## JUST DIAGNOSED





## In this section, you will learn about:

- Your health care team and the role of your family doctor
- Understanding your diagnosis
- Preparing for your first visit
- Return visits
- Advance care planning
- Information and support for cancer patients who smoke
- Health information management



## Meet Your Health Care Team

- Your health care team at LRCP (Oncologist, Primary Nurse, Chemotherapy Nurse, Pharmacist, Dietitian, etc.) is responsible for your cancer treatment and care.
- Your **Family Doctor** is responsible for all non-cancer related health care (e.g., blood pressure, diabetes, etc.).

Your health care team at LRCP and other sites may include any of the following people:

#### **Doctors**

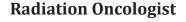
## Oncologist

An oncologist is a doctor who specializes in caring for people with cancer. You may have more than one type of oncologist on your health care team, depending on your treatment plan.

## **Medical Oncologist**

Medical oncologists are doctors who specialize in using drug

therapy to treat cancer. Drug therapy includes chemotherapy, immunotherapy or targeted therapy.



Radiation oncologists are doctors who specialize in treating cancer with radiation.

## **Surgical Oncologist**

Surgical oncologists are doctors who specialize in using surgery to treat cancer.



#### Nurses

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Oncology nurses specialize in caring for people with cancer. Nurses work closely with your health care team and help coordinate your care.

## Your **Registered Nurse** will:

- Teach you about your treatment
- Teach you how to manage side effects
- Give you information about services that are available in your community

### **Chemotherapy Nurse**

Chemotherapy nurses have specialized training to give chemotherapy. Your nurse will teach you how to care for yourself during treatment and manage any side effects related to your chemotherapy.



## **Nurse Practitioners (NP)**

Nurse practitioners (NP) can assess your health, order and interpret test results, perform procedures such as biopsies, prescribe medications, order chemotherapy, and screen to prevent other illnesses.

#### **Radiation Nurses**

Radiation nurses work closely with your radiation oncologist and radiation therapists to care for you during your radiation treatments. They assess how you are doing throughout treatment and will help you cope with any changes you may experience.

## Telephone Triage Nurse

If you have a change in your condition, call telephone triage nursing at LRCP for help. The nurses can assess your situation and assist you in getting the help that you need.

Call 519-685-8600 and press '1' for patient, then press '3' to reach the Telephone Triage Nursing Line.

## **Supportive Care Staff**

### **Registered Dietitians**

Registered dietitians can check your nutritional health and identify and treat nutritional problems. They can help you manage side effects through nutrition. See the 'Nutrition' section to learn more about how registered dietitians can help you.

#### **Social Workers**

Social workers can help you and your family cope with the emotional and practical concerns you may experience with cancer. See the 'Counselling' section to learn more about how a social worker can support you.

#### **Radiation Staff**

### **Radiation Therapist**

Radiation therapists deliver your daily radiation treatments. They help plan your treatment and operate the machines that use carefully targeted doses of radiation to kill cancer cells. Radiation therapists will also teach you about side effects related to radiation therapy and how to manage them.

## **Medical Physicist**

Medical physicists work mostly behind the scenes to make sure that every radiation plan is designed and delivered safely. They check every patient's plan to make sure it has been calculated properly. They also make sure that the machines delivering these plans are operating correctly.

#### Other LRCP Health Care Staff

#### **Drug Access Facilitator**

The drug access facilitator can help you understand your drug coverage and the types of help available to you. See the 'Finances' section to learn more about how a drug access facilitator can support you.

#### **Clinical Trials Advisor**

A clinical trials advisor helps connect patients to the research teams overseeing the clinical trials. For more information, you can email cancertrials@lhsc.on.ca or call 519-685-8618.

#### Clinical Research Associate

You may be approached by a researcher to talk about joining a clinical trial. A clinical trial is a research study that is looking at new ways of treating cancer. You will have the final decision about whether you want to take part in a clinical trial.

#### **Palliative Care**

The palliative care team is a group of professionals who support people with advanced cancer. The team consists of doctors, nurses, social workers, a spiritual care specialist, and others. Their focus is on pain and symptom control and meeting the physical, emotional, psychological and spiritual needs of the patient and family.

## Pharmacists/Pharmacy Technicians



The pharmacy provides patients with drugs prescribed by the doctor. They can also answer any questions or concerns you have about your medicines.

## **Indigenous Patient Navigator**

The Indigenous patient navigator provides support for First Nations, Inuit, and Metis (FNIM) and urban Indigenous patients and families with cancer. The Indigenous Patient Navigator addresses cultural and spiritual needs and works to improve access to cancer services for FNIM patients and families.

## **Cancer Genetics Program**



The Cancer Genetics Program provides services to patients who are concerned about their personal and/or family history of cancer. A doctor can refer people who are considered to be at risk for an inherited cancer to the Cancer Genetics Program.

#### **Students**

London Health Sciences Centre is a teaching hospital. Students who are gaining experience in cancer care may be part of your team. Students may include medical students, residents, radiation therapy students, and more.

#### **Volunteers**

There are many LHSC volunteers who volunteer their time in the LRCP. They are available to help make your visit more comfortable. You will see them in their vests all throughout the Centre. They are a great resource and are always happy to answer any questions you may have about the Centre.

#### Cancer Care Delivered at Other Sites

During your cancer journey, you may receive care at a different location than LRCP. In some cases, this means that you will be receiving care closer to home. This may be for chemotherapy or for care transitions after your treatment is complete. No matter where you receive care and who your care provider is, the quality of care is the same.

#### Other Care Providers

You may be receiving support from individuals outside of the hospital for complementary or alternative therapies. **Complementary therapies** are used together with conventional cancer treatments such as chemotherapy and radiation. **Alternative therapies** are used instead of conventional cancer treatments.

It is important for your health care team to keep track of all the therapies that you are participating in outside of the hospital. These may include acupuncture, Ayurveda, chiropractic therapy, naturopathic medicine, Chinese herbal medicine, and special diets or supplements, among others. Tell your health care team about your current or planned therapies. They will be able to tell you if the therapy is safe during your cancer treatment.

It is also important to tell your pharmacist about any vitamins, minerals or herbal products that you are taking to avoid serious interactions with medications. See the 'Nutrition' section for more information.



The flu is serious for people who have cancer. Take action to protect yourself against the flu, so you can focus on the fight that matters most.

## Give the flu the one-two punch this season:

- **1.** Get the flu shot not the nasal spray vaccine
- **2.** Make sure the people who live with you or care for you get the flu shot too

## A flu shot is your best protection against the flu this season.

Talk to your health care team about when to get your flu shot if you are receiving chemotherapy.

## Understanding Your Diagnosis

Everyone will have a different experience with their diagnosis. **Ask for all of the details that you feel need at each visit.** 



Some people like to know all the details about their diagnosis, while others want to know less. **Be sure to ask for all the details you want to know.** You will have many chances to get more information – you do not have to get all the details at once.

To help you understand your diagnosis, some important details to write down include:

- The type of cancer
- The grade of the cancer (e.g., what does it look like under a microscope?
  How aggressive is it?)
- The stage of the cancer
- If it has spread to other parts of your body
- What treatment is suggested for you
- Is there a clinical trial that is right for you

**Ask Questions.** If there is something you do not understand or want to know more about, do not be afraid to ask. Sometimes it can be confusing to understand the details about your diagnosis or treatment. Cancer can bring a new language into your life so let your team know if there is something that is not clear. They can explain it in a different way or write it down if you want to look for more information later.

**Talk to an Information Specialist**. You can also call the Canadian Cancer Society's Cancer Information Service line toll-free at 1-888-939-3333. The helpline is available to cancer patients, caregivers, families, friends, the general public, and health care professionals. An information specialist will answer your questions and provide you with information.

## Information About My Diagnosis

Your doctor will explain your diagnosis. You can write this information here for quick reference.

Date of diagnosis:	 	
Type of cancer:	 	 
Grade:	 	 
Stage:	 	 
Has it spread?	 	 
Notes		

## My Treatment Plan



This section is a place where you can work with your health care team to map out how your cancer will be treated. You will be able to see what the next steps in your treatment will be.

Surgery						
Type of surgery	When	Notes				

Radiation Therapy									
Start date	Stop date				Area to be treated				
Chemotherapy									
Start date	Stop date	How many		Туре		Drugs			
		☐ IV Treatment ☐ Pill Treatment							
		Both IV & Pills							
		☐ IV Treatment							
		☐ Pill Treatr☐ Both IV &							
		_	IV Treatment						
		☐ Pill Treatment ☐ Both IV & Pills							
						<u> </u>			
C	ther Treatment	(e.g. Hormon	al Dru	ıg The	erapy)				
Start date	Stop date	Drug	Notes						

#### Your First Visit

## How long will my first visit take?



Your first visit may last several hours. It depends on many things, including the types of tests that need to be done and how many members of your health care team you will meet that day.

### Help us understand your symptoms.

You will experience a range of physical and emotional symptoms related to a cancer diagnosis and treatment. To better understand how you are feeling before you start treatment, you will be asked to rate your symptoms at a touch screen computer called a kiosk. A volunteer can assist you if you would like help.

You will also be asked to rate how the disease is impacting your daily life. Your answers will help you and your health care team identify changes in your symptoms and get you the support you need. A symptom screen report must be completed at every visit.

### How was your visit today?

Your Voice Matters is a survey that gives you the chance to share your thoughts about each visit to your cancer centre or hospital. You can complete the Your Voice Matters survey at the same kiosk where you do your symptom screening questionnaire.



# My appointment is delayed. Why is this happening?

Clinic appointments can be delayed if another patient is unwell or if there is an emergency. Your appointment may also start late if there is a delay with a computer, machine or blood work results. This will not affect the amount of time your health care provider spends with you.



It takes time for blood work results to come back from the lab. Arrive at the time that you are instructed to so that your results are back before your scheduled appointment with your doctor.

## Why am I being given a pager?

Pagers allow you the freedom to move around the centre while you wait for your clinic appointment. While you are waiting, you can carry your pager and visit the Patient and Family Resource Centre, go to the washroom, or have a coffee at Tim Hortons on Level 1. The pager will vibrate and flash when it is time for your appointment.



## Return Visits

Be prepared to stay between 1 - 6 hours for return visits. If you are coming in for systemic therapy or radiation therapy, the amount of time you spend at the LRCP will depend on your treatment. Speak with a member of your health care team for more information so that you can plan ahead.

## Should I still see my family doctor?

Yes, your family doctor is still responsible for all non-cancer related health care (e.g. blood pressure, diabetes, etc). Your health care team at the LRCP looks after your cancer treatment and care. Your family doctor will receive notes from the LRCP updating them on your cancer care.

If you do not have a family doctor, call the Health Care Connect Patient Registry: 1-800-445-1822



## When should I call my family doctor?

Contact your family doctor if:

- You have a concern **not** related to cancer, e.g. a heart condition, high blood pressure, diabetes, etc
- You have any changes in your health between visits to the LRCP such as a cold or the flu
- You need a refill on a prescription that is not related to your cancer care
- You need a regular check-up



## Recommended Resources

#### **LRCP Orientations**

Visit the LRCP website at <a href="https://www.lhsc.on.ca/london-regional-cancer-program/lrcp-orientations">https://www.lhsc.on.ca/london-regional-cancer-program/lrcp-orientations</a> to view the tour. This video can give you a better understanding of what to expect at your appointment.

The **Patient and Family Resource Centre** offers computers with internet access, books, and pamphlets with information about cancer, cancer treatment, nutrition, coping with cancer, and much more.

The volunteers in the Resource Centre can help you find what you are looking for.



The Patient and Family Resource Centre can also be a quiet place to sit and relax. It is located on Level 1 of LRCP, underneath the main set of stairs.

## Advance Care Planning

If you become unable to agree or refuse treatment or other care, it is helpful to let others know what your health and personal care choices are. Advance care planning is about reflection and communication. It is a time for you to reflect on your values and wishes.

Talking to your family, close friends, and your health care team is an important part of advance care planning. Creating a plan of care will make sure your wishes are respected. It can also lower some of your caregivers' worry about making decisions for you.

**Advance care planning** - This involves about speaking with family and friends, especially your 'substitute decision-maker', and writing down your wishes. It may also include talking with health care providers, financial specialists, and legal professionals about your care choices.

**Advance Care Plan** - An advance care plan can be written down or simply told to someone who is authorized to speak for you, such as a substitute decision-maker. It can guide your substitute decision-maker to make medical decisions on your behalf if they are asked by a health care provider.

**Substitute Decision-Maker** - A person who makes medical decisions on your behalf when you are not able to express your wishes on your own. This person might also be known as a health representative or a Power of Attorney for Personal Care.

**Power of Attorney / Power of Personal Care** - A person who is legally chosen to speak on your behalf. To make it legal, you need to have a written document naming your Power of Attorney / Power of Personal Care and what their responsibilities are. If you do not select someone as your Power of Attorney, your health care team will ask the person closest to you based on a list of substitute decision-makers set by law.

You can create a power of attorney yourself, using the free kit provided by the Ontario government. For more information, visit: <a href="http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/incapacity/poa.php">http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/incapacity/poa.php</a>

To get a Power of Attorney kit:

- Download at <a href="http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/poa.pdf">http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/poa.pdf</a>
- Call ServiceOnatrio toll free at 1-800-267-8097 to have one mailed to you.

**Informed Consent** – This means that you are giving health care providers permission for medical inquiries and/or treatments. Health care providers give you detailed explanations of the inquiries/treatments and their risks before you verbally agree or sign the consent form.

**Cardiopulmonary Resuscitation (CPR)** – This refers to medical procedures used to restart your heart and breathing when the heart and/or lungs stop working suddenly. CPR can be mouth-to-mouth breathing, pumping of the chest, electric shocks that restart the heart or machines that breathe for you.

**Do-not-resuscitate (DNR)** – A do-not-resuscitate (DNR) order tells medical professionals to not perform CPR. This means that doctors, nurses and emergency medical staff will not attempt emergency CPR if you stop breathing or your heartbeat stops.

**Palliative Care** – This refers to care provided when you have a lifethreatening illness. Palliative care is effective early in the development of illness and can be used with other therapies that may help lengthen life (e.g. chemotherapy and radiation therapy). It focuses on providing a good quality of life and keeping you as comfortable and free of pain as possible. Palliative care may involve medicines, treatments, physical care, psychological services, social services, and spiritual support. This can be provided for both you and for those who are helping to care for you. A Palliative Care Outreach Team may be involved at some time along your cancer journey.

### Medically assisted dying

Death and dying can be difficult subjects to think and talk about. If you are thinking about medical assistance in dying, talk to someone who can help you understand your options: a doctor, nurse practitioner or other health care provider.

You can also visit the following links for more information:

- https://www.ontario.ca/page/medical-assistance-dying-and-end-life-decisions
- http://www.health.gov.on.ca/en/pro/programs/maid/docs/maid.pdf

#### What You Can Do

- Talk with your family, friends, and health care team about your wishes for treatment and medical care.
- Choose your substitute decision-maker.
- Document your wishes in a 'Power of Attorney for Personal Care' form. The form can be found at: <a href="http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/incapacity/poa.php">http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/incapacity/poa.php</a>

## For More Information: Speak Up



More information about advance care planning can be found on the 'Speak Up' website at: <a href="http://www.advancecareplanning.ca">http://www.advancecareplanning.ca</a>

## Information and Support for Cancer Patients Who Smoke



Making the decision to quit or reduce the number of cigarettes that you smoke can be difficult during this time. It is important to know that becoming a non-smoker can help make your cancer treatment more safe and more effective.

### Quitting smoking can help your radiation therapy treatment

Radiation therapy works better if the level of oxygen in your body is normal. When you smoke, carbon monoxide gets into the blood and makes it harder for radiation to do its job. If you do not quit smoking, you can improve your treatment by not smoking at least two hours before and two hours after radiation therapy treatment.

### Quitting smoking can help your chemotherapy treatment

When you smoke, the nicotine in tobacco makes some chemotherapy drugs less effective. This means that they may not work as well as they are supposed to.

### Quitting smoking can improve the results of your cancer surgery

Patients who quit before surgery:

- Use less sedation medication
- Have a lower risk of heart and lung complication
- Are at a lower risk of developing infections
- Heal faster
- Have a safer surgery

If you do not quit smoking, it is helpful to not smoke one week before your scheduled surgery date.

## Help is available!

Call Telehealth Ontario at 1-866-797-0000. Care Coach Assistants are available 24/7 for help with:

- Quit plans
- Managing cravings
- Finding local support

# Health Information Management at the London Regional Cancer Program



Health Information Management is also known as Health Records, Medical Records or Correspondence. The office is located on Level 3 of the London Regional Cancer Program.

### I have forms that I need my doctor to fill out.

The office will gladly accept your forms by mail, fax or in person. They will make sure your doctor's office completes them. After they are completed, they will be returned to you or the party that requested them.

The office keeps track of your requests and makes sure that your private information is allowed to be released. They will attach copies of all required medical records to the form.

Please look for the space to fill in your name and date of birth on your form. It is also important to sign and date the form before we give it to your doctor to complete. If needed, the office has a consent form that can be completed and signed by you to release your records to another party.

\*Please note that the office does not keep a supply of forms, they only accept the forms that you give them.

If you need help with Drug Coverage and forms related to drug coverage, please call the Drug Access Facilitator at 519-685-8500 extension 54519.

If you need help finding financial support and services in your community or help completing the patient/claimant part of forms, you can contact a member of the social work team. See the 'Counselling' and 'Finances' sections for more information.

## I need a letter from my doctor.

If you would like to request a letter from your doctor, the office will make that request for you. You may request a letter by telephone, in person, mail or fax. They will contact you when the letter is ready.

# My family doctor or other health care provider needs to request copies of my medical records.

If your doctor or healthcare provider need copies of your medical records, they can fax a request on their letterhead to the office. The office will send them the requested information.

You can also complete a request/consent form for the health records office. They can send your records as directed by you.

## I want to request copies of my medical records for myself.

The office will provide copies of your medical records at your request. They need a completed consent form and will need to view your government issued photo ID. The office charges a small fee to process your request. Please contact the office in person or by telephone for more information.

### I need a list of all of my appointments

The office will print a list of appointments for the time period that you need. They will need a completed consent form and will need to view your government issued photo ID. Please contact the office in person or by telephone for more information.



If you have any questions or concerns, please call or visit in person during office hours (Monday - Friday from 8:00 a.m. - 4:00 p.m.).

London Regional Cancer Program - Health Information Management 800 Commissioners Rd. E., Room A3-828 PO Box 5010 London, Ontario, Canada N6A 5W9

Telephone: 519-685-8630 / 519-685-8500 extension 53254

Fax: 519-685-8628