and make practical changes in your life so you feel better.

Counseling is an acceptable and modern way to help you through a difficult time.

Talking tip: Sharing the negative feelings with a counselor can leave more room in your relationship for the good feelings.

How patient groups can help

A support group can put you in touch with other caregivers and people who have lived with cancer, or who are having this experience now.

They can give you information and practical advice. Some groups can also give advice on how to request certain treatments or support.

Sometimes, just talking to someone who really understands can help you feel better. Ask the cancer team or your own doctor 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 patient. Its website 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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IPOS Multilingual Core Curriculum in Psycho-Oncology. Available at: www.ipos-society.org/professionals/meetings-ed/core-curriculum/core-curriculum-pres.htm



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Professional journals

Psycho-Oncology is the official journal of IPOS and publishes widely on psycho-social care issues. See www3.interscience.wiley.com/journal/5807/home

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