

From Diagnosis to Treatment

Coping with Lung Cancer

B R E A T H E
the lung association



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Introduction

This guide was designed to provide important information that will help you and your family understand your lung cancer diagnosis and the resources that are available to you. Being diagnosed with lung cancer can be devastating, and you likely have many questions about what will happen and where to find resources to help you cope. Understanding lung cancer can help you work with your cancer care team to find the best treatment for you.

The questions listed in this guide are ones that people diagnosed with lung cancer have indicated are important to them. The answers provide some basic information, but we encourage you to seek further information by contacting us at our Lung Health Info Line (1-888-344-5864) or by using the resources listed at the end of the guide.

It is important to talk about any concerns or questions with your physician and other members of your cancer care team. They can be helpful sources of information and assistance. They can provide advice specific to your individual needs. They will also know what services and resources are available in your local area.



I've just been diagnosed with lung cancer and I'm still in shock. What are the types of things I need to start looking into?

BEING DIAGNOSED WITH LUNG CANCER CAN BE DEVASTATING. MANY PEOPLE SAY THAT THEY FEEL NUMB AND OVERWHELMED, WITH A SENSE OF PANIC AND HEIGHTENED ANXIETY. AT TIMES, YOU MAY FEEL THAT YOU CANNOT THINK CLEARLY OR SORT OUT WHAT TO DO. KNOWING WHAT QUESTIONS TO ASK YOUR CANCER CARE TEAM CAN HELP YOU UNDERSTAND YOUR LUNG CANCER AND WHAT YOU CAN DO NEXT. HAVING INFORMATION WILL HELP YOU MAKE THE DECISIONS YOU NEED TO MAKE.



Here are some questions that people with lung cancer find helpful when talking to their health care professionals about lung cancer:

- What is lung cancer?
- **What type of lung cancer do I have?**
- Has the cancer spread and, if so, where has it spread?
- **Do I need to have more tests?**
- What treatment options are suitable for me?
- **How will the treatments affect me?**
- How will the treatment affect my quality of life and everyday living?
- **Are the treatments available where I live or will I have to travel to receive treatment?**
- What type of support is available for me and my family?

Lung cancer describes a growth of abnormal cells inside the lung. These cells divide and grow more quickly than normal cells and form a tumour, which is a cluster of cells. If the cancer starts in the lungs, it is called primary lung cancer. It can also spread (metastasize) to other parts of the body. Lung cancers are divided into non-small cell lung cancer and small cell lung cancer based on where the cancer started. Other types of lung cancer are mesothelioma and a carcinoid tumour.

As with most cancers, the treatment of lung cancer is individualized. The treatment is specific for you. The decision about which treatment is best for you is based on many things including your health, where the cancer is located, whether it has spread, and your personal situation and wishes. A number of tests, including x-rays or scans, biopsies, and sputum cultures may need to be completed before a final decision can be made about your treatment.

Lung cancer treatment options vary and are based on the severity of the disease. They can include surgery, chemotherapy, radiation, immunotherapy and targeted drug therapy. Also, clinical trials (research studies) can be used in treatment approaches. Sometimes, only one type of treatment is needed. This is called the primary treatment. In other cases, a combination of treatments is used to more effectively treat the cancer. When a combination of treatments is used, they

may be given together or at different times, depending on the type or stage of cancer. Sometimes, chemotherapy or radiation is given before the primary treatment to shrink a tumour so it is easier to treat with the primary therapy. In other cases, treatment after the primary therapy helps destroy any remaining cancer cells or reduces the risk of recurrence. Recent advances in treatments for lung cancer (i.e., with personalized medicine approaches or targeted therapies) mean that the survival times for individuals with lung cancer are improving.

A number of therapies are also used together with treatment to manage symptoms and side effects. As well, many cancer centers have psychosocial or supportive care programs that can offer emotional, psychological, and practical support to you or your family.

What can I expect in terms of symptoms and on what timeline?



THE SYMPTOMS YOU MAY EXPERIENCE CAN BE DUE TO THE DISEASE ITSELF AS WELL AS SIDE EFFECTS FROM TREATMENT. THE MOST COMMON EARLY SYMPTOMS OF LUNG CANCER INCLUDE:

- Persistent or stubborn cough (which can interfere with sleep)
- Coughing up blood or rust-coloured sputum (phlegm)
- Laboured breathing or shortness of breath, wheezing
- Chest pain (deep in the lungs on lifting, coughing, or laughing)

Any side effects that you may experience will depend on the type of treatment you receive. Before starting your treatment, your doctor or cancer care team will talk with you about what you might expect and how any side effects will be managed.

It is important to talk with your physician and cancer care team about the physical changes in your body. These physical symptoms need to be managed and monitored over time. Without appropriate management, these symptoms can become worse and lead to other problems (e.g. coughing may interrupt sleep, causing fatigue and leading to irritability, etc.).

Everyone experiences symptoms and side effects differently. Although they can affect your well-being and quality of life, many can be treated or managed. The following is a list of symptoms and side effects that may occur. It is important to tell your health care team about any side effects or symptoms you experience so they can find the cause and provide treatment.

Anemia

Anemia is caused by a low level of healthy red blood cells. Cancer and its treatment can decrease the amount of red blood cells and the hemoglobin level in the blood.

Symptoms can include:

- Fatigue
- Pale skin, especially noticeable around the lips and nail beds
- Dizziness
- Weakness
- Shortness of breath
- Low blood pressure
- Feeling cold
- Headache
- Difficulty concentrating

Constipation

Constipation is when the stool is hard and difficult to pass. It can be caused by chemotherapy and radiation, as well as some pain relievers or anti-nausea drugs.

Symptoms can include:

- Bloating or feeling full
- Cramping or pain
- Gas
- Belching
- Loss of appetite
- No regular bowel movement for two or more days
- Straining to have a bowel movement

Diarrhea

Diarrhea is the frequent passing of loose, watery stool and can be caused by cancer treatment.

Symptoms of diarrhea can include:

- Gas
- Cramping
- Bloating
- Weight loss
- Rectal pain or bleeding
- Dehydration

Difficulty breathing

Difficulty breathing is feeling like you can't get enough air. This can be caused by a tumour blocking, narrowing or putting pressure on an airway, radiation therapy to the lungs or lung surgery.

Symptoms can include:

- Trouble catching your breath
- Working hard to breathe
- Fast breathing or heartbeat, or both
- Wheezing
- Coughing

Difficulty swallowing

Some types of cancer treatments can make it hard to swallow.

Symptoms can include:

- Feeling like food is stuck in the throat
- Difficulty starting to swallow
- Trouble moving food from the mouth to the throat
- Food getting stuck in the cheeks
- Coughing, choking or gagging when swallowing

Disseminated intravascular coagulation

Disseminated intravascular coagulation (DIC) is a condition where the blood clots too much. Blood clots in the bloodstream block small blood vessels in organs or limbs. When these blood clotting factors are low, it can cause excessive bleeding. DIC can be caused by tumours in the lung.

Symptoms can include:

- Bleeding and bruising easily
- Shortness of breath
- Pain or swelling in the arms and legs
- Jaundice, which includes yellow skin and whites of the eyes
- Low blood pressure
- Low blood oxygen level
- Bleeding at an intravenous site or in the

gums, skin, muscles, digestive tract or abdominal cavity

Fatigue

Fatigue is a lack of energy or exhaustion. It is different from usual tiredness. It is not necessarily related to activity and may not be relieved by rest or sleep. Tumours competing with your body for nutrients can cause fatigue. Other causes include surgery, chemotherapy, biological therapy or radiation.

Symptoms can include:

- Exhaustion, even after a good night's sleep
- Lowered energy all of the time
- Trouble concentrating or thinking clearly

Hair loss

Chemotherapy or radiation can cause hair loss. Some biological therapies can dry or thin hair.

Hair loss is a common side effect of chemotherapy, but not all drugs cause hair loss. In most cases, hair loss is temporary. Radiation can cause hair loss in the area where the radiation was given. The amount of hair loss and whether it will grow back depends on the dose of radiation. Hair loss often begins two to three weeks after chemotherapy or radiation starts.

Hypercalcemia

Hypercalcemia is when too much calcium is in the blood. It develops when the bones release too much calcium or the kidneys cannot get rid of enough calcium. It can be caused by advanced stages of lung cancer.

Symptoms can include:

- Nausea and vomiting
- Loss of appetite

- Constipation
- Muscle weakness
- Increased thirst
- Frequent urination
- Dark yellow urine
- Little or no sweating
- Confusion and difficulty concentrating
- Bone pain or bone fracture

Infection

Infections happen because cancer treatment lowers the number of white blood cells in the body, which play a major role in defending the body against viruses and bacteria. With lung cancer, recurring bronchitis or pneumonia may occur.

Symptoms of infection can vary, depending on what part of the body is affected. Having a fever is the most common sign of infection. But sometimes you can have an infection without a fever.

Symptoms can include:

- Chills or shivering
- Unusual sweating
- Redness, heat, swelling or discomfort from a wound, surgical cut or area around an intravenous line or vascular access device site
- Sore throat
- Cough, which may produce phlegm
- Shortness of breath or rapid breathing
- Diarrhea
- Vomiting
- Weakness
- Sinus pain

Loss of appetite

Cancer treatment can affect the way food tastes or make you not feel like eating.

Symptoms can include:

- Feeling like food tastes “funny”

- Being put off by certain food odours
- Not liking a food that was once a favourite
- Eating only one or two types of foods
- Feeling full sooner than expected

Low blood cell counts

Low blood cell counts happen when bone marrow doesn't produce the normal number of blood cells. Chemotherapy and radiation can affect the bone marrow and cause low blood cell counts.

A low red blood cell count is called anemia.

Symptoms can include:

- Fatigue
- Pale skin or lips
- Increased heart rate
- Tiring easily with exertion
- Dizziness

A low white blood cell count is called neutropenia or leukopenia. It puts you at greater risk of infection.

Low platelet levels

Platelets are made in the bone marrow and help the blood to clot. Chemotherapy, biological therapies or other drugs can cause platelet levels to drop.

Symptoms can include:

- Easy bruising
- Bleeding from the nose, gums or mouth
- Tiny red spots on the skin
- Blood in the urine
- Dark or black bowel movements

Nausea and vomiting

Nausea and vomiting are common side effects of cancer treatment and often occur together. Causes include chemotherapy and radiation or pain medication.

Pain

Pain is a common side effect of cancer and its treatments, but having cancer doesn't mean you have to live with pain. Talk to your healthcare team so they can help you manage it.

Peripheral nerve damage

The peripheral nervous system includes the nerves outside of the brain and spinal cord. Sometimes cancer or its treatment can damage the nervous system.

Symptoms can include:

- Tingling or burning sensations in the hands or feet
- Pain
- Feeling heat or burning when touching something cold
- Discomfort when your body comes in contact with something, such as a blanket

Pleural effusion

Pleural effusion is a build-up of fluid in the pleural cavity, which is the space between the lungs and the chest wall. It can be caused by cancer cells spreading to the pleura. It can also develop if cancer cells block or change the flow of lymph fluid in the pleural cavity.

Symptoms can include:

- Shortness of breath or difficulty breathing
- Coughing
- Pain or a feeling of heaviness in the chest

Radiation pneumonitis

Radiation pneumonitis is inflammation of the lung caused by radiation to the chest. It most commonly develops one to three months after treatment. Radiation pneumonitis is more likely to happen with high doses of radiation or when a large area of the lung is treated. Some chemotherapy drugs can also increase the risk of developing radiation

pneumonitis if given along with radiation therapy.

Symptoms can include:

- Cough
- Chest congestion or pain
- Shortness of breath

Sleep problems

Cancer or its treatments can alter your usual sleep patterns. Sleep problems can be caused by anxiety or depression or by symptoms of cancer or side effects of treatment, such as pain, nausea or shortness of breath.

You may have trouble falling asleep or staying asleep, not feel refreshed after sleep or you may sleep too much.

Sore mouth

A sore mouth and throat can be side effects of chemotherapy and radiation. Sores and inflammation can develop in the mouth, back of the throat and the lips.

Superior vena cava syndrome

The superior vena cava is the large vein that carries blood from the head, neck, arms and chest to the heart. Superior vena cava syndrome is a group of symptoms that occur when there is pressure on the superior vena cava or it is partially blocked and blood can't flow back to the heart properly. This causes more pressure in the veins and face, which leads to a buildup of fluid or swelling.

Symptoms can include:

- Shortness of breath, especially when bending over or lying down
- Feeling of fullness in the head
- Swelling in the face, neck, upper body or arms
- Hoarseness

- Chest pain
- Bluish colour on the lips and skin

Syndrome of inappropriate antidiuretic hormone

Syndrome of inappropriate antidiuretic hormone develops when there is too much antidiuretic hormone (ADH) in the body. ADH helps regulate the balance of fluids in the body by decreasing the amount of urine the body makes and increasing the amount of water the kidneys take up. Too much ADH leads to water retention, electrolyte imbalances and a low level of sodium in the blood. This syndrome can be caused by lung cancer or by some cancer treatments or pain medications.

Symptoms can include:

- Fatigue
- Headache
- Nausea and vomiting
- Muscle cramps
- Lethargy, agitation, confusion, delirium, disorientation or hallucinations

I've been suffering from extreme fatigue since my treatment. How long can I expect this to last and is there anything I can do to give myself more energy?

FATIGUE IS ONE OF THE MOST COMMON SIDE EFFECTS OF CANCER TREATMENT. THE FATIGUE WITH CANCER TREATMENT IS DIFFERENT THAN USUAL FATIGUE. THE DIFFERENCE, FOR CANCER PATIENTS, IS THAT THIS CONSTANT EXHAUSTION IS NOT RELIEVED BY REST.

Not all patients experience fatigue, but many notice their fatigue becomes worse over the course of their treatment. Sometimes it can feel particularly severe immediately following the end of treatment. Energy levels then tend to improve over the course of several months.

Experiencing fatigue may mean that you will have low energy for many of your usual activities including housework, social engagements, working, leisure or sports activities, or sexual relations. For a time, you may have to make choices about what you do each day. You may need to pick what is most important to you and do not try to do everything.

You may find the following strategies helpful in managing your fatigue:

Exercise

- Ask your healthcare provider if there are any restrictions on the amount or type of exercise you can do
- If you are new to exercise, start slow and gradually increase the amount and intensity
- Include strength training, by lifting weights or using your body weight with exercises such as sit-ups and push-ups

- Take a break if you feel sore or out of breath
- If you need help, your healthcare provider can refer you to an occupational therapist, personal trainer or rehabilitation specialist

Get a good night's sleep

- Go to bed and wake up at the same time each day, even on weekends
- Take shorter naps (less than one hour), as longer naps can make you groggy and interfere with nighttime sleep
- Limit coffee, tea and cola in the evening
- Wind down before bed
 - About an hour before bedtime, take 20 minutes to write down your worries and your plans for the next day
 - For the next 20 minutes, finish tasks like tidying or making the next day's lunches
 - For the final 20 minutes, do something relaxing, such as a warm bath, meditation or reading
- If you can't fall asleep after 20 to 30 minutes, get out of bed until you feel sleepy and then go back to bed
- Talk to your doctor about issues that may disturb your sleep, such as depression, anxiety and stress

Manage your stress

- Change or stay away from situations that cause you stress
- Do something you enjoy, such as going to a movie or visiting friends
- Try activities such as yoga, massage, progressive relaxation, writing in a journal or walking in nature
- Talk to a friend or family member about your feelings
- Join a cancer support group
- Ask your healthcare provider to refer you to a social worker, spiritual care provider or psychiatrist if you want to talk to a professional

Pace yourself

- Rest regularly throughout your day
- Perform tasks such as cleaning in chunks throughout the day or week
- Ask family or friends to help you with housework, shopping and child or pet care
- Arrange your home so that most activities can be done on one floor
- Keep things you need often nearby
- If necessary, use aids such as a cane, walker or grab bars
- Say no to less important activities to save energy for what is most important to you
- Schedule activities for the times of day when you tend to have more energy

Eat a balanced diet

- Eat healthy, whole foods to give you more energy
- Eat fresh foods rather than processed foods as often as possible
- Eat small meals and snacks throughout the day
- When you have energy, make extra food to keep in the freezer
- Buy healthy but convenient food, such as pre-cut fruit and vegetables
- Carry a bottle of water with you so you can stay hydrated

Sometimes even after following these tips, you may still feel fatigue. Be kind to yourself during this difficult time.

Tell your healthcare team if you experience dizziness, loss of balance or falls, fatigue that is suddenly much worse or sudden shortness of breath.



What can I do to manage shortness of breath?

SHORTNESS OF BREATH IS A COMMON SYMPTOM OF LUNG CANCER. HAVING DIFFICULTY BREATHING CAN BE A LONELY, FRIGHTENING AND OVERWHELMING EXPERIENCE, BUT IT CAN BE MANAGED. AS THERE ARE DIFFERENT REASONS WHY YOU MAY BE SHORT OF BREATH, IT IS IMPORTANT TO DISCUSS THIS SYMPTOM WITH YOUR HEALTH-CARE TEAM. THEY MAY NEED TO INVESTIGATE IT FURTHER AND DETERMINE WHAT IS CAUSING IT.

In the meantime, here are some general strategies that may be helpful to you:

- Move slowly and pace activities/plan ahead (try not to overexert yourself)
- Allow time to rest before and after activities
- Learn and practice breathing exercises such as pursed lip breathing
- Learn and practice relaxation techniques such as visualization, self-hypnosis and slow, deep breathing
- Be aware of your breathing patterns; notice when you become short of breath and do not hold your breath when you are engaged in activity
- Tell family and friends what they can do to help you (e.g. turning on a fan, staying with you, coaching you to breathe slowly, etc.) including issues of potential treatments such as thoracentesis or inhalers.
- Check out if there are local rehabilitation programs or Chronic Lung Programs that could help with breathing retraining

Resources to help with managing shortness of breath:

www.youtube.com/user/ManagingSOB



I've been feeling angry/fearful/depressed/ anxious every day since the diagnosis. Is this normal, and what can I do?

IT IS COMPLETELY NORMAL TO BE UPSET WHEN YOU ARE GIVEN A LUNG CANCER DIAGNOSIS. EMOTIONAL DISTRESS IS VERY MUCH A PART OF THE EXPERIENCE OF HAVING A CANCER DIAGNOSIS. A LUNG CANCER DIAGNOSIS CHANGES PEOPLE'S LIVES.

Following the immediate shock of hearing about a diagnosis, you may feel anger, fear, guilt, sadness and anxiety, often cycling around and around. Many people with lung cancer also describe feeling lonely, confused, helpless and isolated at different times during their treatment. Intense emotions can surface and you might feel overwhelmed and a sense of being out of control.

However, it is important to realize that you are not alone; you do not have to suffer in silence on your own. There are others who can help you cope with these emotions and manage the situation. You may find the following strategies are helpful to regain a sense of control over what is happening to you:

- Make a list of questions to ask your doctor or healthcare team members
- Take an active part in the decision-making about your treatments
- Accept help when it is offered but do not hesitate to ask for support
- Think about what is important to you and what you would like to see happen
- Set achievable goals and plan how to reach them
- Talk with others about how you are feeling (talk with other patients or with healthcare professionals)

Most individuals with cancer experience emotional upset following their diagnosis. At times, these emotions can interfere with your daily activities, your relationships, and concentrating or making decisions. It is important to realize that these feelings of anxiety, depression, and fear are very common and are a normal part of response to a life-changing situation like having lung cancer. It is also important to realize that you do not have to deal with these on your own. There are supports available to help you and your family. Talk with your cancer care team to learn about the programs and support services in your local area.

You may find the following strategies are helpful for you in coping with your emotions:

- Remember that emotional reactions are completely normal when dealing with a difficult situation; everyone will experience some degree of emotional upset when faced with a diagnosis like lung cancer
- Learn as much as you can about your illness and the resources available to you
- Think about the reasons you might be feeling the way you do - what is the source of your emotions? What did you do in the past to deal with similar emotions?

- Take a look at your support system (family, friends, etc.) and evaluate its strengths; who is available to support you emotionally?
- Find someone you are comfortable sharing your feelings with to discuss what you are going through; if there is no one available, consider writing in a journal
- Look for support groups or cancer support organizations (in-person, online, or both)
- Consider a consultation with a psychosocial or supportive/palliative care counsellor or your primary care physician/family doctor
- Take care of yourself (eat well, get enough sleep, reduce stress, nurture spirituality, etc.)

Resources for understanding and managing the emotional reactions to cancer:

The Emotional Facts of Life of Cancer
<http://capo.ca/docs/bookletREVISED.pdf>

www.cancer.ca/en/cancer-information/cancer-journey/recently-diagnosed/emotions-and-cancer/?region=on

www.cancerview.ca/treatmentandsupport/thetruthofitvideoseris

www.copingwithcancer.ca



How am I going to tell my family? What about my friends?

TELLING YOUR FAMILY AND FRIENDS ABOUT A LUNG CANCER DIAGNOSIS CAN BE A BIG CHALLENGE. YOU MAY STILL BE REELING FROM THE NEWS YOURSELF. THIS CAN MAKE DECIDING WHO TO TELL AND HOW TO TELL THEM EVEN MORE DIFFICULT. YOU MIGHT BE WORRIED ABOUT BEING ABLE TO TALK ABOUT IT WITHOUT LOSING CONTROL, OR YOU MAY BE UNCERTAIN ABOUT WHAT TO SAY BECAUSE YOU DO NOT FULLY UNDERSTAND THE DISEASE OR WHAT TREATMENT OPTIONS WILL BE AVAILABLE FOR YOU.

Who you tell, as well as how and when you tell them, is a personal decision. There is no right or wrong way to do it. Most importantly, you need to be comfortable with other people knowing about your diagnosis and with the process of telling them. Here are a few things you might want to think about when planning how to tell people:

- What is your relationship with this person? Is this a close friend who may want to know a lot of detail or an acquaintance who only needs to know a few key points about your situation?
- How do you usually talk with this person? Are your conversations often serious or are they light-hearted? Do you see each other often or send emails infrequently? Do you usually talk on the phone or in person?
- How old is the other person? Children, teenagers, adults and the elderly all have different ways of communicating and understanding information.
- Where would be comfortable having the conversation? For example, if you are in a public place you may want to keep the discussion factual and brief, rather than emotional.

If you are worried about the effect the other person's reaction will have on you, you may want to have a third person there to support

both you and the person you are telling. Be prepared for people to ask questions about the disease and treatment. If you do not want to talk about it or feel that you do not have all the information you need to discuss it, referring them to other resources may be the best strategy.

You may decide to only tell selected close family and friends at first. Or, you may want everyone to know. You may want to tell people yourself, or have a family member or close friend tell them. It is also fine to use different approaches to tell different people. For example, you might share the news in person with some but find a way to use social media to tell others. It is your decision. You are the one who must be comfortable with it.

Here are some ideas about what to do when you are ready to talk:

- Ensure you are somewhere you will not be interrupted. Turn off the TV and put your smartphone away
- If it makes you feel more comfortable, have someone who already knows about your diagnosis with you
- Provide information a few sentences at a time to give the person a chance to absorb the details
- As you speak, periodically ask if they have any questions

- Don't be alarmed by silences, the person may just need some time to take everything in
- If you do want to break the silence, you can ask "What are you thinking?"

Talking about your diagnosis may help you adjust to the situation and start to think about the way forward. It can be helpful to talk with a social worker at the cancer centre or in the community about this topic. Psychosocial programs at the cancer centre will also have staff who can discuss this topic with you.

Telling children and teenagers

Telling children about a cancer diagnosis can be a particular challenge for a number of reasons. You may worry about upsetting or burdening them. You may worry they simply will not understand the situation. There is also a strong desire to protect children from bad news.

When speaking with children or teenagers, respond in an open and honest way, tailoring the amount of details to their age and developmental stage, knowledge, capacity for understanding, relationship to the person with the diagnosis, and prognosis of the disease.

Even young children can sense when something is wrong within the family. If you try to hide the situation, a child may imagine all sorts of scenarios to make sense of what they are observing. By providing information, you teach them they can trust what adults are telling them, as well as their own instincts, and you show them how to work through difficult times with loved ones.

To clear up any misunderstandings, you may want to ask the child if they have any concerns. For example, a child might think the illness is contagious or that they did something to cause it. You can also tell other family members what you are sharing with the child so everyone communicates the same message.

You may want to tell children about possible cancer symptoms or the side effects of treatment. This way, they can be prepared if a loved one is more tired than usual or can't participate in certain activities, for example. Teenagers usually understand what's going on in terms of the cancer, but can be reluctant to talk about it. They may find it hard to show how they feel. Encourage them to ask questions and suggest they talk to a close friend or family member about their feelings.

Just like many adults, children and teenagers may not be prepared to discuss everything all at once. Look for cues as to how much they are ready to take in and follow their lead. Tell them they can ask you questions at any time.

When should I tell my co-workers? And how?

YOU DO NOT HAVE TO TELL YOUR CO-WORKERS IF YOU DON'T WANT TO. THE DECISION ABOUT WHO TO TELL, WHEN TO TELL, AND HOW TO TELL PEOPLE IS A PERSONAL ONE. THERE IS NO RIGHT OR WRONG WAY OF PROCEEDING. AS WITH TELLING FRIENDS AND FAMILY, YOU WILL WANT TO THINK ABOUT WHAT YOUR WORK RELATIONSHIPS ARE LIKE (I.E., CLOSE, FRIENDLY, DISTANT) AND THE WAY YOU HAVE BEEN COMMUNICATING. YOU MAY WANT YOUR EMPLOYER OR ANOTHER CO-WORKER TO SHARE THE NEWS WITH OTHERS, IF YOU DO NOT WANT TO DO IT YOURSELF. IT IS UP TO YOU. THE MOST IMPORTANT CONSIDERATION IS YOUR COMFORT WITH THE SITUATION.

You may wish to start the conversation with your employer and decide together about how to tell others. In addition, applications for leave or disability may need your employer's support. It may also be beneficial to share a plan with your boss about how your workload will be managed.

A trusted co-worker may be able to help you decide how to approach others. You may choose to tell co-workers during a group meeting or by email, so that you don't have to repeat the details. You can talk about your diagnosis and treatment, how long you may be off work and how it may affect your energy and appearance—or you may want your boss or a close co-worker to share this information with others.

There is no right answer for everyone, it is all up to you. You may only want to tell your boss and a few co-workers you know best. You may need to tell others if it could affect their workload or responsibilities. But if you don't feel comfortable, you don't need to share details.

If you're a manager or own a business, you will need to tell most of your employees, especially if it's going to affect work routines.

Be prepared for different reactions. Some co-workers may be preoccupied with how your illness will affect them—that it may diminish the quality of your work or increase their workload. Some people will be very supportive and seem to know just what to say and do. Others may not know what to say. They may feel sad and uncomfortable and be afraid of upsetting you. Some may act overly cheerful and attentive.

Ask for support if you need it. You may be able to receive counselling through an employee assistance program, if your company has one. Your human resources department may be able to tell you about other programs or employee benefits that may help you.

What support is available for my family/friends?

CANCER HAS AN IMPACT ON FAMILY MEMBERS AND FRIENDS IN ADDITION TO THE INDIVIDUAL DIAGNOSED WITH THE DISEASE. FAMILY MEMBERS ARE OFTEN SHOCKED BY THE DIAGNOSIS AND FEEL UNCERTAIN ABOUT HOW TO HELP YOU AS A PATIENT. THEY WILL ALSO EXPERIENCE EMOTIONAL RESPONSES TO THE SITUATION AND NEED TO FIND WAYS TO COPE.

It is important to acknowledge that these reactions are normal and family members may benefit from seeking support from others in the same situation. They will also have many of the same questions that you have as a patient. They will benefit from understanding more about lung cancer, its treatments, and the possible emotional reactions.

Family members and friends may worry about upsetting you if they share what they are feeling. In this case, support groups for caregivers may provide a more comfortable setting for talking to others about the challenges they are facing as family members. Many cancer support organizations offer these types of programs.

It is valuable to continue with usual family activities and ways of doing things; but during treatment and recovery, you may not be able to do your normal tasks such as household chores or going to work. This may mean family responsibilities need to change for a time. For example, a partner may need to grocery shop, pay bills or take out the garbage, or a child may need to do more chores. Sometimes it's hard for family members to get used to a new routine. It may be helpful to talk together as a family about what is important to each of you and make plans together about how things will be handled during the times of treatment.

You may also have questions or concerns about intimate relationships. Cancer can affect how you feel about yourself and have an influence on sexuality. Sexuality can be a very personal issue and one that is difficult to talk about. However, an open and honest conversation often offers the best chance of coping with the changes from cancer and its treatment.

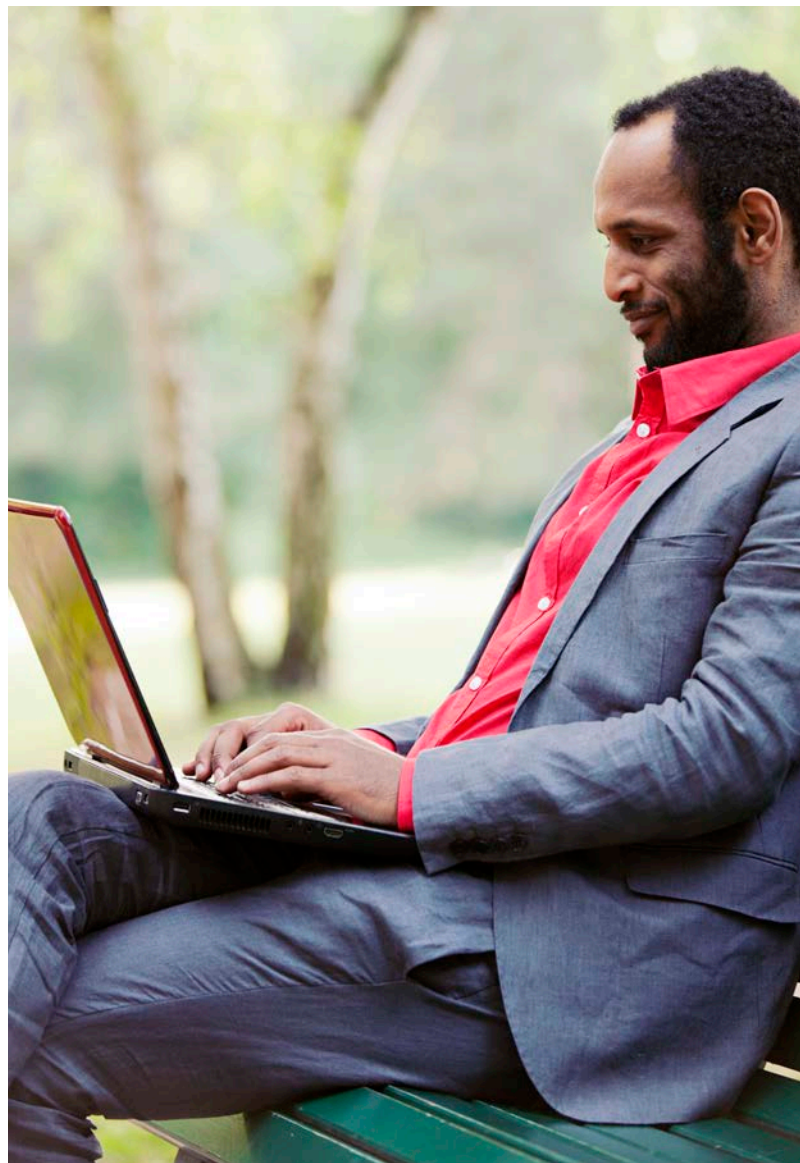
Talking to your partner can help you deal with fear and insecurity. You can also let your partner know where you are feeling pain or what sexual activities you are not ready for. Your partner may also have concerns that you can address, such as a fear of hurting or pressuring you. Explaining how cancer or treatment have affected how you feel about sex can help your partner understand and let them know not to feel rejected.

Do not hesitate to talk with your physician or cancer care team about the changes your body is experiencing. It may make you feel uncomfortable, but it's always OK to ask your doctor questions about your sexuality. If there's someone else you trust on your healthcare team, such as a nurse or social worker, you can have the conversation with them.

How do I find help in my community?

THERE ARE A NUMBER OF WAYS TO FIND HELP IN YOUR LOCAL AREA:

- Speak with your physician or cancer care team members; often social workers or oncology nurses are aware of resources available in your local area
- Contact the Cancer Information Service at 1-888-939-3333 (TTY 1-886-786-3934); you can talk with a cancer information specialist about all aspects of cancer; you or your family can make the call
- Contact The Lung Association's Lung Health Info Line at 1-888-344-5864
- Search the Internet for online support groups or chat/discussion groups;
 - the following are specifically for Canadians with lung cancer:
 - <http://www.lungcancercanada.ca/Get-Involved/Peer-To-Peer.aspx>
 - <https://cancerchat.desouzainstitute.com/about>
 - the following are peer support or discussion groups for all type of cancer patients
 - <http://www.cancer.ca/en/support-and-services/support-services/connect-with-our-online-community/?region=on>
 - http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Support/Support/Discussion+Forums.aspx



I live a four hour drive away from the nearest cancer centre. What can I do?

THE FIRST STEP IS TO TALK TO YOUR HEALTH-CARE TEAM ABOUT THE TIME AND TRAVEL COMMITMENTS FOR THE TREATMENT YOU HAVE CHOSEN. IF YOUR TREATMENT REQUIRES REGULAR VISITS (FOR EXAMPLE, RADIATION CAN REQUIRE DAILY APPOINTMENTS AT THE CANCER CENTRE) THEN YOU MAY NEED TO FIND A PLACE TO STAY CLOSE TO THE CANCER CENTRE FOR A PERIOD OF TIME. YOU MAY BE ABLE TO MAKE ARRANGEMENTS FOR THIS TYPE OF STAY THROUGH THE STAFF AT THE CANCER CENTRE. SOME CANCER CENTRES HAVE HOSTELS OR PARTNERSHIPS WITH LOCAL HOTELS.

If you require fewer trips to the cancer centre, you might make travel arrangements with family and friends. You should also talk to your health-care team to see if some parts of your treatment are available at a health-care facility closer your home. This would mean you would not have to make a lengthy trip to the cancer centre.

Many cancer centres have arrangements for parking passes that cancer patients can use when they come for an appointment. Be sure to ask the staff at the cancer centre about such arrangements.

Resources regarding transportation for cancer patients:

www.cancer.ca/en/support-and-services/support-services/transportation-on/?region=on

Resources regarding hostels for cancer patients:

www.cancer.ca/en/support-and-services/support-services/travel-and-accommodations-on/?region=on



How can I find others who are going through the same thing?

TALKING TO PEOPLE WHO ARE GOING THROUGH THE SAME PROCESS AS YOU CAN BE VERY VALUABLE. THIS CAN HELP YOU FEEL LIKE YOU ARE NOT ALONE. IT IS ALSO A GREAT WAY TO GET ADVICE ON HOW TO HANDLE DIFFERENT SITUATIONS THAT CAN ARISE. OTHERS WILL LIKELY HAVE EXPERIENCED SOME OF THE SAME ISSUES YOU HAVE EXPERIENCES. TALKING WITH OTHER PATIENTS CAN ALSO HELP YOU GET A BETTER UNDERSTANDING OF THE DISEASE AND HOW IT AFFECTS A PERSON.

Peer support programs exist in cancer centres, local communities, and online. Choosing which of these to become involved in (or whether to become involved with them at all) is up to you and how you like to engage with others. Some programs meet in person and others occur over the Internet.

Various peer support programs are available. Some programs focus on cancer education, while others provide a way to meet other people who have been diagnosed with the disease. Speak to the staff at your cancer centre or call your local cancer support organization to find out what programs they offer.

Some organizations also offer peer-to-peer telephone support services that provide both educational and emotional support. There are also a number of online programs available in various formats, including discussion boards, chat lines, blogs, and real-time facilitated support groups. Some people find simply reading about other patients' experiences is helpful.

Resources for peer support:

www.cancer.ca/en/support-and-services/support-services/connect-with-our-online-community/?region=on

www.lungcancercanada.ca/Get-Involved/Peer-To-Peer.aspx

<https://cancerchat.desouzainstitute.com/about>



How do I navigate the healthcare system?

LUNG CANCER DIAGNOSIS AND TREATMENT INVOLVES MANY HEALTH-CARE PROVIDERS. THIS CAN BE CONFUSING. IT IS NOT UNCOMMON TO FEEL UNCERTAIN ABOUT WHAT IS HAPPENING AND WHO IS INVOLVED IN MAKING DECISIONS ABOUT YOUR TREATMENT. NAVIGATING THE CANCER CARE SYSTEM REQUIRES LOTS OF COMMUNICATION.

It is important to make sure you know who is a part of your cancer care team. In addition to your primary care provider, who may be a family physician or a nurse practitioner, you will likely be working with a team of specialists. This could include a respirologist, a surgeon and one or more oncologists (either a radiation or a medical oncologist). You will also be interacting with nurses, and possibly social workers, pharmacists and radiation therapists. You may find it useful to keep your own list of contact names and numbers of each member of your cancer care team.

In addition, it may help to keep a record of the decisions made at each appointment, any medications discussed and any educational materials provided. If you are feeling overwhelmed, this will allow you to go back and review what has happened and why. It will also help you ask informed questions when you communicate with your health-care team members. If you are struggling to keep track of what is happening, remember that by law patients are allowed to see their own medical records and can keep copies of these reports for themselves. Some institutions use electronic medical records, allowing patients to access their own charts online.

You should not be afraid to ask questions when learning to navigate the health-care system. Asking questions is helpful in clarifying what is to happen, avoiding misunderstandings, and determining where to go for help when you need it.

Family members and/or friends can also be a key resource in navigating the health-care system. They can provide support, be a voice for you if you are struggling, ask questions that might be useful, and help you remember information provided by members of your health-care team. Think about having someone go with you to appointments if you are concerned about remembering everything or finding your way through the health-care system on your own.

For additional support in navigating the healthcare system, please contact us at our Lung Health Info Line (1-888-344-5864)

I still smoke. I feel like it's useless to quit now. Are there any benefits to quitting now that I have lung cancer?

MANY RESEARCH STUDIES INDICATE THAT STOPPING SMOKING AT ANY TIME IS BENEFICIAL. FOR INDIVIDUALS WHO HAVE BEEN DIAGNOSED WITH LUNG CANCER AND ARE UNDERGOING TREATMENT, THERE IS EVIDENCE THAT CONTINUING TO SMOKE DECREASES THE EFFECTIVENESS OF THE TREATMENT (I.E., RADIATION, CHEMOTHERAPY) AND INCREASES THE RISK OF TREATMENT COMPLICATIONS, INCLUDING THE RISKS ASSOCIATED WITH SURGERY.

Quitting smoking can improve both survival odds and survival time. Quitting also reduces the rate of death from other causes and the development of second cancers. Many hospitals now have programs that can be useful to those who decide to stop smoking; ask the staff about these programs.

Resources to help with quitting smoking:

Journey 2 Quit, A Workbook to Help You Quit Smoking, The Lung Association
www.on.lung.ca/document.doc?id=1217

- Contact The Lung Association's Lung Health Info Line at 1-888-344-5864



I did smoke, but have quit. I feel like I've brought this on myself. How do I get over the guilt?

MANY PEOPLE WHO SMOKED IN THE PAST AND NOW HAVE LUNG CANCER EXPERIENCE THIS SAME CHALLENGE. FEELINGS OF GUILT, SHAME AND REGRET ARE FREQUENTLY DESCRIBED BY PEOPLE WHO FEEL THAT THEY HAVE DEVELOPED A SELF-INFLICTED DISEASE. THE SUBSEQUENT FEELINGS OF SELF-BLAME CAN BE HEIGHTENED IF FAMILY, FRIENDS, AND EVEN THE GENERAL POPULATION, SEEM TO SHARE THESE BELIEFS. THE STIGMA INDIVIDUALS WITH LUNG CANCER FACE CAN BE HURTFUL AND ADD TO THE BURDEN THEY ARE ALREADY CARRYING.

It is important to work to overcome these feelings and move beyond them. The feelings can lead to more intense feelings of being alone and depressed if they are allowed to go on. In some cases, they could lead to not seeking help for the disease or not seeking support to cope. Always remember that everyone is worthy of treatment and support. No one deserves lung cancer.

A starting point to deal with the feelings of being isolated and blaming oneself, is to understand that the past is gone and cannot be changed; focus on the present and find ways to be as healthy as possible. Do not hesitate to ask others for help in moving forward. You do not have to go through this alone.

Some ideas you might use, that other people living with lung cancer have found helpful, include:

- No one deserves lung cancer
- There are a number of causes of lung cancer; smoking is one, but there are other factors, and not all cases of lung cancer are caused by smoking
- At one time we did not realize the dangers of smoking and its addictive aspects; it was considered fashionable and sophisticated (even recommended by physicians), and many public role models smoked
- Find a support group and talk about how you are feeling; lung cancer only support groups are rather rare, but there is value in attending a general support group as well

What do I say when someone asks, “Did you smoke?”

ONE OF THE MOST CHALLENGING SITUATIONS PEOPLE WITH LUNG CANCER FACE IS RESPONDING TO COMMENTS ABOUT SMOKING. THESE COMMENTS OFTEN CARRY A SENSE OF BLAME AND JUDGEMENT AND CAN ADD TO EXISTING FEELINGS OF SELF-BLAME. THERE IS A STIGMA ASSOCIATED WITH LUNG CANCER THAT IS UNIQUE TO THIS DISEASE AND IT IS OFTEN BASED ON MISUNDERSTANDING.

If you choose to respond to this type of question, there are a few key messages that can be helpful:

- Lung cancer has a number of causes, of which smoking is only one
- Many people who smoke do not develop lung cancer
- Many people who don't smoke are diagnosed with lung cancer



Does my employer have any obligation to let me work modified hours or duties while I'm undergoing treatment? What if I can't work? What are the responsibilities of my employer?

THE SIDE EFFECTS FROM CANCER AND CANCER TREATMENT CAN IMPACT YOUR ABILITY TO WORK. YOU MAY NOT BE ABLE TO WORK IN THE SAME WAY YOU DID BEFORE YOUR DIAGNOSIS, OR YOU MIGHT NOT BE ABLE TO WORK AT ALL. SOME OF THE CHALLENGES PEOPLE FACE IN THIS SITUATION RELATE TO TELLING OTHERS ABOUT THE DIAGNOSIS, THE UNCERTAINTY ABOUT HOW THEY WILL FEEL FROM DAY TO DAY, THE ABILITY TO PERFORM AT THE REQUIRED LEVEL CONSISTENTLY, AND THE INVISIBLE NATURE OF THEIR SIDE EFFECTS.

Fatigue and cognitive changes are two of the side effects cancer patients say are most problematic in relation to work performance. These are relatively invisible to co-workers who may not know about the cancer diagnosis. Employers need to understand the nature of the illness and be willing to accommodate the individuals undergoing treatment. For many cancer patients, this is still uncharted territory.

Human rights law offers protection for employees in these situations. However, these laws can be difficult to interpret, can change, and differ from province to province. The following information outlines key elements of the laws regarding your rights, but if you have any questions or concerns about your particular situation, it is best to consult a lawyer for advice.

By law, an employer has a duty to reasonably accommodate an individual who has a disability unless there is undue hardship for the employer. In deciding what is considered "undue hardship" for the employer, a number of factors need to be thought about: the

cost to the employer for accommodating the individual with a disability, the size and flexibility of the workplace, and any health and safety issues that could arise (either for the diagnosed employee or for other workers). No two workplaces are the same. What might work for one workplace, may not be feasible for another.

Communication is important because decisions about any modifications required to accommodate the affected individual requires co-operation from the employer, the employee, and the union (if applicable). The primary responsibility for accommodating an employee who is unable to work in the usual manner lies with the employer. However, the employer, employee and union all have a duty to cooperate and be reasonable in the process.

Resources regarding working during cancer treatment and returning to work:
www.cancerandwork.ca

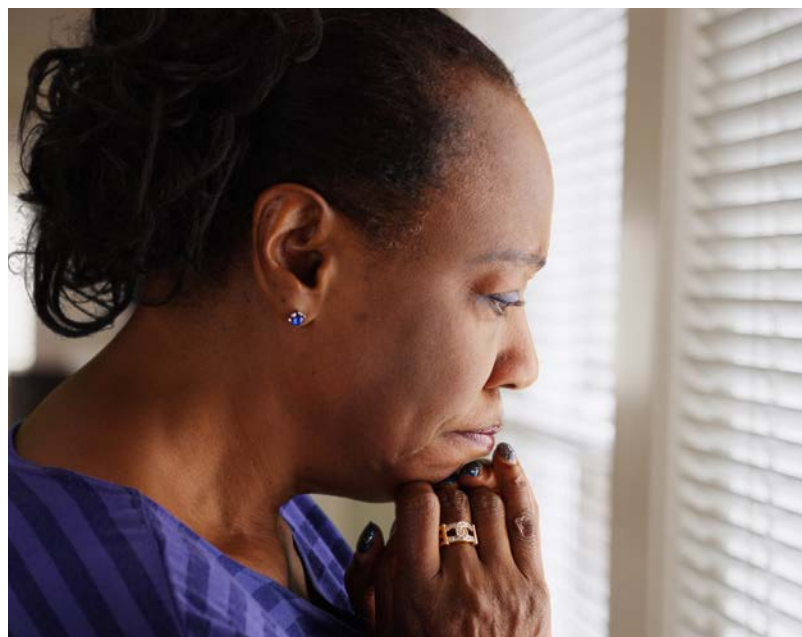
I'm self-employed. What financial supports should I be looking into?

UNLESS YOU HAVE YOUR OWN PRIVATE LONG-TERM DISABILITY FINANCIAL PLAN, THE ONLY SOURCE OF FUNDING IF YOU ARE SELF-EMPLOYED IS THE CANADIAN PENSION PLAN DISABILITY BENEFIT.

This is not a guaranteed source of funding and you will need to meet certain criteria. To be eligible, you must:

1. Be unable to work at any job on a regular basis because of a severe and prolonged disability or illness
2. Have paid sufficiently into the plan
3. Be under 65 years of age

<https://www.cancerandwork.ca/survivors/finances-and-disability/government-programs>



I've tried returning to work since my treatment, but my memory and concentration just aren't up to speed. How can I improve these symptoms?

ISSUES WITH MEMORY AND CONCENTRATION CAN HAPPEN WITH LUNG CANCER TREATMENT. THEY CAN BE A CONCERN FOR PEOPLE WHO CONTINUE WORKING THROUGHOUT THEIR TREATMENT AND FOR PEOPLE WHO RETURN TO WORK AFTER TREATMENT. THEY CAN BE A RESULT OF TREATMENT OR OF DRUGS THAT ARE PART OF TREATMENT, SUCH AS ANTI-NAUSEA MEDICATION. FATIGUE, ISSUES WITH SLEEP, ANXIETY OR DEPRESSION CAN ALSO PLAY A ROLE. TALK WITH YOUR PHYSICIAN OR HEALTHCARE TEAM MEMBER TO SEE IF ANY OF THE FACTORS ARE TREATABLE.

Here are some strategies that other cancer patients have found helpful in dealing with memory and concentration changes:

- Write everything down – keep lists and carry them with you
- Keep a journal (dates, times, conversations)
- Highlight different activities in different colors
- Use your smartphone's calendar to fill in all appointments and important events
- Use a task or lists app on your smartphone to set reminders with an alarm for things you need to do
- Develop a reminder system using a chart board or white board in the kitchen
- Keep objects in the same place so they are easier to find
- Don't try to do too much at once – do not attempt to multi-task
- Keep your brain active – try crosswords and play number games

- Use a joke once in a while – laugh about it!
- Stay positive; recognize it is part of your life now
- Consider doing things in new ways (e.g. read a magazine and not a book)
- Plan activities that require concentration for the times of the day when you feel rested

Another thing you can do to help you manage is to tell family members and friends. They may even have some helpful suggestions. You can get others to help you so you have less to think about and you can give your mind a break. For example, ask a family member or friend listen and take notes at medical appointments.

I was told I should consider having an Advanced Care Plan. What is that?

ADVANCED CARE PLANNING IS A PROCESS OF THINKING, TALKING AND TELLING OTHERS ABOUT WHAT WE WANT FOR THE HEALTHCARE WE WANT TO RECEIVE IN THE FUTURE.

When you have a serious illness, it is important to talk with your healthcare team about several things: what might lay ahead, what type of care you might need, what choices might be available for you, and the type of decisions that might need to be made. Talking these things over with your family and your healthcare team members, and letting them know about your wishes, will help you feel comfortable and confident about future decisions that could be made on your behalf.

Taking the time to write your instructions down is another important step. This document is called an advanced care plan.

Resource to assist with advanced care planning:

<http://www.advancecareplanning.ca/what-is-advance-care-planning/>

http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Topics/Topics/Decisions/Advance+Care+Planning+Across+Canada.aspx



How can I get involved and help others going through the same thing?

There are a number of ways you can help, depending on the time you have available, your skills, and what you are comfortable doing. Some of the roles available include peer support volunteer, spokesperson on an issue related to lung cancer (at a public meeting or to a political representative), providing input or advice on an educational program or committee for a relevant organization, or serving on the volunteer board of an organization.

Please contact us at our Lung Health Info Line (1-888-344-5864) to learn more about how you get involved.

Additional Resources:

www.lungontario.ca

www.cancer.ca

www.lungcancercanada.ca

www.cancerview.ca

www.copingwithcancer.ca

www.virtualhospice.ca

www.cancerandwork.ca



B R E A T H E
the lung association