Lung Cancer

Information guide

and

Personal record

Prepared for you by

The Ottawa Hospital Cancer Centre
Lung Cancer Clinical Pathways Initiative

Made possible by

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and
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Tina M. St. John (With Every Breath – Lung Cancer Guide Book)

Women’s Breast Health Centre Personal Information Binder

My personal information

NAME ____________________

Address ____________________

____

Telephone: Home ____________________

Work ____________________

Other ____________________

Health Card # ____________________

Hospital Unique # ____________________

Private Insurance Card #____________________

The Ottawa Hospital Regional Cancer Centre Chart # ____________________

Other Information ____________________

____

____

____

Personal contacts

NAME ____________________

Relationship ____________________

Address ____________________

____

Telephone ____________________ or ____________________

Person going with me to appointments or driving me (if different from above)

NAME ____________________

Telephone ____________________ or ____________________

NAME ____________________

Telephone ____________________ or ____________________

In case of emergency, please notify (if different from above)

NAME ____________________

Telephone ____________________ or ____________________

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SECTION 1

How do I use this Information Guide and Personal Record?

Frequently asked questions:

Q What is the Lung Cancer Information Guide and Personal Record?

Q How can I use the Lung Cancer Information Guide and Personal Record?

Q Who will be part of my lung cancer treatment?

Q Where will I receive care?

What is the Lung Cancer Information Guide and Personal Record?

This guide will:

- Provide you with some basic information about lung cancer, its treatment and the possible effects of lung cancer on you and those close to you.
- Help you to organize the information you collect about your lung cancer and make sense of this information.
- Allow you to add personal information about your lung cancer to help you find answers to your specific questions
- Help you to understand the cancer care system.
- Allow you to share the information you have gathered with your healthcare team.

How to use the Lung Cancer Information Guide and Personal Record?

Living with lung cancer can be overwhelming and confusing. This guide contains some basic information as well as a list of resources that can further assist you. This information is organized into sections that address different needs. Your family and friends may also use the information in your guide.

Guide sections include

- A list of common questions.
- Answers to commonly asked questions.
- A glossary is included in Section 11.

People with lung cancer want various types of information, in different amounts and at different times. As you collect information that is helpful to you, it can easily be added to your guide.

You can take your guide to medical appointments so that

- You can use it as a reference.
- Your health care professionals can see the information that you have collected so that they can help you to understand the information.

Other considerations

- It is important to remember that you are carrying confidential information about yourself and you must keep it secure at all times.
- You can photocopy any part or section of the guide, for example, additional pages to record appointments or medications.
- It is important to remember that you do not need to complete or keep up-to-date every section in the guide. You can use this guide in whatever way it best helps you.

Who will be part of my lung cancer treatment?

Having treatment for lung cancer can be a complex process for both you and your family. This Information Guide and Personal Record provides a source of information about lung cancer as well as a way to keep track of all the appointments, treatments, medication, and people related to your medical care.

Your care will be provided by a team of health care professionals who will help you to decide on a treatment plan that is best for you. Depending on the kind of treatment you receive, your healthcare team may include surgeons, medical and radiation oncologists, nurses and radiation therapists.

Other members of your treatment team, such as social workers, spiritual advisors and Community Care Access Centre (CCAC) case managers can help you cope with your treatment and disease by providing counseling for you and your family, care in the home and spiritual support. Physiotherapists and occupational therapists can provide a treatment plan to help you physically function at your best. A dietician can give you advice about eating well. Palliative care providers have expertise in managing symptoms such as pain, nausea and breathlessness and will work with you and your family to address these needs and offer other support if the need arises.

Where will I receive care?

If you need treatment or surgery for your cancer or for symptoms and conditions related to your cancer, you might be admitted to the Hospital. If this is the case, the health care team at the hospital will provide the care and services that you need while you are in the hospital and make arrangements for you when you are discharged.

Many patients will visit the Cancer Centre for appointments and for radiation and/or chemotherapy. In addition, the Regional Cancer Program provides chemotherapy and some cancer care to patients living outside the city in various outlying communities. You may be able to receive treatment closer to home if you live an area that is served by this program.

Community health care professionals where appropriate or necessary, will visit you in your home to help you manage side effects, to teach about medication and help you and your family members cope at home. A Community Care Access Centre (CCAC) Case Manager can help arrange such services for you and also help you to obtain other services such as physical care and emotional support if necessary.

Because you are likely to be seeing several healthcare providers and may be receiving care in more than one place, section 2 of this guide will help you to keep track of your care and treatment.

If you have any questions about your cancer or treatment, or if there is any information in this guide that you don't understand, don't hesitate to ask your nurse, doctor or other healthcare provider. If you need help obtaining any of the services mentioned in the binder, such as financial assistance, ask to be referred to a social worker or to someone else who can help you.

We hope you will find this binder helpful in understanding and taking part in your care.

SECTION 2

I have been diagnosed with lung cancer

Frequently asked questions:

Q What is lung cancer?

Q What type is my lung cancer?

Q How do I make sense of all of the information?

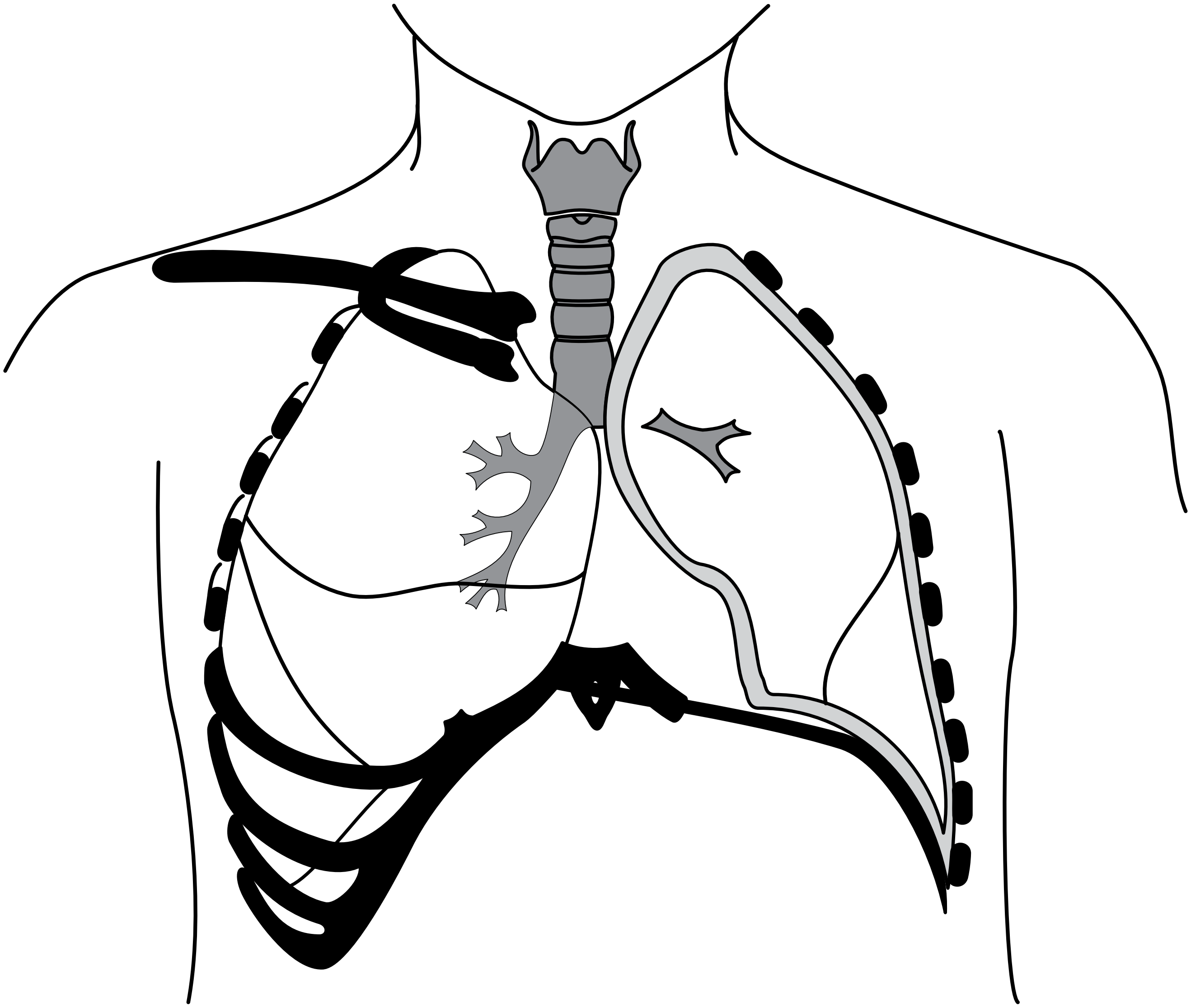
Q What is a common reaction to a diagnosis of lung cancer?

Q How should I share my diagnosis?

Q How do I cope with lung cancer?

The lungs

Have your doctor use this diagram to help explain your lung cancer and its treatment.



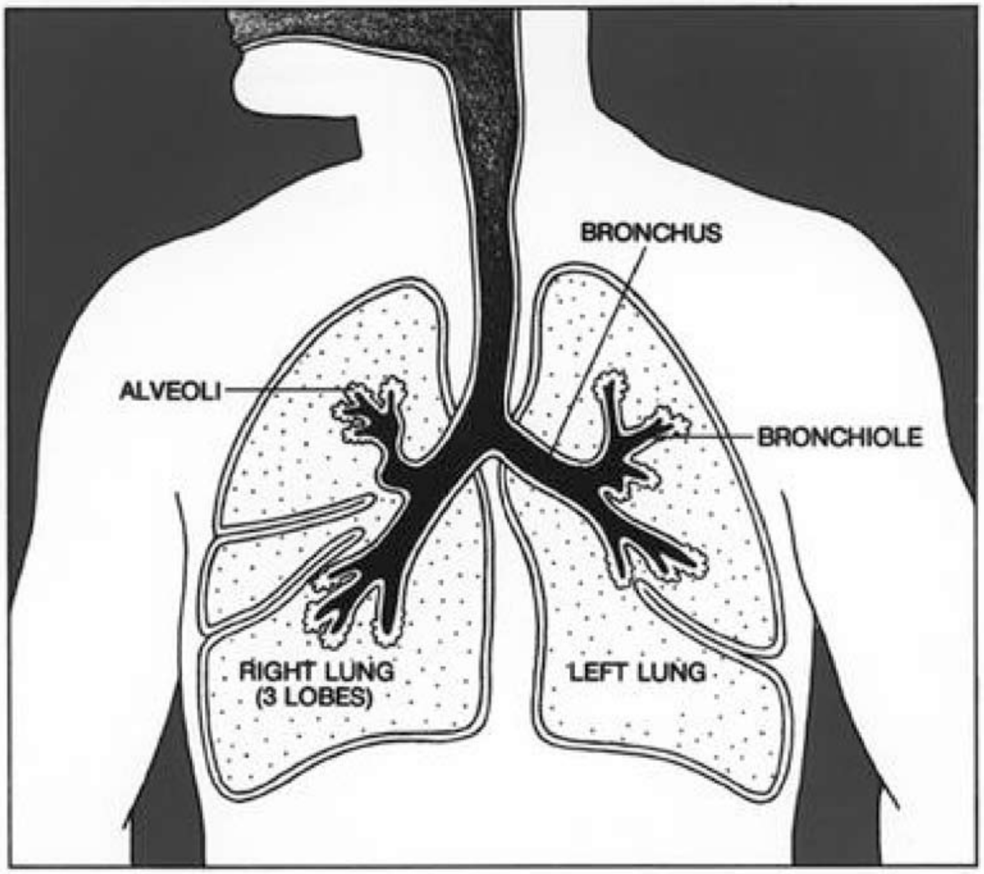
What is lung cancer?

Lung cancer occurs when cells develop abnormally in one or both of the lungs and grow out of control to form a **tumour**. **Tumours** make it difficult for the lungs to work properly.

There are two major types of lung cancer: **non-small cell** and **small cell**. The terms non-small cell and small cell refer to how the cells look when seen through a microscope. The terms refer to the kinds of cells that make up the tumour, not the actual size of the tumour.

The lungs

Every cell in our body needs oxygen to survive. The lungs are the organs that enable the transfer of oxygen to our cells as well as the removal of carbon dioxide. The inside of the lungs contain air passages called bronchioles that end in tiny air sacs called alveoli. It is in the alveoli where the exchange of oxygen and carbon dioxide occurs.



What type is my lung cancer?

The first step in diagnosing lung cancer is to determine whether it is small cell lung cancer or non-small cell lung cancer. Your initial biopsy is sent to a pathologist to be looked at. The pathologist will examine the tissue sample and report the findings back to your physician. Your physician will discuss the results with you. You may request a copy of your pathology report as it contains an invaluable blueprint of your cancer and is used to plan further treatment.

Non-small cell lung cancer

Over 75% of all people diagnosed with lung cancer have non-small cell lung cancer (NSCLC). Most people diagnosed with NSCLC are smokers or former smokers. There are four major types of non-small cell lung cancer:

Squamous carcinoma

This type generally begins in one of the larger breathing tubes (bronchus). It tends to spread less quickly than other forms of lung cancer. It currently occurs most frequently in men and older people of both sexes.

Adenocarcinoma

This type begins near the outside surface of the lung and can vary in both size and how fast it grows. It is the most common lung cancer in North America.

Bronchoalveolar

This is another less common type of Adenocarcinoma. It causes changes on an x-ray that may be mistaken for pneumonia.

Large-cell carcinoma

This type may occur in any part of the lung. However, it usually starts in the smaller bronchioles. Tumours are usually large at the time of diagnosis and occur with the same frequency in men and women.

Small cell lung cancer

Small cell lung cancer is a more rapidly growing type of lung cancer than non-small cell lung cancer. Most people diagnosed with small cell lung cancer are smokers or former smokers. It usually starts in the main breathing tube (bronchus) and it tends to grow rapidly.

Other

Other types of lung cancer cell types occur in a small number of patients, e.g. carcinoid.

What are the major causes of lung cancer?

- Most people who get lung cancer smoke or have smoked cigarettes.
- Exposure to second-hand smoke – even people who do not smoke can develop lung cancer from cigarette smoke.
- Environmental factors – a person's risk of developing lung cancer is increased by exposure in the home or in the workplace to harmful substances such as asbestos.

Why do some non-smokers get lung cancer?

- A number of conditions and circumstances have been identified that will increase a non-smoker's chance of developing lung cancer.
- People exposed to second hand smoke in the home or workplace may be more likely to get lung cancer.
- Some people who have never smoked, but who have worked with asbestos or have been exposed to random gas may develop lung cancer.
- Your genetic makeup may play a role in developing lung cancer. Numerous studies have shown that lung cancer is more likely to occur in both smoking and non-smoking relatives of those who have had lung cancer than in the general population. Genetic differences may also explain why some smokers do not develop lung cancer.
- Despite all of the above factors, in most cases there is no specific reason identified to explain why a non-smoking person gets lung cancer.

What are the symptoms of lung cancer?

- There is no one single symptom of lung cancer.
- Symptoms are not always obvious during the early stages of the disease.
- Symptoms are varied and can include: a persistent cough, pain, coughing up blood, shortness of breath, or hoarseness.
- More frequently, lung cancer is detected after a growing tumour causes symptoms to appear. Sometimes the first symptom of lung cancer is a symptom from the cancer spreading outside of the lung.

Why is lung cancer often detected at a late stage?

Lung cancer can take a long time to develop and it is very difficult to detect at an early stage. Because of the large size and elastic nature of the lungs, cancer may grow for many years without any symptoms. Symptoms of lung cancer (e.g. persistent cough, etc.) do not always appear in the early stages of lung cancer. Even then, a persistent cough may be diagnosed as bronchitis and treated with antibiotics.

Unlike some other cancers, there is no one test that can detect lung cancer. It is known that chest x-rays and CT scans can detect small **tumours**. However, these types of tests are usually ordered after the patient has developed symptoms. In some cases, lung cancer is found during a routine check-up.

How do I make sense of all the information?

When you are diagnosed with lung cancer, you will receive a lot of information from many sources. It is important to keep the following points in mind:

- Consider how much information you want to get about your cancer and its treatment and ask for the information. Some people want as much information as they can possibly get and others may only want a little.
- **Write down questions as you think of them. Take your notes with you to each appointment.**
- **Record your conversations (i.e., take notes; use tape recorder) with your health care providers or bring along a friend or family member to listen and take notes. It's sometimes hard to listen, understand and remember everything that you are being told.**
- **Write down instructions or ask for them in writing.**
- **Ask your health care provider to explain if you do not understand.**
- If you are feeling overwhelmed with the amount of information you have received, make an appointment to discuss it with one of your health care providers (i.e., doctor, nurse, social worker).
- Sometimes friends and family members try to help by giving you information that you really don't feel you can take in. Thank them for their help and tell them that you will read the information when you are feeling up to it.

- If you have questions about information that you have read, do not hesitate to ask your health care providers. It is often difficult to judge if information is coming from reliable sources or how it might be useful to you.
- It is important to remember when reading information that there may be differences between American and Canadian standards of care, insurance and health care systems.

Remember:
Not everything you read will apply to you. Read so that you can know the types of questions to ask about your situation. Also, information needs change as people progress through their cancer treatment. Sometimes patients do not want to read anything at the start, but later will feel the need to know more. Some patients rely on family members and friends to gather information for them.

What is a common reaction to a diagnosis of lung cancer?

A diagnosis of lung cancer brings with it many different reactions, which may make thinking clearly and problem solving hard. The first reaction may be a feeling of shock, disbelief and fear. “Am I going to die?” This is a common reaction. A sense of panic and overwhelming anxiety can take over. Because of the association of lung cancer to smoking, some people may also feel guilty and ashamed. They may be reluctant to seek health care advice because they fear that health care professionals will blame them for their illness. Other possible reactions can be fear, denial and anger.

Many individuals with lung cancer may feel tired, have difficulty sleeping, may have changes to their appetite. Feelings of sadness and grief may bubble to the surface. It is OK to cry.

Each person deals with this situation differently. It may be helpful to talk about how you are feeling and learn how you might deal with these feelings.

How should I share my diagnosis?

The most important reason for sharing with others is that it allows family and friends to be supportive and people who have support seem to do better. You may also find it helpful to talk about your lung cancer.

Reasons for telling

- As you tell others, it may help you to understand the information you have been given.
- It avoids secrets. People who find out from someone else do not know if they have permission to talk to you.
- Some people such as close family may need to know, as it would cause them greater distress to be left out.
- It may lift the burden of keeping it to yourself.

How to tell family and friends

There is no easy way to say it. Here are a few tips to think about when sharing this news:

- First give the headline:
  e.g. *I have undergone a series of tests and my doctor has told me I have lung cancer.*
- Give them any other information you have:
  e.g. *I expect to be starting treatment soon*.
- Allow them to ask questions:
  e.g. *Do you have any questions? You may not have the answers; tell them this.*
- Tell them how you are feeling:
  e.g. *I'm frightened and need your support.*
- Tell them what they can do:
  e.g. *I need you to tell Aunt Susan about my diagnosis.*

Often family and friends feel helpless as to what they can do to help. It will be up to you to let them know that you need them as an important part of your support team. You may not be certain what you need specifically but only that their support will be important.

The way in which you tell certain family members and friends will be different.

How do I cope with lung cancer?

Here are some tips to help you cope with your lung cancer diagnosis:

Step 1

Caring for you is priority number one.

Step 2

Do not be afraid to ask your family, your friends, or your community for help when you need it.

Step 3

Take on one issue at a time: Leave the things that can be left, try not to jump ahead.

Step 4

Develop a good working relationship with your health care team: Ask questions and share your feelings, develop a sense of trust, include your family doctor.

Step 5

Make changes slowly: Only do the things that make sense to you. Any change is difficult, do not add stress by expecting too much of yourself.

Remember you are truly unique, and your journey belongs to you!

SECTION 3

Keeping track

- **Q** Who makes up my health care team?
- ⌘ Business card holder
- ⌘ Summary of my lung cancer diagnosis
- ⌘ My symptom diary
- ⌘ My medication record
- ⌘ My appointments
- ⌘ Questions for my health care provider(s)
- ⌘ My test results
- ⌘ Decisions
- ⌘ Personal notes and diary

> *"When someone tells you that you can't go any farther, just tell them to look behind you and see how far you've come."*
>
> —Linda Pitre

My health care team

Doctors involved in my care

Family Doctor ______________________________ ☎ ____________________

Surgeon ______________________________ ☎ ____________________

Medical Oncologist ______________________________ ☎ ____________________

Radiation Oncologist ______________________________ ☎ ____________________

______________________________ ☎ ____________________

______________________________ ☎ ____________________

______________________________ ☎ ____________________

Others involved in my care

Nurse(s) ______________________________ ☎ ____________________

Patient Designated Nurse: ______________________________ ☎ ____________________

Case Manager(s) ______________________________ ☎ ____________________

______________________________ ☎ ____________________

Community Nurse(s) ______________________________ ☎ ____________________

______________________________ ☎ ____________________

Pharmacist/Drug Store ______________________________ ☎ ____________________

Social Worker(s) ______________________________ ☎ ____________________

______________________________ ☎ ____________________

Dietician ______________________________ ☎ ____________________

Dentist ______________________________ ☎ ____________________

Optometrist/Ophthalmologist

______________________________ ☎ ____________________

Chaplain ______________________________ ☎ ____________________

Complementary care providers

(Such as massage therapists, chiropractors, exercise specialist, physiotherapist, and occupational therapists)

______________________________ ☎ ____________________

______________________________ ☎ ____________________

______________________________ ☎ ____________________

______________________________ ☎ ____________________

Other supports

(e.g. neighbours, volunteer driver, clergy)

______________________________ ☎ ____________________

______________________________ ☎ ____________________

______________________________ ☎ ____________________

______________________________ ☎ ____________________

______________________________ ☎ ____________________

______________________________ ☎ ____________________

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Summary of my lung cancer diagnosis

Many people on your health care team will ask you similar questions about your lung cancer. You may find it helpful to complete this section so that you will have a record that you can share when these questions are asked. You may need your doctor or nurse to help you. Section 3 contains the information describing lung cancer, which may be helpful to refer to when you fill out this part.

1. Date of your most recent chest X-ray: ________ / YY ________ / MM ________ / DD

2. Have you ever had a surgery or procedure that involved your lungs? If so, which side, what kind, and when (approximate date)?

	☐ **Right**	☐ **Left**
☐ Bronchoscopy	_____/YY_____/MM_____/DD	_____/YY_____/MM_____/DD
☐ Mediastinoscopy	_____/YY_____/MM_____/DD	_____/YY_____/MM_____/DD
☐ Lobectomy	_____/YY_____/MM_____/DD	_____/YY_____/MM_____/DD
☐ Pneumonectomy	_____/YY_____/MM_____/DD	_____/YY_____/MM_____/DD
☐ Thoracotomy	_____/YY_____/MM_____/DD	_____/YY_____/MM_____/DD
☐ Needle biopsy	_____/YY_____/MM_____/DD	_____/YY_____/MM_____/DD
☐ Other	_____/YY_____/MM_____/DD	_____/YY_____/MM_____/DD

3. Date of diagnosis: _____/YY_____/MM_____/DD

4. What did your doctor tell you was found during the procedure(s) or operation?

5. What kind of lung cancer do you have?

☐ Small Cell ☐ Non-small Cell

6. What stage was your lung cancer when you were first diagnosed?

☐ **Small Cell:** ☐ Limited Stage ☐ Extensive Stage

☐ **Non Small Cell:** ☐ Stage I ☐ Stage II ☐ Stage IIIA
☐ Stage IIIB ☐ Stage IV

7. Other (including other medical history):

MY SYMPTOM DIARY

Keeping track of symptoms helps you to:

- Report to your health team more accurately;
- Recognize possible trends in your symptom development;
- Identify what makes your symptoms worse and what makes them better;
- Keep a record of medication and other treatments used and how they are working.

Date and Time	**Symptom** Example: Pain, breathlessness, fatigue, nausea, other	**What was I doing?** Example: physical activity, emotional event, sleeping, eating, other	**How bad is the symptom?** Circle a number	**What did I do to make the symptom better?**	**Did it help?**
			1 2 3 4 5 6 7 8 9 10 1 = least bad 10 = the most severe	Medication amount: Other:	
			1 2 3 4 5 6 7 8 9 10 1 = least bad 10 = the most severe	Medication amount: Other:	
			1 2 3 4 5 6 7 8 9 10 1 = least bad 10 = the most severe	Medication amount: Other:	
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Date and Time	**Symptom** Example: Pain, breathlessness, fatigue, nausea, other	**What was I doing?** Example: physical activity, emotional event, sleeping, eating, other	**How bad is the symptom?** Circle a number	**What did I do to make the symptom better?**	**Did it help?**
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You can photocopy the page as many times as you need.

MY MEDICATION RECORD

This form is to keep track of the medications you are taking. You should list any non-prescription medications or therapies (vitamins, Tylenol, or herbal remedies), as well as prescription medications you are using, in this section.

NAME OF MEDICATION and dosage instructions	Time of day taken	Reason for taking	Doctor	Side effects	Advice for side effect relief	Date started	Date stopped and reason for stopping

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NAME OF MEDICATION and dosage instructions	**Time of day taken**	**Reason for taking**	**Doctor**	**Side effects**	**Advice for side effect relief**	**Date started**	**Date stopped and reason for stopping**

My appointments

Date __________________ Reason for visit ______________________________

Health care provider _________________ Name of clinic ____________________

Location ____

Transportation arrangement (i.e., relative, friend, volunteer driver) _________________

Questions, answers or comments _______________________________________

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Next appointment ____

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Date __________________ Reason for visit ______________________________

Health care provider _________________ Name of clinic ____________________

Location ____

Transportation arrangement (i.e., relative, friend, volunteer driver) _________________

Questions, answers or comments _______________________________________

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Next appointment ____

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Date __________________ Reason for visit ______________________________

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Questions, answers or comments _______________________________________

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My appointments

Date ______________________ Reason for visit ____________________________________

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Location ____

Transportation arrangement (i.e., relative, friend, volunteer driver) ____________________

Questions, answers or comments ____

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Next appointment ____

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Date ____________________ Reason for visit ____________________

Health care provider ____________________ Name of clinic ____________________

Location ____

Transportation arrangement (i.e., relative, friend, volunteer driver) ____________________

Questions, answers or comments ____

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Health care provider ____________________ Name of clinic ____________________

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Questions, answers or comments ____

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My appointments

Date ____________________ Reason for visit ______________________________

Health care provider ____________________ Name of clinic ____________________

Location ____

Transportation arrangement (i.e., relative, friend, volunteer driver) ____________________

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My appointments

Date ______________________ Reason for visit ____________________________________

Health care provider _____________________ Name of clinic _________________________

Location ____

Transportation arrangement (i.e., relative, friend, volunteer driver) _____________________

Questions, answers or comments ____

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Date ______________________ Reason for visit ____________________________________

Health care provider _____________________ Name of clinic _________________________

Location ____

Transportation arrangement (i.e., relative, friend, volunteer driver) _____________________

Questions, answers or comments ____

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Next appointment ____

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Date ______________________ Reason for visit ____________________________________

Health care provider _____________________ Name of clinic _________________________

Location ____

Transportation arrangement (i.e., relative, friend, volunteer driver) _____________________

Questions, answers or comments ____

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Next appointment ____

QUESTIONS FOR MY HEALTH CARE PROVIDER(S)

Date	Question	Answer

QUESTIONS FOR MY HEALTH CARE PROVIDER(S)

Date	Question	Answer

QUESTIONS FOR MY HEALTH CARE PROVIDER(S)

Date	Question	Answer

QUESTIONS FOR MY HEALTH CARE PROVIDER(S)

Date	Question	Answer

MY TEST RESULTS

Name of test	Date	Reason for test	When I can expect results	Result of test	Copy in my binder	
					Yes	No

MY TEST RESULTS

Name of test	Date	Reason for test	When I can expect results	Result of test	Copy in my binder	
					Yes	No

Ottawa Personal Decision Guide

What is the Decision Guide?

The decision guide is a tool that is designed to help individuals think through information to help them make difficult decisions. It is a step-by-step process that helps you to make the decision and then plan how to carry it through. You can share this tool with your health care providers for any further support or feedback that you may need.

What are some of the difficult decisions?

After a diagnosis with lung cancer, you will be faced with a number of decisions. For example: What is the best treatment for you? What are the best medications for your symptoms? Challenging personal decisions also arise: Who to share your diagnosis with? How to manage your finances? Should you consider **complementary therapies**? This guide is not focused on any **one** decision; rather, it can lead you through thinking about any decision that you are dealing with.

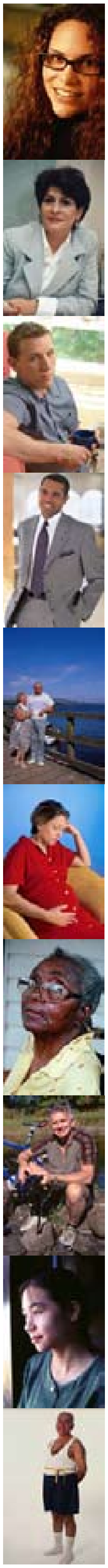
Do I need to use this guide?

The following signs may mean that you are having a hard time making a decision. The guide may be helpful if you are experiencing:

- Feeling unsure about what to do.
- Feeling worried about the outcomes of the decision.
- Feeling upset when you think about the decision.
- Feeling like you can't get the decision off your mind.
- Wavering between the choices you face.
- Wanting to put off making the decision.
- Questioning what is important to you in making the decision. And
- Physical signs of stress when you think about the decision.

During a time where emotions and anxieties may be quite high, this guide may help you to think through some of the more difficult challenges that you will be faced with throughout your cancer journey.

Ottawa Personal Decision Guide For People Facing Tough Health or Social Decisions



You will be guided through four steps:

❶ Clarify the decision.
❷ Identify your decision making needs.
❸ Explore your needs.
❹ Plan the next steps.

❶ Clarify the decision.

What is the decision you face?		
What is your reason for making this decision?		
When does this decision have to be made?		
How far along are you with your decision?	☐ I have not yet thought about options ☐ I am considering the options	☐ I am close to choosing an option ☐ I have already made a choice
Are you leaning toward a specific option?	☐ Yes If yes, which one?	☐ No

❷ Identify your decision making needs.

A. Support	Do you have enough support and advice from others to make a choice?	☐ Yes	☐ No
	Are you choosing without pressure from others?	☐ Yes	☐ No
B. Knowledge	Do you know which options are available to you?	☐ Yes	☐ No
	Do you know both the benefits and risks of each option?	☐ Yes	☐ No
C. Values	Are you clear about which benefits and risks matter most to you?	☐ Yes	☐ No
D. Certainty	Do you feel sure about the best choice for you?	☐ Yes	☐ No

People who answer “No” to one or several questions are more likely to delay their decision, change their mind, feel regret about their choice or blame others for bad outcomes. Therefore, it is important to work through steps **three** and **four** that focus on your needs.

❸ Explore your needs.

A. Support

Who else is involved?	Name:	Name:	Name:
Which option does this person prefer?			
Is this person pressuring you?	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
How can this person support you?			
What role do you prefer in making your choice?	☐ I prefer to share the decision with ______________________ ☐ I prefer to decide myself after hearing the views of ______________________ ☐ I prefer that someone else decides. Who? ______________________		

Ottawa Personal Decision Guide For People Facing Tough Health or Social Decisions

B. Knowledge
In the balance scale below, list the options and main benefits and risks that you already know. Underline the benefits and risks that you think are most likely to happen.

C. Values
Use stars (★) to show how much each benefit and risk matters to you. 5 stars means that it matters "a lot". No star means "not at all".

D. Certainty
Circle the option with the benefits that matter most to you and are most likely to happen. Avoid the option with the risks that are most important to avoid.

	☺ **BENEFITS** Reasons to choose this option	How much it matters Add ★ to ★★★★★	☹ **RISKS** Reasons to avoid this option	How much it matters Add ★ to ★★★★★
Option #1 is:				
Option #2 is:				
Option #3 is:				

❹ Plan the next steps based on your needs.

✓ **Things making the decision difficult**	✓ **Things you are willing to try**
A. Support ☐ You feel you do NOT have enough support	☐ Discuss your options with a trusted person (e.g. health professional, counsellor, family, friends) ☐ Find out what help is on hand to support your choice (e.g. funds, transport, child care)
☐ You feel PRESSURE from others to make a specific choice	☐ Focus on the opinions of others who matter most. ☐ Share your guide with others. ☐ Ask others to complete this guide. Find areas of agreement. When you disagree on facts, agree to get information. When you disagree on what matters most, respect the other's opinion. Take turns to listen, mirror back what the other has said matters most to him or her. ☐ Find a neutral person to help you and others involved.
B. Knowledge ☐ You feel you do NOT have enough facts	☐ Find out about the chances of benefits and risks. ☐ List your questions and note where to find the answers (e.g. library, health professionals, counsellors):
C. Values ☐ You are NOT sure which benefits and risks matter most to you	☐ Review the stars in the balance scale to see what matters most to you. ☐ Find people who know what it is like to experience the benefits and risks. ☐ Talk to others who have made the decision. ☐ Read stories of what mattered most to others. ☐ Discuss with others what mattered most to you.
☐ Other factors making the decision DIFFICULT	List anything else you need:

Personal notes and diary

Personal notes and diary

"If I have the belief that I can do it, I shall surely acquire the capacity to do it even if I may not have it at the beginning."

— Mahatma Gandhi

SECTION 4

How will my lung cancer be treated?

Frequently asked questions:

- **Q** What is **staging**?
- **Q** How will my lung cancer be staged?
- **Q** How will my lung cancer be treated?
- **Q** What are **clinical trials**?
- **Q** What is new on the horizon?

What is staging?

To describe your lung cancer and plan the right treatment, doctors give it a number, or *stage*, based on how far along it is. The stage is based on the size and location of the cancer, whether is has affected the **lymph nodes**, and whether it has spread to other parts of the body.

How will my lung cancer be staged?

As part of staging, your physician may suggest/recommend the following tests if they have not already been done:

1. Chest x-ray
2. **CT scans of chest and upper abdomen**
3. Blood tests such as: serum chemistries, CBC, kidney and liver function tests
4. CT scan of the brain
5. **Bone scan**
6. **Bronchoscopy**
7. **Mediastinoscopy**

The stages of non-small cell lung cancer

Non-small cell lung cancer has four stages:

Stage I: The cancer is only in the lung and has not spread to the **lymph nodes**.

Stage II: The cancer has spread to nearby **lymph nodes** but not to **lymph nodes** in the area between the lungs (mediastinum); or the cancer has grown into the chest wall.

Stage III: The cancer has spread to the **lymph nodes** in the area between the lungs (mediastinum); or; the cancer has spread to the **lymph nodes** on the other side of the mediastinum or to the neck.

Stage III is further divided into:

Stage III-A: Potentially the **tumour** could be surgically removed.
Stage III-B: Usually the **tumour** cannot be surgically removed.

Stage IV: The cancer has spread to one or more other parts of the body, such as the bones, liver, brain, or other organs.

The stages of small cell lung cancer

Small cell lung cancer is usually staged using the terms listed below:

Limited-Stage: The cancer involves one lung and possibly **lymph nodes** on the same side of the chest as the cancer.

Extensive-Stage: The cancer has spread beyond the extent of limited-stage small cell lung cancer including other parts of the body such as the bones, liver and brain.

What are lymph nodes?

Lymph nodes are located throughout the body in bunches including the neck region, the underarms, the space between the lungs (mediastinum), throughout the abdominal region, and in the groin. They are part of the immune system and function to rid the body of harmful invaders such as bacteria. The presence of cancer cells in **lymph nodes** generally indicates that the cancer is more likely to spread to other parts of the body.

How will my lung cancer be treated?

Surgery

If the cancer is found early enough – and you are reasonably healthy – surgery is the likely treatment. You may be put on chemotherapy or radiation before surgery to make the **tumour** smaller. This allows the doctor to remove it more easily.

Your doctor may also recommend that you take chemotherapy or radiation therapy after the surgery to make sure all the cancer cells are killed. This is known as **adjuvant therapy**.

If you are going to have surgery, you will be provided with extra information to help you prepare before your admission to the hospital.

What is chemotherapy?

Chemotherapy is the treatment of cancer with drugs. There are a number of chemotherapy drugs used to treat lung cancer. Although the chemotherapy drugs work differently, they all kill cancer cells or prevent their growth. A single dose of chemotherapy will only kill a percentage of cancer cells. Therefore multiple doses or cycles are necessary.

Every lung cancer patient is different. How frequently the treatment is given will depend on the drugs being used, how well you tolerate the treatment and how your cancer responds to the chemotherapy. Individual patients respond differently to chemotherapy. Before starting chemotherapy, you should discuss with your doctor the **side effects** that you are most likely to experience and the impact that they may have on your quality life.

Most chemotherapy is given by intravenous injection. Normally, you can expect to receive your chemotherapy as an outpatient at the cancer centre or a hospital clinic. Patients are rarely admitted to hospital for chemotherapy treatment. You can expect to be given written information by your nurse at the cancer centre about the specific chemotherapy you will receive.

Chemotherapy treatment normally continues for four to six months. Your individual treatment plan may require that you have a chemotherapy treatment one to four times a month. In addition to your chemotherapy treatments, you will also be asked to have blood tests on a regular basis, sometimes as often as once a week, at the lab near your home. Approximately once a month, you and your doctor will assess whether the **tumour** is responding to treatment and decide if the treatment should continue.

What is radiation therapy?

Radiation therapy is the treatment of cancer with high-energy rays. At least 50% of patients with lung cancer will require radiation therapy at some point during their illness. Radiation therapy may be used with or without surgery in an attempt to eliminate the **tumour** (**radical radiotherapy**) or to reduce its size to relieve symptoms such as pain and breathlessness. Individual patients respond differently to radiation therapy.

Before starting radiation therapy, you should discuss with your doctor the **side effects** that you are most likely to experience and the impact that they may have on your quality of life. The number of treatments varies from patient to patient. Each radiation therapy treatment usually lasts between two and five minutes. You will not feel any pain or any other sensation during the treatment. Because you will need to be carefully positioned on a firm table before you receive each treatment, you should allow up to an hour for each radiation therapy treatment when scheduling transportation or other appointments. You will know before you begin treatment how many treatments you will have.

What are clinical trials?

Clinical trials, also called research studies, test new drugs, new ways of giving drugs or radiation, new approaches to surgery, and new methods such as gene therapy. Each **clinical trial** attempts to answer specific scientific questions that will ultimately lead to better treatment. All trials are strictly monitored to ensure that the participant receives the best available care. Standard treatments are those which have been well studied in **clinical trials** and which have been proven to be helpful for the most patients.

There are many clinical trials occurring at the cancer centre. Each trial is designed to answer specific scientific questions. If you are interested in participating in a clinical trial, you can discuss this option with your physician. It is the best way to learn whether or not an appropriate trial is available in Ottawa.

Participating in a **clinical trial** is voluntary. You must consider all your choices when deciding to join in a **clinical trial** and keep in mind that although the decision to participate is entirely yours once you are enrolled in a trial, you may not be able to choose all of the treatment(s) you will receive. You should expect to receive treatment that is anticipated to be at least as good as current conventional (standard) therapies.

It is important to know that if you do not wish to participate in a clinical trial, you will continue to receive the best possible standard of care.

What is new on the horizon?

Monoclonal antibodies

Tumours need their own blood supply in order to grow large enough to become life threatening. To do this, they give off various substances to stimulate special tissue lining cells to form new blood vessels. One of these substances is called vascular endothelial growth factor (VEGF).

Anti-VEGF is a protein designed in the lab that has the ability to interfere with the blood supply of some kinds of lung **tumours**. Some studies have shown that this medication, used with conventional chemotherapy, can prolong the time before relapse in some individuals with advanced lung cancer. **Clinical trials** with anti-VEGF are ongoing.

EGFR inhibitors

In our body, substances called **Growth Factors** encourage our cells to grow. Some cancer cells have a greater than normal ability to attract growth factors and use them to grow and divide very rapidly. They do this by having a greater number of **growth factor receptors** on their outer surface. EGFR (epidermal growth factor receptor) inhibitors block those receptors on the cancer cell and prevent them from attracting growth factors; therefore slowing down or prevent the cancer cells from growing.

Currently, **clinical trials** are going on with individuals with non-small cell lung cancer that are testing whether or not EGFR Inhibitors are useful in the treatment of this kind of cancer.

Gene therapy

Gene therapy involves the use of specially designed genes to interfere with the ways that cancer cells grow and divide. Currently there are **clinical trials** for some kinds of lung cancer underway using gene therapy together with regular chemotherapy to interfere with the cancer cell's ability to survive.

Selenium

Selenium is a trace mineral that, in small amounts, is essential to good health. Selenium helps to prevent cellular damage from free radicals. Some research has shown that free radicals may contribute to the development of chronic diseases such as cancer and heart disease. Currently, some **clinical trials** are looking at selenium supplements in some individuals who have had their lung cancer surgically removed to evaluate its effectiveness in preventing **recurrence** of the lung cancer.

Radiofrequency ablation

Radiofrequency Ablation (RF) is a type of treatment that uses high temperatures to kill cancer cells. This procedure is done in the X-ray department and involves inserting an electrical probe into the cancer tumour. Once activated, the extreme heat of the probe causes tumor cell death. Recent studies have shown that this procedure can be used both for tumours that cannot be removed by surgery or to help relieve some of the symptoms caused by the tumour.

Interventional bronchoscopy

Interventional bronchoscopy describes a group of different treatments that can be used to relieve shortness of breath, difficulty breathing and other symptoms caused by lung cancer. Sometimes, lung cancer grows into or around the air passages in the lungs and begins to block or squeeze them. This can cause breathlessness, coughing, coughing up of blood, and sometimes, lung collapse. In some cases, a **bronchoscope** can be used to administer treatments such as *photodynamic therapy, argon photocoagulation*, or, widening of the air passages to enlarge the airway.

Photodynamic therapy

Photodynamic therapy is a type of treatment that can be used to treat some symptoms of lung cancer. In this therapy, the patient is given a type of drug called a photosensitizer, which makes certain body tissues extremely sensitive to specific light wavelengths.

The first step in photodynamic therapy is to inject the photosensitizer into the blood stream. Initially, all the cells in the body absorb the photosensitizer but whereas normal cells have the ability to break it down in a short period of time, cancer cells do not seem to be able to get it out so quickly. Therefore, after a period of several hours, when the normal cells are safe but the cancer cells are not, the tumor cells are exposed to light, which reacts with the photosensitizer and causes tumor cell damage and death.

Argon plasma coagulation

Argon Plasma Coagulation (APC) is a type of treatment that uses a form of electrical energy to destroy cancer tissue or to stop bleeding from the tumor site. It is used to alleviate some of the symptoms of lung cancer such as breathlessness or coughing up blood. Argon gas is ionized which allows it to conduct electricity. Using a special device through the bronchoscope APC can deliver a high frequency electrical current to the tumor site and cause tissue destruction or, if bleeding is the problem, it can coagulate the tissue and stop it from bleeding.

SECTION 5

How do I cope with my lung cancer?

Frequently asked questions:

Q How can I cope with the physical symptoms?

Q What can I do to feel my best during treatment?

Q What side effects can I expect from treatment?

Q How do I manage my anxiety?

Q Will I be able to keep my regular schedule?

Q How do I manage my financial and personal care issues/concerns?

Q Should I consider other treatment(s) such as nutritional support, relaxation techniques, massage, aromatherapy, acupuncture or other related approaches?

How can I cope with the physical symptoms?

Pain and other symptoms can be managed through a variety of methods. There are specialists available who can help you to mange pain, breathlessness, fatigue and other symptoms that you may be experiencing. The following is some general advice on a few of the more common symptoms that you may experience. It is important to discuss symptom management with your nurse or physician; they may have other helpful suggestions for you.

Pain

Pain management usually includes medications and non-medicinal treatments that will work together to get your pain well controlled. Pain medications are meant to be taken regularly and at a dose that will treat the pain. Your physician and the health care team will work with you to find the best dose to treat the pain and to help you to understand how to adjust the dose of medication depending on your needs. The amount of pain that you will need to block varies from day to day so it is important that you participate in determining the doses. Many people fear the **side effects** of pain medication or they fear that they will become addicted to the pain medication. Addiction almost never occurs in cancer patients. Many **side effects** wear off in time or are easily managed with other medications.

Pain is not just a physical thing. The ability to cope with pain is worse if you are tired, sad, angry, afraid, or stressed. Family and friends may be able to provide emotional support, but sometimes counseling or support groups are helpful as well.

Breathlessness

Shortness of breath, also called dyspnea, is a common symptom of people with lung cancer. People often describe dyspnea as just not being able to get enough air into their lungs. It is important to discuss your breathlessness with your physician. They will be able to help you to understand why you are becoming breathless and what you can do to help it.

The Canadian Lung Association offers the following tips to help control breathing.

S.O.S. for S.O.B. (Help for Shortness of Breath)
When on the brink . . . Think

- Stop and rest in a comfortable position
- Get your head down
- Get your shoulders down
- Breathe in through your mouth
- Blow out through your mouth
- Breathe in and blow out as fast as is necessary
- Begin to blow out longer, but not forcibly — use pursed lips if you find it effective
- Begin to slow your breathing
- Begin to breathe through your nose
- Begin diaphragmatic breathing
- Stay in position 5 minutes longer

http://www.lung.ca/copd/management/coping/sos.html






Many patients have found the following tips helpful to control their breathing. Not everything works for everyone. It is important to remember to get help if these techniques are not working for you.

Pursed lip breathing encourages you to completely exhale each breath.

- Breathe in through your nose.
- Form your lips into the position used to whistle or blow out candles and breathe out for twice the number of seconds that it took you to breathe in.

A fuller breath out results in an automatic rush of air into your lungs, which can decrease the severity of breathlessness and increase your stamina, as well as your confidence level.

Abdominal (diaphragmatic) breathing helps the lungs to function at their best. It also can promote a feeling of relaxation which many patients have reported, in and of itself, helps with breathlessness.

- Recline in a comfortable position.
- Breathe in through your nose and out through your mouth.
- Place a small pillow, tissue box, or small paperback book on your stomach.
- Place your hands at your sides.
- As you breathe in, practice making the object on your stomach move up and as you breathe out, practice making the object move down.
- When breathing out, use the pursed lips technique described above.

The act of pushing out your abdomen helps to slow down your breathing and may enable your lungs to expand a bit more and get more oxygen in.

Relaxation techniques may help to relax your muscles, which will then reduce the amount of oxygen they need.

- Rotate your shoulders in a circle a few times, or shrug them up and down.
- Practice relaxing your shoulder and arms throughout the day.
- Be aware of times when you are tense or likely to become tense and practice relaxing before you become short of breath.
- If you are experiencing an especially bad bout of breathlessness, sit down in a chair next to a small table. Place a few pillows on the table. Fold your arms, place them on the pillows and relax into the pillows. Concentrate on relaxing your shoulders and arms. Stay in this position until you feel your breathing slow down.

Altering the breathing rhythm focuses on helping you ease the pace of your breathing, which helps you to breathe more efficiently.

- Sit in a comfortable position
- Breathe in through your nose and out from your mouth
- As you breathe in, count to 4, slowly
- As you breathe out, count to 4, slowly
- Continue with this more natural, slower pattern

The use of a fan blowing a breeze over the face has been reported as being helpful for some people.

Other techniques that patients have reported as being helpful include:

- Pacing activities
- Resting between activities
- Anticipating activities that may increase breathlessness and planning for them

Oxygen therapy may be helpful in dealing with breathlessness. You and your physician can determine whether this option will benefit you.

Medication may also be useful in dealing with dyspnea. Morphine (not being used for pain but for breathlessness), Dilaudid, steroids, or medication to lower anxiety levels may be helpful for some people. You may want to discuss medication with your physician and health care team.

Decreased appetite and weight loss

Weight loss is common in lung cancer. In many cases, weight loss occurs because the body's ability to absorb calories and nutrients is decreased. It may also occur because of the tendency of cancer treatments to decrease your appetite. It is generally accepted that eating well may help you to cope better with the effects of cancer and its treatment. Canada's Food Guide recommends eating a variety of foods from the different food groups. The following tips explain how to maintain a healthy nutrition level throughout your diagnosis and treatment.

- Meet your basic calorie needs. Getting enough energy is important during treatment to maintain your weight and strength. It is best to get your energy from foods that are nutritious.
- Get plenty of protein. Protein rebuilds and promotes tissue healing. The best sources of protein include foods from the dairy group (milk, cheese, yoghurt) and meats (meat, fish, or poultry), as well as eggs and legumes (beans). Protein drinks can help particularly at times when your appetite is decreased.
- Drink plenty of fluids. A minimum of eight cups of fluid per day will prevent dehydration. Fluids can include water, juice, milk, broth, milkshakes, and other beverages. Beverages containing caffeine do not count. Keep in mind that you'll need more fluids if you have treatment side effects such as vomiting or diarrhea.
- If you are feeling nauseated or your appetite is low, try eating 5 or 6 small meals per day rather than 3 standard meals.
- If you need more information about nutrition, the Canadian Cancer Society (CCS) has a booklet called *Good Nutrition: A guide for people with cancer*. This booklet

provides information to help you maintain good nutrition with tips on how to make sure your body gets the nutrients it needs, ideas on how to cope with side effects, which may prevent you from eating properly, and recipes. You can get this booklet on the CCS website www.cancer.ca or talk to your health care team.

Fatigue

Fatigue is different from feeling tired. Many people who are living with lung cancer experience mild to extreme fatigue. Fatigue is an excessive feeling of tiredness that may not be relieved by extra amounts of sleep or rest. You may find yourself having difficulty in performing everyday tasks, even simple self-care tasks such as bathing and eating.

Fatigue has many causes such as prolonged emotional stress, a diet without enough iron, **side effects** from your treatments, loss of lung function, or anemia. The following suggestions may help you to make the most out of your day.

Reassess your daily goals to make them realistic and reachable.

- Keep a record of your fatigue patterns throughout the day and record in your symptom diary.
- Find patterns in your daily fatigue levels and use them to plan your day to minimize those activities that fatigue you the most.
- Spread your activities throughout the day. Rest between activities; let others help you with meals, housework, or errands. Do not do more than you can manage. Ask for help with tasks when you need it.
- Rest and sleep are important but don't overdo it. Too much rest can decrease your energy level. Long afternoon naps (greater than 1 hour) can interfere with the quality of your nighttime sleep.
- Stay as active as you can. **Exercise** has been shown to decrease fatigue and promote feelings of well-being.
- Daily exercise will maintain your muscles and promote energy conservation. Some people find it is best to exercise early in the day. Start with 10 minutes per day and increase, as you are able.
- Drink plenty of liquids. Eat as well as you can.
- Do activities that you enjoy and make you feel good.
- Fatigue is often made worse by stress. Anticipate that your treatment may be tiring and stressful and plan ahead.

Good sleeping practices increase a feeling of being rested.

- Avoid long afternoon naps.
- Go to bed and get up at the same time every day.
- Wait until you are sleepy before you go to bed.
- Make your sleeping area comfortable, not overly warm and with minimal light and noise.
- If you find that you are waking up in the middle of the night thinking about your situation, jot down your thoughts and questions – this way, you can fall back asleep knowing that, in the morning, you can deal with your thoughts and questions more productively.

What can I do to feel my best during treatment?

- Taking an active role in your treatment may give you a sense of being in control.
- Have a friend or family member accompany you to treatments.
- Expect to feel tired and make plans to rest frequently.
- Exercise daily, in whatever way you are able: daily exercise prevents the deterioration of muscle and maximizes the recovery from surgery and treatment.
- Use a good sunscreen daily (SPF at least 15) no matter what time of year.
- Have a treat to look forward to: dinner at a favourite restaurant, a drive in the countryside.
- Talk to someone who has *been there*. It might be a big help and also lessens the stress on you family.

What side effects can I expect from treatment?

Individuals receiving surgery, chemotherapy or radiation therapy may have specific concerns regarding pain, nutrition, weight loss, hair loss and other **side effects** of cancer treatment. Suggestions to cope with these can be found in specific information booklets listed in the resources section of the binder. Teaching sessions with a nurse or radiation therapist are often available.

How do I manage my anxiety?

Try to prepare yourself for treatment

- Understand what your treatment will be and how it will help you.
- Anticipate the **side effects** and plan how you will manage them.
- Take a friend/relative who has a calming influence with you to treatment. Choose the sort of person who will be most helpful to you.

Between treatments, plan to be gentle and kind to yourself. Remember that treatment is temporary and will come to an end. Many people with cancer find it helpful to seek out others who have had similar experiences. There are support groups or other opportunities to seek out this kind of contact. For some people, thoughts about spirituality become important. If you have a close spiritual community, they will become an essential part of your support system. The hospital chaplain is also available to provide you with spiritual support.

Will I be able to keep my regular schedule?

For many people, keeping to routines keeps a sense of order and control. If you feel you are able to maintain the activities and schedule that you normally do, then it may help you to feel a bit more normal during treatment. However, this may be the time to ask family and friends for help. For individuals receiving chemotherapy or radiation therapy or who are recovering from surgery, it may be helpful to have friends and family cook some nutritious meals to have on hand.

Hobbies can be very important at this time. Whatever gives you pleasure, whatever you have the energy to do – those are the right things to be doing.

The rule is: Do those things that you enjoy and are helpful to your physical and mental health, try to avoid or ask others to do those things that are a burden.

Work issues

Many people with lung cancer may decide as soon as they get their diagnosis to take sick leave immediately. The thoughts of trying to juggle a busy and stressful job, doctor's appointments, treatment schedules and family commitments can be overwhelming. However, if your work is part of your support system or if, financially, you are not able to take a leave, you may continue to work. Depending on your condition, you may want to consider doing reduced hours or going part time for a while. Your treatment may change your ability to function normally at work or you may need to take prolonged absences depending on your treatment plan. You will need to maintain ongoing discussions with your employer and physician.

How quickly can I return to work after surgery?

If you have surgery, you will have a follow-up appointment with your surgeon 4 to 6 weeks after your discharge from hospital. At that time you will be able to discuss returning to work with your physician.

Can I work while I have chemotherapy or radiation therapy?

Some people are able to work throughout their treatment for lung cancer however, there will be times when you are particularly tired and nauseous. Chemotherapy treatment can make you more susceptible to colds and flu making it very important that you guard yourself against exposure to other people who may be ill. Radiation treatment occurs on a daily basis for up to several weeks and can be very tiring. Working out of your home or scheduling your treatments around your work schedule can help. Maintaining open discussion with your employer may help to work out the best arrangement during your treatment time.

How do I manage my financial and personal care issues/concerns?

You may have specific questions related to financial concerns such as; "Can I get disability pay or employment insurance benefits while I am getting treatment?" Information is listed in the Resources section of this Guide. If you need more information and guidance, social workers are part of the health care team. They can provide assistance by informing you about community support for finances, extra help at home, transportation assistance to treatments, power of attorney and making a will; etc.

Should I consider other complementary treatment(s) such relaxation techniques, massage, aromatherapy, acupuncture or other related approaches?

Complementary therapies are more and more being accepted as part of the care of people with cancer. **Complementary therapies** are used to decrease symptoms and to enhance the quality of a person's life along with conventional medical care. One aim of complementary health care is to help people take charge of their health care and lifestyle. They can help you live your daily life in a healthy way, even when faced with a life-changing illness. An experienced complementary therapist will work with you to find treatments that will be most effective for you. It is important to tell your physician, nurse, and pharmacist that you are using complementary therapy.

A selection of complementary therapies frequently used in cancer care

The following list includes very brief descriptions of some therapies. As most **complementary therapies** are not regulated, the best way to find a therapist is through personal recommendation. Look for personal and professional experience with cancer patients, ask questions, and look for someone who is working full-time in the business. Extended Health Care Insurance covers an increasing number of complementary therapies.

Acupuncture

Acupuncture is an ancient Chinese medical procedure, based on the principle that health related energy flows through the body through energy lines called meridians. Any type of stress or illness can cause blocks in this flow of energy. The insertion of fine needles into various acupoints along these meridians may change or increase energy flow through the body. Symptoms may decrease; energy and a sense of wellness may be improved.

Some promising results from scientific **clinical trials** are showing that acupuncture may be useful in relieving pain and treating nausea and vomiting related to chemotherapy.

Aromatherapy

Aromatherapy is the use of aromatic essences from plants called essential oils, to effect changes in well-being. Massage, inhalation and baths containing essential oils are used to transport the essences throughout the body to produce sedation, stimulation and improved digestion. The effect varies depending on the type of essence used.

Massage therapy

Massage therapy uses therapeutic stroking and kneading, usually using oil and working in a systematic pattern. The goal is to treat a specific problem and/or to create relaxation in the body. The techniques are designed to relax, or strengthen and stimulate; both may happen at the same time.

Relaxation techniques

Relaxation techniques can help to decrease the anxiety and stress that result from day-to-day life. These methods help you relax, working with the mind and/or the body. They are techniques that can be easily learned, and something that people can do for themselves. You can buy or borrow tapes that can talk you through relaxation exercises. The basis for all relaxation is focusing on breathing. This could include learning deep abdominal breathing or simply learning to focus on the breath coming in and out of the body. Some specific relaxation techniques include:

Imagery

Imagery is a technique that uses relaxation to create a sense of health and well being through visualization, touch, smell, taste, movement and hearing. Many psychotherapists utilize this method.

Meditation techniques

Meditation is a method of relaxation from ancient times. Meditation is stilling of the mind by focusing on one thing at a time, whether it is breathing, counting or repeating one word. Yoga classes may offer instruction.

SECTION 6

Should I change my lifestyle practices?

Frequently asked questions:

Q What can I do to promote a healthy lifestyle?

Q What is the role of my family physician in my overall general health?

What can I do to promote a healthy lifestyle?

Because of your lung cancer, adopting healthy lifestyle choices may be beneficial in helping you through your treatment experience. Your health care team can help you with any changes that you may be planning. The following suggestions are changes that may help you, throughout your treatment, to stay as healthy as possible. After treatment, they will help you maintain an overall sense of well-being.

Exercise can help to improve your energy and your sleep; it can help you to fight off infections and can lift your spirits during treatment. Consult your doctor before you begin exercising.

- Make a habit of going outside everyday for short walks, even better if you can go with someone whose company you enjoy. Increase the distance, as you are able.
- Do stretching exercises while you are at rest, for example: when watching TV.
- If gardening or light yard work gives you pleasure, try it for short periods.
- Eating well is an important part of your lung cancer treatment. Keeping well hydrated and nourished will help you to manage your treatment and its **side effects**.
- Eat 5 or more fruits and vegetables per day.
- Eat several small meals per day. This helps you to get in the amount of nutrition and calories that your body needs to stay healthy particularly at times when your appetite may be affected by the cancer or by the treatments you are having.
- Limit alcohol intake, particularly during treatment.
- Quitting smoking is the most important thing that you can do for your health now. Quitting smoking will help your treatments be more effective, and help reduce complications of surgery. Your physician or your nurse will be able to make arrangements to help you.

Quitting smoking

The Heart Check Smoking Cessation Program	613-761-4753
Ottawa Public Health Information Line	613-580-6744 Ext. 24179
Renfrew County & District Health Unit, Health Info Line	613-735-8666 1-800-267-1097

Leeds, Grenville & Lanark District Health Unit, Health Action Line	(613) 345-5685 1-800-660-5853
Eastern Ontario Health Unit, Tobacco Use Coordinator	(613) 933-1375 1-800-267-7120

What is the role of my family physician in my overall general health?

The role of your family physician during the course of your treatment should remain much the same as before your cancer diagnosis. He/she will receive reports about your appointments, as well as results of any diagnostic or staging test. It may be helpful to specifically ask for copies of test results, appointments, etc. to be sent to your family physician. Your family physician can serve as a vital link between you and your lung cancer health care team by assisting in the coordination of your care, as well as providing information and support for your entire family. It is recommended that, occasionally throughout the course of your treatment, you make an appointment to see your family physician. Although you can feel overwhelmed with numerous appointments, it is important to remember to attend to all areas of your health.

If you do not have a family physician, it is vital that you find one to be part of your health care team. The College of Physicians and Surgeons of Ontario: www.cpso.on.ca has a “doctor search” section on their website which can help your search. If you still cannot find a family doctor, speak to your nurse or social worker for help.

SECTION 7

What happens when my treatment is over?

Frequently asked questions:

Q How will I be followed when my treatment is over?

Q How will I feel at the end of my treatment?

How will I be followed when my treatment is over?

Regardless of the type of treatment you have for your lung cancer, you will have regular follow-up appointments with your surgeon or oncologist. Depending on your type of treatment, your follow up care may also occur at the Cancer Centre. Regular visits will be scheduled during which time you can expect to be seen by a nurse and an **oncologist**. In many cases you can expect to have a chest X-ray or a CT scan before your appointment.

Some people find follow up appointments difficult. Waiting to find out whether your lung cancer is coming back can cause a certain amount of uncertainty and anxiety. Sometimes it helps to bring a trusted friend or family member along.

How will I feel at the end of my treatment?

When your treatment is finished, plan to take time to recover. As with any experience that has taken total energy and commitment, there can be a sense of loss when it ends. Sometimes it helps to talk to others who have had similar experiences.

SECTION 8

What about my family's needs?

Frequently asked questions:

Q How do families normally react when someone is diagnosed with lung cancer?

Q Are my family members at higher risk of developing lung cancer?

Q How can I talk to my children about lung cancer?

How do families normally react when someone is diagnosed with lung cancer?

A diagnosis of lung cancer affects everyone in your family. Shock, disbelief, confusion, anger, anxiety, guilt, fear and other difficult feelings are common. Your family wants to help but sometimes they feel helpless.

Suggestions for family members and caregivers to help you

- Face the cancer together. It is reassuring and comforting for your loved one to know your support will always be there. We can bear more when we have someone to share with.
- Don't assume you know what your loved one is thinking or feeling. Talk to each other about your emotional reactions and concerns.
- Communication can also be physical; holding hands, hugging etc.

Frequently everyone feels they have to maintain a positive attitude. Pretending that everything will be all right denies the person with cancer the opportunity to discuss fears and anxieties. Also avoiding discussions about cancer, out of concern to protect each other, results in feelings of isolation.

Suggestions for family members and caregivers to help themselves

- Take time for yourself and remember to be good to yourself. This is not selfishness; it's keeping yourself replenished and healthy in order for you to continue caring for your loved ones needs.
- Take care of your own body. To avoid stress-related illness, pay attention to your own physical needs by eating a healthy diet, exercising, getting sufficient sleep and finding time to relax. Don't put off your own medical and dental checkups.
- Delegate responsibility and accept help from outside the home. Often other family members and friends want to help but are not sure what they can do. This makes them feel useful and helps reduce stress.
- Be assertive. Be realistic about what you can and cannot be responsible for right now.
- Discuss your feelings and reach out for support.

- Give yourself permission to ask questions from health care professionals. Having answers to your questions can be a great stress reducer.
- Set priorities. Don’t try to do everything.
- Laugh. It is said that 20 minutes of belly laughter is equal to 5 hours of deep meditation.

Are my family members at higher risk of developing lung cancer?

For the most part, lung cancer is an acquired disease caused from exposure to toxins in our environment such as cigarette smoke or certain chemicals. If we were not exposed to these toxins, we would most likely not develop this disease. However, if you have a family history of lung cancer—if your parents or siblings have had the disease—you are at higher risk. Although this may be partly explained by having a shared environment that contains cigarette smoke and other pollutants, recent research is demonstrating some evidence that there may be lung cancer susceptibility genes that can be inherited from parent to child. Carriers of this inherited gene, even with the slightest amount of smoking, are at increased risk of developing lung cancer. Currently, there are no reliable screening methods for early detection of lung cancer.

How can I talk to my children about lung cancer?

When someone they love is ill, children experience sadness, loneliness, confusion, anger, fear of separation, and of being left alone. They worry about the safety of the family. Depending on their ages, they will react differently. Sometimes they “act out,” withdraw, or overcompensate by taking on too many responsibilities. Children tend to express their emotions in actions rather than words.

Explain, in terms they understand, about your lung cancer, treatments, and any side effects you may have. Be open and honest from the start (Children have wonderful antennas—they pick up when something is wrong. Their imagination may be worse than the reality). Let them know that you will keep them informed if there are changes, and that they can ask any questions. A child has a right to know about anything that affects the family, as a diagnosis of lung cancer does. Not telling is a breach of trust. It is also OK to say you don't know the answer to their question when you don't have the answer.

Reassure the children that there is nothing wrong with feeling sad, crying, and being angry. Drawing, reading storybooks, and having special play times sometimes allow children to express their fears.

Tell them that lung cancer is not an illness that you can catch from someone else such as the flu, or colds. Assure them nothing they have done, said, or thought caused the lung cancer to occur (Sometimes, when children are angry with their parents, they wish they were dead).

Things you can do to help your children cope include the following.

- Involve your children in your treatment program.
- Try to keep the family routine as much as possible, including being consistent with discipline.
- Notify teachers and all significant adults in the child's life such as sitters, coaches, neighbors, as soon as possible. They can offer extra attention and support.
- Communicate with your children on a regular basis. Try to reserve consistent time for them.
- Encourage your children to keep up their outside activities.

SECTION 9

What support is available for people with advanced lung cancer?

Frequently asked questions:

- **Q** What is palliative care?
- **Q** How do I plan for end of life care?

What is palliative care?

When lung cancer comes back or is at an advanced stage, the possibility of a cure becomes very unlikely. This is the time when palliative care takes on a bigger role in your care. Treatment is focused on managing the symptoms caused by lung cancer as well as helping you to maintain your quality of life.

Radiation and chemotherapy can also be used for **palliation** to help reduce symptoms such as breathlessness, pain, or coughing. In many cases, the doses of radiation therapy and chemotherapy are modified for comfort and to reduce side effects. The goal is to allow you to live more comfortably and to improve the quality of your life.

When you are diagnosed with advanced lung cancer, you may continue to be cared for by your oncologists and family doctor. A special palliative care team that consists of physicians, nurses, social workers and other health care professionals may also become involved in your care. Your health care providers will help you to decide your own goals and preferences for how your needs are met and how your symptoms are managed.

How do I plan for end of life care?

A diagnosis of advanced or recurrent lung cancer reminds us of what we have known all along: that our time here is limited. Tomorrow and the future are suddenly thrown into doubt and we are reminded that we must prepare for death, whenever it may come.

One of the aspects of death that many people find frightening is lack of control. You have an opportunity, now, to prepare for death whether it comes now or many years from now. Taking the time to prepare for death allows you to have some control over how that time in your life will unfold. Having a plan in place may give you peace of mind that, when the time comes, you and your family will be prepared.

The phrase is often heard, “You need to get your affairs in order” but many people have no idea where to start with this process. In general, it means organizing your personal life: legal papers, income information, insurance policies, financial information such as investments or loans and making sure that the right people know how to access this information. Making sure that your family knows what will happen after your death can bring a sense of peace of mind and comfort through your journey to the end of your life.

Planning for your end of life care in advance can also give you a sense of more control. Discussion with your physician, your palliative care team, and with your loved ones how your want your care to be carried out can relieve them of making difficult decisions when you may not be able to express your choices.

Some of these tasks are very difficult to think about. Sometimes it is easier if you allow others to help you with these preparations. In many cases your family can help you; sometimes the members of the health care team can be a source of advice and counseling. You have today. You can make choices about how you want to live the time you have in the present.

> *You matter because you are you and you matter to the last moment of your life. We will do all we can to help you live until you die and not only to die peacefully.*
>
> — Cecily Saunders, 1976

SECTION 10

Support and information resources at The Ottawa Hospital Regional Cancer Centre and in the community

The Ottawa Hospital Regional Cancer Centre

- Social Workers
- Champlain Community Care Access Centre
- Spiritual Care Services
- Look Good …Feel Better Program

Community resources

- Canadian Cancer Society
- Finding a Family Doctor
- Financial Information
- Hospice at Maycourt
- Lodging and Transportation
- Smoking Cessation Programs

Telephone support

- Canadian Cancer Society
- Lung Cancer Canada
- Pain and Symptom Management Team

Information resources for lung cancer patients and their families

- Ninon Bourque Patient Resource Library
- The Ottawa Hospital Web Site
- Publications by The Ottawa Hospital
- Lung Cancer Resources (books, videos, etc)
- Lung Cancer Websites
- Coping with Cancer
- Complementary Therapies
- For Family Members and Friends
- Palliative and End of Life Care

The Ottawa Hospital Regional Cancer Centre

The Ottawa Hospital Regional Cancer Centre Patient Information Guide, which you will be given on your first visit to the Cancer Centre (also on The Ottawa Hospital's web site at http://www.ottawahospital.on.ca/sc/cancer/index-e.asp), has information and telephone numbers for many services in the community.

Social Workers

Social workers at The Ottawa Hospital Regional Cancer Centre provide counseling services. They can also help you with practical issues such as access to medication coverage, transportation, financial support and work-related issues. This service is available to all patients with a cancer diagnosis and their families. Your doctor or nurse can make a referral to a social worker on your behalf, or you can call the Social Work Counseling line at 613-737-7700 ext 70516. As well as providing individual and family counseling, the Social Work Department runs several support groups.

Champlain Community Care Access Centre

The Oncology service of the Champlain Community Care Access Centre (CCAC) is available to patients at the Regional Cancer Centre. The CCAC provides support services in the home, as well as access to long-term care. If you feel you need a referral to community care, ask your nurse or physician who will make the referral for you. You can also contact the CCAC yourself. A CCAC case manager can meet with you at the Regional Cancer Centre to talk about what you may need. Your case manager can also advise you about additional services and supports in the community and how to access them. Your case manager will see you if you are admitted to hospital and will reassess you needs before you are discharged.

Information about the Champlain Community Care Access Centre is also available on the web site at www.ottawa.ccac-ont.ca or phone 613-745-5525 or 1-800-538-0520.

Spiritual Care Services

Professional interfaith chaplains are part of the health care team. The chaplain can help people who are experiencing distress by providing spiritual care and support and by helping to find inner sources of personal spiritual strength. To speak with a chaplain, call 613-798-5555 Ext. 78126 (General Campus) or Ext 14587 (Civic Campus).

Look Good ... Feel Better Program

The Look Good…Feel Better program offers free workshops about skin care, makeup and options for hair loss for women who are receiving cancer treatment. The workshop is offered twice a month, alternating between the Civic and General Campus. Pre-registration is required. To register and for more information, call 613-737-7700 ext 10315.

Community resources

Canadian Cancer Society

The Canadian Cancer Society offers a wide range of services to cancer patients. These services include transportation, emotional support, information, wigs, smoking cessation, etc. The Canadian Cancer Society has the following local offices in the Ottawa area:

Canadian Cancer Society Unit Office	Phone number
Ottawa Unit	613-723-1744
Lanark, Leeds and Grenville Unit (Brockville, Carleton Place, Gananoque, Perth and Smith Falls)	1-800-367-2913 or 613-267-1058
Renfrew County Unit (Arnprior, Deep River, Eganville, Pembroke, Petawawa and Renfrew)	1-800-255-8873 or 613-735-2571
Stormont, Dundas, Glengarry and Prescott Russell Unit (Cornwall, Hawkesbury and Russell)	1-800-669-4181 or 613-932-1283

You can also find out about resources in your community on the Ontario Division section of the Canadian Cancer Society’s web site at www.ontario.cancer.ca.

Finding a family doctor

If you do not have a family physician, you can call The College of Physicians and Surgeons of Ontario to find out who is taking new patients. Call 1-800-268-7096 ext 626 or visit the web site at: http://www.cpso.on.ca/Doctor_Search/dr_srch_hm.htm.

Financial information

If you have financial concerns related to your lung cancer and treatment, you can contact the social work department at the Cancer Centre or The Ottawa Hospital. The following organizations can also provide you with information:

- **Ontario Health Insurance** 1-800-268-1154
  . . . . or (416) 314-5518
  http://www.health.gov.on.ca/english/public/program/ohip/ohip_mn.html
- **Ontario Trillium Drug Program**. 1-800-575-5386
  . . . . or (416) 326-1558
  http://www.health.gov.on.ca./english/public/pub/drugs/trillium.html
- **Ontario Disability Support Program**. 1-888-789-4199
  http://www.cfcs.gov.on.ca/CFCS/en/programs/IES/default.html
- **Employment Insurance Benefits** 1-800-206-7218
  or contact your local Human Resources and Skills Development Canada office, listed in the federal government services pages of your phone directory
  http://www.servicecanada.gc.ca
- **Canada Pension Plan – Disability Benefits** 1-800-277-9914
  http://www.servicecanada.gc.ca

The Canadian Cancer Society does not provide financial assistance, but does have information in the web site at www.ontario.cancer.ca. (Select "service directory" from the "get support" section and then "where will my money come from" from the menu on the left. http://www.ontario.cancer.ca/ccs/internet/standard/0,3182,3543_316353__langId-en,00.html).

You can also phone any of the Canadian Cancer Society offices listed above for information.

Hospices

Hospices provide care and support for people diagnosed with a life-threatening illness and their families.

- The Hospice at Maycourt, located at 114 Cameron Avenue, Ottawa, offers home support and day hospice as well as a caregiver support program and an in-patient unit. There is no charge for any of the programs at the Hospice at May Court. For more information, call 613-260-2906 ext 226 or visit the web site at http://www.hospicemaycourt.com.

- Friends of the Hospice Ottawa offers home support and day hospice, tel: 613-838-5744, http://www.friendsofhospiceottawa,ca.
- A palliative outreach program for francophones “Une fleur à la main” provides volunteers for home support / respite. For information, phone 613-241-1266.

Lodging and transportation

The **Maurice J Grimes Lodge**, located at 200 Melrose Avenue, Ottawa, provides accommodation for cancer patients who live more than 40 kilometres from the Regional Cancer Centre and who are coming to the Centre for tests or treatment. The Lodge is open from Monday to Friday. For more information, call 613-725-6328 ext. 10355.

The Ottawa Hospital Intern’s Residence, 751 Parkdale Avenue, Ottawa, rents apartments for short stays for out-of town families of The Ottawa Hospital patients. For more information, call 613-761-5400.

If you need transportation to medical appointments, the following are some options:

Canadian Cancer Society volunteers may be able to provide transportation. Call your local Cancer Society unit office (see above). Social workers can also help you to make transportation arrangements.

Smoking cessations programs

There are several programs available in the Ottawa area to help you to quit smoking.

- **The Heart Check Smoking Cessation Program** 613-761-4753
- **Ottawa Public Health Information Line** . . . . . 613-580-6744 Ext. 24179
- **Renfrew County & District Health Unit, Health Promotion, Health Promotion**. . . . . 613-735-8666 or 1-800-267-1097
- **Leeds, Grenville & Lanark District Health Unit, Health Action Line** . . . . 613-345-5685 or 1-800-660-5853
- **Eastern Ontario Health Unit, Tobacco Use Coordinator** . . . . 613-933-1375 or 1-800-267-7120
- **The Canadian Cancer Society** (www.cancer.ca) . . . . 1-877-513-5333 has smoking cessation information, including the Smokers’ Helpline Ontario

- **The Smokefree Ottawa** website (http://www.smokefreeottawa.com) has information of programs offered in the Ottawa area.

Telephone support

Canadian Cancer Society

- **Cancer Information Service** 1-888-939-3333
  Provides information on all aspects of cancer treatment, risk reduction and community support. The service is available Monday to Friday, from 9 am to 6 pm.
- **Cancer Connection Ontario (Peer Support)** 1-800-263-6750
  Peer support to cancer patients and their families provided by volunteers who have had cancer themselves or been caregivers to cancer patients.
- **Smokers' Helpline Ontario** 1-877-513-5333
  A free, confidential telephone service for all smokers, whether are not they are ready to quit, as well as family and friends of smokers.
- **Lung Cancer Canada** 1-888-445-4403
  Telephone support for lung cancer patients and their families.
- **Palliative Care Pain and Symptom Management Team**
  . . . . 613-562-6398 or 1-800-651-1142
  The purpose of the Palliative Care Pain and Symptom Management Team is to enhance the quality of life for people living with a terminal illness and to provide information on palliative care resources in the community.

Information resources for lung cancer patients and their families

Ninon Bourque Patient Resource Library

- The Ninon Bourque Patient Resource library is dedicated to providing up-to-date, reliable cancer information to patients and their families.
- The Library has over 1,500 books, video and audiocassettes, CDs and CD-ROMs about cancer and related topics, such as nutrition, coping with cancer, relaxation techniques and more. Most of these items can be borrowed for three weeks.
- There are also two computers, which you can use to search for medical information on the Internet.
- Library staff will help you to find information and can suggest reliable web sites and other resources for cancer information.
- The Library is located at The Ottawa Hospital Regional Cancer Centre General Campus on the main floor between the chemotherapy waiting room and Module A and is open Monday to Friday from 8:30 to 12:30 and from 1:00 to 3:30.
  Phone: 613-737-7700 ext. 70107
  E-mail: consumerhealth@ottawahospital.on.ca

The Ottawa Hospital web site – http://www.ottawahospital.on.ca

The web site provides information about the programs and services offered at The Ottawa Hospital. The *Patient Services* section tells you what you need to know if you are admitted to the hospital or coming for an appointment and includes maps, parking information and bus schedules. The Cancer Centre section contains information specifically for people having treatment for cancer (http://www.ottawahospital.on.ca/sc/cancer/index-e.asp).

Publications by The Ottawa Hospital

- **Pulmonary Resection Patient Information (2002)**
  What to expect when you are having lung surgery, preparing for surgery, after surgery and exercises to help with your recovery. Available on The Ottawa Hospital web site at http://www.ottawahospital.on.ca/hp/dept/surgery/thoracic/prjuly02-e.pdf.

The Ottawa Hospital Regional Cancer Centre has produced several booklets, which you may find helpful while having treatment at the Centre. The following booklets are also available on the Cancer Centre's web site at http://www.ottawahospital.on.ca/sc/cancer/index-e.asp.

- **The Ottawa Hospital Regional Cancer Centre Patient Information Booklet**. This guide prepares you for your first visit to the Cancer Centre by giving an overview of treatment, support services at the Centre and in the community, transportation, financial considerations, etc.
- **Chemotherapy Patient Information Booklet** has general information about what chemotherapy is and how it is given, possible side effects, and frequently asked questions about chemotherapy.
- **Radiation Therapy Patient Information Booklet** has general information about radiation treatment, how radiation treatment is given, coping with possible side effects, etc.

Lung cancer resources

Resources are provided for your information only and are not intended as a substitute for medical care. If you have any questions about your cancer treatment, you should talk to your doctor or other healthcare provider. The inclusion of a resource in this list does not necessarily imply endorsement by The Ottawa Hospital Regional Cancer Centre. Many of the following resources are available for loan from the Ninon Bourque Patient Resource Library at the General Campus of The Ottawa Hospital Regional Cancer Centre. Library staff can also help you to find information on any cancer-related topic. The library is open Monday to Friday, or you can request information by phone at 613-737-7700 ext. 70107 or by e-mail at consumerhealth@ottawahospital.on.ca.

Books

The following books are written specifically for lung cancer patients and their families, and contain information about both small and non-small cell lung cancer. Topics include information about the lungs, what lung cancer is, treatment options, coping with side effects, etc.

- **100 questions & answers about lung cancer**. Karen Parles and Joan Schiller. Jones and Bartlett, 2003 (ISBN 0-7637-2056-9)
- **Lung cancer: a guide to diagnosis and treatment**. Walter Scott, Addicus Books, 2000 (ISBN 1-886039-43-7)

- **Lung cancer: making sense of diagnosis, treatment and options**. Lorraine Johnston. O'Reilly & Associates, 2001 (ISBN 1-596-50002-5)
- **Lung cancer: myths, facts, choices and hope**. Claudia Henschke and Peggy McCarthy. WW Norton & Co, 2002 (ISBN 0-393-04154-9)
- **Understanding lung cancer: a guide for patients and their families**. Cancer Care Ontario, 2004. Available on Cancer Care Ontario's web site at http://www.cancercare.on.ca/pdf/UnderstandingLungCancer.pdf.
- **With every breath: a lung cancer guidebook**. Tina M St John. Not yet in print, but available on the Internet at http://www.lungcancerguidebook.org/book.htm.

Pamphlet

- **Lung cancer: what you need to know**. Canadian Cancer Society, 2004. Available from your local Canadian Cancer Society officer, from the Canadian Cancer Society website at www.cancer.ca or from the Cancer Information Service at 1-888-939-3333.

Decision aid

- **Making choices: treatment of stage IV (metastasis) non-small cell lung cancer. A decision aid for patients**. WK Evans, V Fiset, AM O'Connor, J Logan, C Degrasse. Ottawa Health Decision Centre, 2001. A 31-page workbook and cassette tape to prepare you for an informed discussion with your physician for treatment options for Stage IV non-small cell lung cancer.

CD-ROM

- **Understanding lung cancer**. Oncology Interactive Education Series. Toronto: Jack Digital Productions Inc., 2001

Video

- **Preparing for your lung operation**. The Ottawa Hospital Civic Campus This video was produced by the Thoracic Surgery team at The Ottawa Hospital Civic Campus and refers specifically to the treatment at the Civic Campus of The Ottawa Hospital.

Lung cancer web sites

- **Lung Cancer Canada** – http://www.lungcancercanada.ca
  Lung Cancer Canada is a charitable organization established in 2002 with the aim of providing education, awareness and support with respect to lung cancer.
- **Lung Association** – http://www.on.lung.ca
  This site has a section about lung cancer at http://www.lung.ca/diseases/cancer_lungs.html.
  It also contains the site of the Canadian Thoracic Society (http://www.lung.ca/cts/home.cfm).
- **Lung Cancer Alliance** (U.S) – http://www.lungcanceralliance.org
  A not-for-profit organization dedicated solely to helping those living with lung cancer improve the quality of their lives through advocacy, support, and education. The site has information about lung cancer in the news and latest research findings.
- **Lungcanceronline** (U.S.) – http://www.lungcanceronline.org
  Lungcanceronline.org is a comprehensive, annotated directory to Internet information and resources for patients and families. This site has information on searching for information in medical databases, links to treatment guidelines and summaries of papers presented at lung cancer meetings and conferences.
- **It's time to focus on lung cancer** (U.S) – http://www.lungcancer.org
  Web site for patients and healthcare professionals. As well as print materials, has an archive of telephone workshops where you can hear discussions of treatments and support for lung cancer patients. This site has a section, which deals specifically with women and lung cancer. Supported by the Oncology Nursing Society.
- **MedlinePlus – Interactive Health Tutorials** (U.S)
  http://www.nlm.nih.gov/medlineplus/tutorial.html
  A series of slide shows which explain a procedures or conditions in easy-to-read language. You can also listen to the tutorial. Topics include lung cancer http://www.nlm.nih.gov/medlineplus/tutorials/lungcancer/htm/index.htm), thoracotomy - surgery for lung cancer (http://www.nlm.nih.gov/medlineplus/tutorials/thoracotomyfortumorresection/htm/index.htm) and smoking – the facts (http://www.nlm.nih.gov/medlineplus/tutorials/smokingthefacts/htm/index.htm)

Smoking cessation web sites

- http://www.smokefreeottawa.com/english/cease.htm
  Details of smoking cessation programs available in Ottawa
- **Canadian Cancer Society "Quit Smoking"** web site
  http://www.cancer.ca/ccs/internet/standard/0,3182,3172_368202_langId-en,00.html or go to the Canadian Cancer Society's web site at www.cancer.ca and select "tobacco" from the "get information" section.

Clinical trials

- **Ontario Cancer Trials** – http://www.ontariocancertrials.ca
  New cancer therapies are tested in clinical trials. You may wish to consider participation in a clinical trial when deciding on the best option for your treatment. You can search a database of all clinical trails taking place in Ontario and find out more about what clinical trials are.

Clinical practice guidelines

- **Lung Cancer Disease Site Group**
  http://www.cancercare.on.ca/index_lungCancerguidelines.htm
  A clinical practice guideline is a summary of the best evidence that is currently available to develop a treatment plan for each patient. This web site is updated regularly to give guidelines for the treatment of various types of lung cancer.

General cancer information web sites

The following web sites have detailed general information on prevention, treatment and coping with cancer.

- **Canadian Cancer Society** – www.cancer.ca
  In addition to information and support services, this site contains lots of resources about tobacco and quitting smoking.
- **The Patient Information Website of the American Society of Clinical Oncology (ASCO)** – www.plwc.org
  This website is designed to help patients and families make informed health care decisions about their cancer and its treatment. This site provides information on more than 85 types of cancer, clinical trials, coping, side effects, etc. The cancer information in this website has been approved by American oncologists (cancer specialists).

- **U.S. National Cancer Institute** – www.cancer.gov
  The National Cancer Institute coordinates the U.S. federal government's cancer research program. The website has information for patients and healthcare professionals on all aspects of cancer prevention, treatment, coping, etc and includes information on cancer clinical trials taking place around the world.
- **MedlinePlus** – www.medlineplus.gov
  A service of the U.S. National Library of Medicine, this site provides a portal to health information. Some of the information is provided in the form of videos and slide shows and there is also "easy to read" information.

Coping with cancer

Resources to help you cope with the side effects of lung cancer and its treatment. Topics include pain, fatigue, nutrition, etc.

Books

- **100 questions and answers about cancer symptoms and cancer treatment side effects**. Joanne Frenkel Kelvin. Jones & Bartlett, 2004 (ISBN 0763726125)
- **Coping with chemotherapy and radiation**. Daniel Cukier. McGraw-Hill, 2004 (ISBN 0-07-144472-6)
- **Living well with cancer: a nurse tells you everything you need to know about managing the side effects of your treatment**. Katen Moore and Libby Schmais. GP Putnam's Sons, 2001 (ISBN 0399146873)
- **Eating well, staying well during and after cancer**. Abby S. Bloch. American Cancer Society, 2004 (ISBN 0944235514)
- **What to eat when you don't feel like eating**. James Haller. 1994 (ISBN 0889995583)

Web sites for coping with cancer

You will find information about coping with cancer in the many of the sites listed above. The following site deals specifically with cancer side effects.

- **Oncology Nursing Society** – http://www.cancersymptoms.org
  Focuses on six of the main cancer and treatment-related side effects: fatigue, anorexia, pain, depression, neutropenia and cognitive dysfunction.

Complementary therapies

Books

- **American Cancer Society guide to complementary and alternative cancer methods**. American Cancer Society, 2002 (ISBN 0-944235-40-9)
- **Unconventional therapies**. British Columbia Cancer Agency, 2000. Available on the Internet at http://www.bccancer.bc.ca/PPI/UnconventionalTherapies/default.htm.

Audiocassettes

- **Beginning your healing journey: an active response to the crisis of cancer** (workbook & audiotapes). Alasdair Cunningham. Key Porter, World Health Services Council, 2001.
- **Health journeys: cancer: guided imagery**. Bellaruth Naparstek. Time Warner, 1993.

The Ninon Bourque Patient Resource Library has a large collection of relaxation, meditation and guided imagery tapes and CDs for loan.

Web sites

- **U.S. National Centre for Complementary and Alternative Medicine** http://nccam.nih.gov/.

For family members and friends

Topics include practical information about care giving and symptom management, how to talk to children about cancer, communication within the family and with the healthcare team and how to handle the stress and challenges of care giving.

Books

- **100 questions and answers about caring for family and friends with cancer**. Susannah L Rose and Richard T Hara. Jones and Bartlett, 2005 (ISBN 0-7637-2361-4).
- **Care giving: a step-by-step resources for caring for the person with cancer at home**. Peter S Houts and Julia A Bucher. American Cancer Society, 2003 (ISBN 0-944235-45-X).

- **Facing cancer: a complete guide for people with cancer, their families and caregivers**. Theodore A Stern and Millael A Sekeres. McGraw-Hill, 2004 (ISBN 0-07-141491-6).
- **When a parent is sick: helping parents explain serious illness to children**. Joan Hamilton. Pottersfield Press, 2001(ISBN 1-895900-40-9).

Palliative and end of life care

Resources for patients and family members about living with a life-threatening illness. Information on ensuring the best possible quality of life, through pain and symptom control, communication and planning for the end of life.

Books

- **Advanced cancer: living each day**. National Cancer Institute. NIH Publication # 94-856, 1994 (on the internet at: http://cancer.gov/PDF/15c0296e-215a-4fb4-a090-99cab2b1590e/advancedcancer.pdf).
- **American College of Physicians home care guide for advanced cancer**. Peter S Houts, editor. American College of Physicians, 1997 (on the internet at http://www.acponline/org/public/h_care/a-solvel.htm).
- **A Guide to advance care planning**. Helping you know and exercise your rights in preparing for a time when you may be unable to make decision about your care. Government of Ontario, 2002. (ISBN 0-7794-2927-3).
  Free 44-page booklet. Phone 1-888-910-1999 for a copy, or on the Internet at http://www.gov.on.ca/citizenship/seniors/english/advancecaretraining.htm.
- **Handbook for mortals: guide for people facing serious illness**. Joanne Lynn and Joan Harrold. Oxford University Press, 1999 (ISBN 0-10-511662-3).

Websites

- **Ottawa Hospice Palliative Care Network** – http://www.ohpcn.ca
  The Ottawa Hospice Palliative Care Network was established in 2005 to provide a forum for collaboration for providers of palliative care services in Ottawa. You will also find links to resources or sources of information about hospice palliative care in the Ottawa area.

- **Caring to the end of life** – www.caringtotheend.ca
  Caring to the end of life is a website produced by the Princess Margaret Hospital, University Health Network, Toronto, for patients, caregivers and health care professionals who need information about palliative care. Caring to the end of life provides information about palliative care, and tools to help cope with the experience of palliative care, all in once place.
- **Growth House Inc.** (U.S) – http://www.growthhouse.org/
  Growth House, Inc. Provides a portal to international resources for life-threatening illness and end of life care.

SECTION 11

Terminology / Glossary

Adjuvant therapy	Additional treatment given after surgery to prevent recurrence or further spread or growth of cancer cells, using radiation, chemotherapy and/or hormone therapy.
Benign	Not cancerous.
Bone scan	A picture of the bones using a radioactive dye that shows any injury, disease or healing. This test helps to determine if cancer has spread to the bones.
Bronchoscopy	The bronchoscopy is a visual examination of the inner surface of the air passages by means of a flexible tube (a bronchoscope) inserted through the mouth or the nostril.
Cancer	A general name for more than 100 diseases in which abnormal cells grow out of control. Cancer cells can invade and destroy healthy tissues and they can spread through the bloodstream and the lymphatic system to other parts of the body.
Clinical trial	A carefully designed scientific experiment for testing a new therapy or treatment approach.
CT scan	A CT scan (computerized tomography), sometimes called a CAT scan is a special X-ray that obtains x-ray data from different angles around the body and then uses a computer to process the information to show a cross-section of body tissues and organs.
Lobectomy	A type of lung surgery where one section or lobe of the lung is removed.
Complementary therapies	Used to decrease symptoms and to enhance the quality of a person's life. They are used together with mainstream (conventional) therapy. Example: Therapeutic touch, Reiki therapy.

Lymphatic system	The system that removes wastes from body tissues and filters the fluids that help the body fight infections.
Lymph nodes	Small bean-shaped organs (sometimes called lymph glands); part of the lymphatic system.
Magnetic Resonance Imaging Scan (MRI)	An MRI scan is a test that produces very clear pictures, or images, of the human body without the use of x-rays. MRI uses a large magnet, radio waves and a computer to produce these images.
Mediastinoscopy	The mediastinoscopy is a procedure in which a tube is inserted into an incision above the breastbone so that the organs in the area between the lungs can be viewed and, in some cases, biopsied.
Needle biopsy	A needle biopsy refers to a procedure where a needle is inserted into a suspicious area of fluid or tissue and cells are aspirated out for examination under the microscope.
Oncologist	Doctor who specializes in the treatment of cancer.
Oncology	The study and treatment of cancer.
Palliation	Act of relieving a symptom without necessarily curing the cause.
Pneumonectomy	A type of lung surgery where an entire lung is removed.
Positronic Emission Tomography Scan (PET scan)	PET scans are a procedure in which a small amount of radioactive glucose (sugar) is injected into a vein, and a scanner is used to make detailed computerized pictures of areas inside the body where the glucose is used. Because cancer cells often use more glucose than normal cells, the pictures can be used to find cancer cells in the body.

Prognosis	The expected outcome of a disease; the life expectancy.
Radical radiotherapy	Refers to a full dose of radiation therapy in which the intent is to eradicate the tumour.
Recurrence	The reappearance of a disease after previous treatment had caused it to disappear.
Relapse	The return of a condition after an initial remission or improvement.
Side effects	Reactions from drugs or radiation that are not intended or wanted.
Spiritual care professions (interfaith chaplain)	A provider of support to patients and their families in their search for meaning and hope in the face of illness. Can help with decision-making, advance directives, and cultural issues.
Staging	Classification of lung cancer according to its size and extent of spread.
Thoracotomy	A surgical procedure where an incision is made through the chest wall so that the organs in the chest can be examined for the presence of cancer or other disease.
Tumour	An abnormal growth of tissue. Tumours may be either benign (not cancer) or malignant (cancer).