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This guide was prepared and reviewed for you by your Cancer Health Care Team including nursing, former patients, radiation oncologists, medical oncologists, surgeons, social workers, dietitians and palliative care team.

Please refer to this guide at different times during your care.
What Cancer Cannot Do

Cancer is so limited…
It cannot cripple love,
It cannot shatter hope,
It cannot corrode faith,
It cannot destroy peace,
It cannot kill friendship,
It cannot suppress memories,
It cannot silence courage,
It cannot invade the soul,
It cannot steal eternal life,
It cannot conquer the Spirit.

Author unknown
My personal information

NAME ____________________________________________________________
Address ____________________________________________________________

Telephone:  Home ____________________________________________________
             Work _________________________________________________________
             Other _______________________________________________________
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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How do I use this Information Guide and Personal Record?

Frequently asked questions:

- What is the Colorectal Cancer Information Guide and Personal Record?
- How can I use the Colorectal Cancer Information Guide and Personal Record?
What is the Colorectal Cancer Information Guide and Personal Record?

This guide will:

- Provide you with basic information about: colorectal cancer, its treatment and the possible effects of colorectal cancer on you and those close to you.
- Outline the Wellness Beyond Cancer Program.
- Help you to organize and understand the information you collect about your colorectal cancer.
- Allow you to keep track of necessary information about your colorectal cancer and to help you find answers to your specific questions (see Section 2).
- Allow you to share the information you have gathered with your health care team.

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

Living with colorectal 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 and an index that are included at the back of this guide.

People with colorectal cancer want various types of information, in different amounts and at different times. As you collect information that is helpful to you, it can be added to your guide in the sections provided for your use.
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.

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 also photocopy any part or section of the guide (for example, if you need additional pages to record appointments you can photocopy a blank sheet).
- Also remember that you can use this guide in whatever way it best helps you.
SECTION 2

Keeping track

- Summary of my colorectal cancer diagnosis
- Who makes up my health care team?
- My appointments
- My test results
- Questions for my health care provider(s)
- My medication record
- My symptom diary
- Decisions
- Personal record

“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
Summary of my colorectal cancer diagnosis

Last colonoscopy ___________________________ Location __________________________
Done by Dr. _____________________________________________________________________

Last chest x-ray ___________________________ Location __________________________
Last CT abdomen __________________________ Location __________________________
The location of my tumour is:

Who will be part of my colorectal cancer treatment team?

Your care will be provided by a team of health care professionals who will help you on a treatment plan that is best for you. Depending on the kind of treatment you receive, your health care team may include surgeons, medical and radiation oncologists, gastroenterologists, nurses, pharmacists and radiation therapists. Other members of your treatment team, such as social workers, psychiatrists, psychologists, spiritual care workers and Community Care Access Centre (CCAC) case managers can help you cope with your treatment and disease by providing support and services to help with such things as finances, care in the home and counselling. Physiotherapists and occupational therapists through CCAC or outpatient clinics can provide a treatment plan to help you with your physical function. Dietitians can give you advice about managing symptoms and eating well. Palliative care providers have expertise in managing symptoms such as pain, nausea/vomiting and fatigue, and will work with you and your family to address these needs and offer other support if the need arises.
# My health care team

## Doctors involved in my care

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<th>Role</th>
<th>Name</th>
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<tr>
<td>Family Doctor</td>
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<td>Medical Oncologist</td>
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<td>Radiation Oncologist</td>
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<td>Gastroenterologist</td>
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## Others involved in my care

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<td>Pharmacist/Drug Store</td>
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Complementary care providers

Massage therapists
Chiropractors
Exercise specialist
Occupational therapist
Physiotherapist

Other supports

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<th>Location</th>
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<th>Questions, answers or comments</th>
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These pages can be used to keep track of your medical appointments.
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<th>Reason for visit</th>
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These pages can be used to keep track of any tests you have (e.g. CT scans, MRI, blood tests, CEA).

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<tr>
<th>Name of test</th>
<th>Date</th>
<th>Ordered by</th>
<th>Reason for test</th>
<th>Where tests done</th>
<th>Result of test</th>
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We recommend that you write down any questions as you think of them so you can ask them at your next appointment. These pages will help you keep track of your questions and the answers you may receive.

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<tr>
<th>Date</th>
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This form is to keep track of the medications you are taking. In this section, you should list any non-prescription medications or therapies (vitamins, Tylenol, or herbal remedies), as well as prescription medications you are using. As some medications may interfere with your treatment, please inform your Oncologist before starting any new medications. Your Patient Designated Nurse (PDN) and/or Pharmacist may also serve as a resource for information.

<table>
<thead>
<tr>
<th>NAME OF MEDICATION and dosage instructions</th>
<th>Time of day taken</th>
<th>Reason for taking</th>
<th>Doctor</th>
<th>Side effects</th>
<th>Advice for side effect relief</th>
<th>Date started</th>
<th>Date stopped and reason for stopping</th>
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## 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.

<table>
<thead>
<tr>
<th>Date and Time</th>
<th>Symptom (Example: Pain, diarrhea, constipation, fatigue, nausea, other)</th>
<th>What was I doing? (Example: physical activity, emotional event, sleeping, eating, other)</th>
<th>How bad is the symptom? Circle a number</th>
<th>What did I do to make the symptom better? Did it help?</th>
</tr>
</thead>
<tbody>
<tr>
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<td></td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td>Medication amount: Other:</td>
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<td>1 = least severe 10 = the most severe</td>
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<td>Medication amount: Other:</td>
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<td>1 = least severe 10 = the most severe</td>
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# MY SYMPTOM DIARY

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<th>Symptom</th>
<th>What was I doing?</th>
<th>How bad is the symptom?</th>
<th>What did I do to make the symptom better?</th>
<th>Did it help?</th>
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Ottawa Personal Decision Guide

- **What is the Decision Guide?**
  The decision guide is a tool 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. An interactive tool is also available at http://decisionaid.ohri.ca/decguide.html.

- **What are some of the difficult decisions?**
  After a diagnosis with colorectal 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?**
  If you are:
  - 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.
  - Physical signs of stress when you think about the decision.

  This guide may be helpful for 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:

1. Clarify the decision.
2. Identify your decision making needs.
3. Explore your needs.
4. Plan the next steps.

**Clarify the decision.**

What is your reason for making this decision?

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How far along are you with your decision?

- [x] I have not yet thought about options
- [ ] I am close to choosing an option
- [ ] I am considering the options
- [ ] I have already made a choice

**Identify your decision making needs.**

A. Support

Do you have enough support and advice from others to make a choice?  
Are you choosing without pressure from others?

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B. Knowledge

Do you know which options are available to you?
Do you know both the benefits and risks of each option?

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C. Values

Are you clear about which benefits and risks matter most to you?

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D. Certainty

Do you feel sure about the best choice for you?

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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.

**Explore your needs.**

A. Support

Who else is involved?  
Name:  
Name:  
Name:  

Which option does this person prefer?

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Is this person pressuring you?  
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How can this person support you?

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What role do you prefer in making your choice?

- [x] I prefer to share the decision with
- [ ] 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.

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<thead>
<tr>
<th>Option #1 is:</th>
<th>☒ BENEFITS</th>
<th>How much it matters</th>
<th>☐ RISKS</th>
<th>How much it matters</th>
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<th>Option #2 is:</th>
<th>☒ BENEFITS</th>
<th>How much it matters</th>
<th>☐ RISKS</th>
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<th>Option #3 is:</th>
<th>☒ BENEFITS</th>
<th>How much it matters</th>
<th>☐ RISKS</th>
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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".

Plan the next steps based on your needs.

✅ Things making the decision difficult

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 record
“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 3

I have been diagnosed with Colorectal Cancer . . .

A patient’s story: Pat Kenny

Frequently asked questions:

Q What is colorectal cancer?

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

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

Q How should I share my diagnosis?

Q How do I cope with colorectal cancer?
Pat Kenny
Age of diagnosis: Age 50
Diagnosis: T3, N0 rectal cancer
Treatment: Radiation, chemotherapy and surgery

Over the years I have heard about people who were on a cancer journey, where they fought a battle with cancer. Ultimately the people who fought this battle and went on this journey and made it through treatment were referred to as survivors. I didn’t really understand what this meant and the words seemed dramatic. I am now 11 months into my own cancer journey, fighting my own battle with cancer and now I understand what it means to be a survivor. It would be difficult to capture this experience without using these words... journey, battle and survivor.

There are many firsts and lasts along the path that are memorable. The day I had my first colonoscopy at 50 years old was the first time I was told I had cancer, November 2011. I had a couple of weeks of outright denial until I had a copy of the pathology report in my hand. Within a month (by mid December) I was in the hospital undergoing my first ever surgery to remove some important real estate from my colorectal area. At this point I was scared but feeling positive, like we were on this mission to eradicate the bad guy. I say ‘we’ because at every step of the way through this battle I was never alone. In my corner were the extensive medical team of health professionals, my family, friends and coworkers. After the surgery I learned that they had to take a little more than they expected and that they needed to give me a temporary ileostomy which redirects the digestive waste material. Reversal would take place by operation a few months down the road. This was another first for me, an ileostomy, and all I can say about that is it was a very major adjustment for me.

A few weeks later (January 2012) when the pathology report was complete I was told by the surgeon that the tumour had breached the wall and I would now be referred to medical and radiation oncologists to discuss further treatment options. And oh, by the way, the ileostomy cannot be reversed until treatment is done. That’s when I started to crack. I remember when the surgeon left the room and I turned to the nurse and said with a combination of indignation and disbelief, “I used to be a vibrant 50 year old woman”. She looked at me and said, “You still are a vibrant 50 year old woman”. She was absolutely right.

Lesson number one, cancer cannot take away who you are at the core. Within a couple of days I was sitting in the room with the Radiation Oncologist trying to process
all of the information he was giving me in order for me to make a decision about whether to move forward with treatment. All I could manage to say at the end of the meeting was, ‘I can’t make this decision today’. It seemed overwhelming. It actually took me three days to make the decision about radiation because after all it is my abdomen and there are lots of important things in the surrounding area that are affected. The next meeting was with the Medical Oncologist who also gave me a lot of information and statistics to consider regarding chemotherapy treatment. The bottom line for me is that I really don’t want the cancer to come back. I really want to live to see my kids grow up and experience the many milestones of life. So, I decided to move forward with any treatment they were willing to offer that would annihilate the enemy, cancer.

Although I remember feeling very anxious and trying to remember to breathe while receiving daily radiation, what stands out in my mind is what happened in the waiting room. There were many occasions when, while waiting for my treatment, we would see someone headed down the hallway with the radiation team to ring the bell that signified the end of their treatment and everyone in the waiting room would cheer. I remember well when this moment came for me, I was happy to reach this milestone.

After radiation was over, my dosage for chemotherapy increased. I started to experience side effects that were moderate and sometimes severe that included pain and swelling of the hands and feet resulting in the skin peeling. I took the chemotherapy in pill form and was sometimes unable to complete a cycle due to side effects. The dosage had to be adjusted down a couple of times after the end of a cycle where the side effects had been severe. When I was little I learned the hard way that you don’t put your hand back on the hot stove or you will get burned. The difficult part of chemotherapy for me was the anxiety that I experienced when every cycle I had to put my hand back on the hot stove. By this time in the journey I had investigated yoga and meditation, joined group sessions, sought counselling and was leaning on many family members, friends and coworkers to get through treatment.

Lesson number two, I learned from cancer just what I mean to people. I had no idea how many people cared. Although I did not ring a bell in the hallway on the last day of chemotherapy I rang the bell virtually, in my mind; a significant last day. This is the part where I really understood why they call cancer patients survivors.

The next steps for me after a recovery period will be the reversal of the ileostomy and return to work. At the risk of sounding overconfident, ‘bring it on’.

Pat Kenny is a colorectal cancer survivor who has learned cancer can be beaten.
A brief overview of colorectal cancer and its treatment is given in this guide. More information is provided to you in the book *Support. Knowledge. Hope: A Companion and Reference Guide for People Living with Colorectal Cancer* that is included in this package.

**What is colorectal cancer?**

Cancer occurs when a normal body cell (or cells) becomes abnormal and grows in an uncontrolled way. Colorectal cancer is a malignant *tumour* that first appears in the *colon* or *rectum*. It grows and progresses fairly slowly and in a predictable way. Colorectal cancer almost always begins as small, slow growing non-cancerous *polyps*—small outgrowths on the inner surface of the colon. Over time, these polyps can grow larger and may become cancerous and invade the colon wall, surrounding blood vessels and lymph nodes. However, most polyps never become cancerous.

Cancer of the small intestine is very rare, so when people talk about bowel cancer they usually mean colorectal cancer. Colorectal cancer is the third most common cancer for both men and women in Canada.

**The gastrointestinal tract**

The gastrointestinal (GI) or digestive tract extends from the mouth to the anus. The mouth is joined to the stomach by a tube called the esophagus. The GI tract continues down through the stomach and into the intestine (also called the bowel). The bowel is divided into 2 parts, the small and the large bowel. The tract continues through the large bowel (also known as the colon or large intestine) to the rectum and ends at the anus.
The colon and rectum

The colon (large bowel) leads from the small bowel or intestine to the rectum and is about 150 to 180 cm (5 to 6 feet) long. The rectum is the last 15 cm (6 inches) of the large bowel, and leads to the anus. The segments starting from the right side of the body and going to the left side are the cecum, ascending colon, transverse colon, descending colon, sigmoid colon and rectum. The colon acts like a sponge and absorbs water from the liquid material as it passes through. The rectum acts as a holding area until the stool is passed out of the body through the anus.

What are the possible causes of colorectal cancer?

There is no single cause of colorectal cancer, but there appear to be several risk factors for developing colorectal cancer. Lifestyle or controllable factors that appear to increase the risk include:

- Obesity
- Diet high in fat, processed meats and red meat and low in fruits and vegetables
- Physical inactivity
- Smoking
- Heavy alcohol intake
The following factors can increase a person’s risk of developing colorectal cancer and cannot be controlled:

- **Age**—if you are over 50 years old, your risk increases.
- **History of inflammatory bowel disease** (ulcerative colitis or Crohn’s disease).
- **Previous history of colorectal cancer** increases risk of new colorectal cancer.
- **Family member with a diagnosis of colorectal cancer.**
- **Family member with history of more than 10 colonic polyps.**
- **Family history of colorectal cancer in close blood relatives such as parents, siblings, or children, especially if it occurs before the age of 50 and in more than one generation.**
- **Family history of multiple primary cancers, especially breast, ovary, uterus, kidney cancer.**

**Genetics**

One inherited type of colorectal cancer occurs in those with *familial adenomatous polyposis* (FAP). These people develop numerous polyps throughout their colon. This is extremely rare and accounts for less than 1% of colorectal cancers.

Another inherited disease that increases the likelihood of colorectal cancer is *hereditary nonpolyposis colorectal cancer* (HNPCC). People with HNPCC tend to develop colorectal cancer in their thirties and forties, although it may occur later in life. Again, this condition is not common and accounts for less than 5% of all colorectal cancers.

If you have several of the hereditary risk factors mentioned above, your doctor may refer you (and your family) for genetic counselling. In Ottawa, this is done at the Children’s Hospital of Eastern Ontario (CHEO).

A genetic counsellor collects the history of cancer occurrences in blood relatives on both your mother and father’s side of the family and decides if you qualify for genetic testing. Genetic testing will determine whether you or your family members carry the inherited tendency on some of your genes to develop colorectal cancer.

If you are positive, you and your family can be recommended for early and regular screening tests and preventative measures to reduce your risk of developing colorectal cancer.
Screening tests can include yearly testing of stool for the presence of microscopic amounts of blood, and a baseline colonoscopy to assess for polyps. Family members can discuss this with their family doctor.

**What are the symptoms of colorectal cancer?**

Colorectal cancer may develop over a long time without causing any signs or symptoms. When symptoms do start to develop they may include:

- Blood in the stool (either bright red or very dark in colour)
- General stomach discomfort (bloating, cramps and/or fullness)
- A feeling that the bowel does not empty completely
- A change in bowel habits (constipation, diarrhea or mucous in the stool) that lasts for more than two weeks
- Unexplained weight loss
- Narrowing of stools
- Inability to pass stool or gas
- Anemia

These symptoms are often vague and easily mistaken for more common illnesses.

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

When you are diagnosed with colorectal 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. Some people want as much information as they can possibly get and others may only want a little. Don’t be afraid to ask for information as you want or need it.
- Write down questions as you think of them. Take these with you to each appointment.
- Take notes during your conversations with your health care providers. Some find it helpful to ask a friend or family member to do this.
- Ask for instructions in writing.
 ■ Ask your health care provider to explain if you do not understand.
 ■ 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.
 ■ 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. Also, information needs can change as you progress through your cancer treatment. Sometimes you may not want to read anything at the start, but later will feel the need to know more.

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**What is a common reaction to a diagnosis of colon or rectal cancer?**

A diagnosis of colon or rectal 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.

Many individuals with colon or rectal 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 okay 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. People who have support seem to do better. 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.

Reasons for telling:
- As you tell others, it may help you to understand the information you have been given.
- Secrets are avoided. People who find out from others do not know if they have permission to talk to you.
- Close family may need to know about your diagnosis as it may provide them with the opportunity for screening.
- 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 colorectal 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?
- 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.

The way in which you tell certain family members and friends will be different.
How do I cope with the diagnosis of colorectal cancer?

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

**STEP 1**
Acknowledge your emotions: Some people believe they have to maintain a positive attitude all the time because it will have an effect on their prospects of recovery. This is not reality. Low periods do occur, no matter how well you are coping.

**STEP 2**
Become self-caring: Putting your own needs first is not selfish. Caring for yourself is most important.

**STEP 3**
Build your team: Do not be afraid to ask family, friends, or your community for help when you need it.

**STEP 4**
Take on one issue at a time: Leave the things that can be left. Try not to jump ahead.

**STEP 5**
Develop a good working relationship with your health care team: Ask questions and share your feelings, develop a sense of trust, include your family practitioner.

**STEP 6**
Take time: Some things do not have immediate solutions and do not require action.

**STEP 7**
Make changes slowly: Only do the things that make sense to you. Any change is difficult; do not add to your stress by expecting too much from yourself.

Remember you are truly unique, and your journey belongs to you!
How do families normally react when someone is diagnosed with colorectal cancer?

A diagnosis of colorectal 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” (Rabbi Kushner).
- 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.
- People often feel 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.
- It is important to have life go on as close to normal as possible. Don’t let the cancer ‘move in’ and take over your home.

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.
- 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. Some families designate one person to co-ordinate offers of help and phone calls. This can help to take the stress away from immediate family members.

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.

**Practical ways for family and friends to be helpful**

The following is a list of suggestions from a patient of ideas on how to be helpful:

1. Don’t avoid me. Be the friend, the loved one you’ve always been.
2. Touch me. A simple squeeze of the hand tells me you still care.
3. Call and tell me you’re bringing over my favourite dish. Bring food in disposable containers so I won’t worry about returning them.
4. Watch my children while I take a little time to be alone with my loved one. My children may also need a vacation from my illness.
5. Cry with me when I cry, and laugh with me when I laugh. Don’t be afraid to share these emotions with me. Pain isolates. Help me reconnect with others.
6. Take me out for a pleasure trip, but know my limitations.
7. Call for my shopping list, and make a special delivery to my home.
8. Before you visit, call to let me know, but don’t be afraid to visit. I need you. I can get lonely.
9. Help me celebrate holidays (and life) by decorating my hospital room or home, or by bringing me flowers or other natural treasures.
10. Help my family. Invite them out. Take them places. I am sick, but they may be suffering too. Offer to come and stay with me to give my loved ones a break.
11. Be creative. Bring me a book of reflections, taped music, a poster for my wall, cookies to share with my family and friends.
12. Let’s talk about it. Maybe I need to talk about my illness. Find out by asking, “Do you feel like talking about it?”

13. Don’t always feel we have to talk. Sitting quietly together is fine. Your presence confirms that I am still important and alive.

14. Can you take me and/or my children somewhere? I may need transportation to a treatment, to the store, or to my physician.

15. Help me feel good about myself.

16. Please include me in decision-making. I’ve been robbed of so many things. Please don’t deny me a chance to make decisions in my family and in my life.

17. Talk to me about the future. Tomorrow, next week, next year. Hope is so important to me.


19. What’s in the news? Magazines, photos, newspapers, and verbal reports keep me from feeling like the world is passing me by.

20. Could you help me with some chores? During my illness, my family and I still face dirty clothes, dirty dishes, and a dirty house.


22. Just send a card to let me know you care.

23. Pray for me and share your faith with me.

24. Tell me how you’d like to help me and when I agree, please do so.

25. Tell me about support groups, so I can share with others.

How can I talk to my children about colorectal cancer?

When someone they love is ill, children experience sadness, loneliness, confusion, anger and fear 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 colorectal 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. It is OK to say you don’t know the answer to their questions when you don’t have the answers.

Reassure a child 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 colorectal 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 colorectal cancer to occur.

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 and structure as close to normal as possible.
- Notify teachers and all significant adults in the child’s life such as sitters, coaches, neighbours, 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 4

Colorectal cancer treatment

A patient’s story: Ken Gibson

Frequently asked questions:

Q How will my colorectal cancer be treated?
Q Where will I receive care?
Q What are clinical trials?
Cancer is one of those things that obviously is not chosen as an experience. However if you are going to experience cancer, you could do worse than to have that experience in the Ottawa area.

Let me give you my rationale for saying this.

Since my retirement, my wife and I had traveled and lived in various countries. I began to experience discomfort when we were first in the United States, and after numerous hospital tests, the doctors decided I could be discharged. The discomfort continued when we were traveling in South America and again after numerous tests, there was nothing found.

While living in Europe, I had the same unexplained pains and was treated for prostatitis for 10 weeks, and at the end of that period the Specialist suggested I should have a colonoscopy. Since we were shortly returning to Canada, I arranged to have a colonoscopy in a private clinic in Toronto. The results of this colonoscopy were inconclusive, although the surgeon said he saw some roughness in the colon but based on his experience said that it was not cancer.

We moved back to Ottawa in the hope of a quiet and healthy retirement and went through the search to find a family doctor. Luckily, we found a cautious doctor, who immediately reacted to the written results of my Toronto colonoscopy. She sent the results to a surgeon who organized a colonoscopy. I will always remember the words used by the surgeon who conducted the colonoscopy: “You might have a ticking time bomb inside you”. Unfortunately, he was correct and I went on to have an operation and six months of Chemotherapy. The Chemotherapy was uncomfortable and the Medical Oncologist reduced the dosage on three different occasions.

Through all of this, I was amazed and pleased at the total support for cancer patients in the Ottawa area: the nursing staff at The Ottawa hospital, the Cancer Assessment group and the after hospital Care group.
After I was diagnosed our family doctor leaned on my wife to have a colonoscopy since two of her siblings had died as a result of colon cancer. She was very hesitant and made all kinds of excuses, including the fact that she had no symptoms, but our Family Doctor organized an appointment. The result of this was the discovery that she had Colorectal Cancer.

We were fortunate that this diagnosis came about two months after my own diagnosis and I was therefore able to provide her some support. She came through the operation and the cancer was successfully removed.

Again, I was very pleasantly surprised with the total support group that was put together for my wife, including the nurses who visited our home. My wife seems to be well on her way to recovery with the ileostomy to be reversed in a few months.

Having experienced hospitalization and medical care in a number of countries, I feel that the organization for treating cancer in Ottawa is second to none.
How will my colorectal cancer be treated?

There are 3 possible ways to treat your cancer: surgery, chemotherapy and/or radiation therapy.

Surgery

Surgery (removing the cancer in an operation) is the most common treatment for all stages of colorectal cancer. You may be put on chemotherapy and/or radiation before surgery to make the tumour smaller. This may allow the doctor to remove it more easily.

If you are going to have surgery, the type of operation will depend upon the exact location of the tumour in the bowel. The large bowel or colon is over 5 feet long. The surgery may be performed either with an open approach, where one incision is made in your abdomen, or a minimally invasive surgical (MIS) resection/laparoscopic colon resection with several smaller incisions (see figure 1). The surgical approach decision is influenced by many factors, including the location of the tumour and history of previous abdominal surgeries.

In either surgical approach, the surgeon will remove the cancer, the surrounding lymph nodes and a part of the colon and/or rectum. The two healthy ends of the bowel are then sewn back together, if possible. If the doctor is unable to sew the two ends of the bowel back together, a stoma (an opening from the bowel to the skin) is made for the stool to pass through (colostomy or ileostomy). An appliance (or bag) is placed around the stoma to collect the stool (see figure 2). The stoma can be temporary or permanent (see figure 3).
**Enterostomal Therapist (ET)**

If you require a stoma, you may see an Enterostomal Therapy (ET) Nurse. The ET is a Registered Nurse with in-depth knowledge and skills caring for persons with ostomies and wounds. ET Nurses’ responsibilities include, but are not limited to, ostomy education and stoma site marking before non-urgent operations, consultation during hospitalization and facilitating the transition to living independently in the community. Your own attitude towards your ostomy will be the most important one. If you have a positive attitude, others will too.

Resuming activities after surgery is of some concern to most people. Your ostomy is in no way a restriction on your previous activities. You are free to enjoy all the activities that you enjoyed before your surgery however, if you play rough contact sports, you may want to discuss this with the ET in advance.

You can continue to wear whatever clothing you wore before your surgery. The appliance is flat and unnoticeable. However, consider loose clothing right after your operation, as your abdomen will be swollen. Once you are discharged home, lists for your community resources or suppliers are available through your local CCAC team.

**Fertility concerns**

If you are considering having children following your treatment for cancer, ask your physician about fertility options open to you. It is very important to do it before your treatment starts. See “Fertility Resources in Ottawa” in Section 9.

Resuming sexual activities takes time after any type of surgery. Honest and open communication with your partner is very important in finding or returning to a satisfying sexual relationship. In time, the presence of the ostomy will make little difference to you and your partner. Your particular surgery may result in other physical changes that could interfere with your normal sexual activities. If you have concerns, discuss these with your doctor and/or health care team.

**The Patient Process map**

A Patient Process map shows the steps you will go through for colon cancer and rectal cancer.
Colon Cancer Patient Process Map

Colonscopy: Diagnosis of colon cancer

Work-up:
- CT Scan
- Blood work, etc.

Possible consultation with:
- Surgeon
- Nurse
- Social Worker
- Internal Medicine
- Medical Oncologist
- Symptom management
- Other specialists (eg. Nutritionist)

Review Treatment Options: Discussed and Decided
(Surgery, Chemotherapy—alone or in combination)

Information Sessions Offered: Surgery and/or Chemotherapy

Surgery
Surgery followed by Chemo
No Surgery, but will have Chemo
No Surgery
No Chemo
No Radiation

Post-surgery patients will:
- review the pathology with surgeon
- have possible referral/follow-up with oncologists
- be informed about future monitoring and colonoscopy

Non-surgical patients will be followed-up with Medical Oncologist and/or with Primary Care Provider.

Discharged to Primary Care Provider/Wellness Beyond Cancer Program

This process map is to provide colon cancer patients, their families and caregivers with a general understanding of the patient’s journey. There may be some variation depending on the patient’s situation.
Rectal Cancer Patient Process Map

Colonscopy: Diagnosis of rectal cancer

Work-up:
• CT Scan
• MRI

Blood work, etc.

Possible consultation with:
• Surgeon
• Nurse
• Social Worker
• Internal Medicine
• Medical Oncologist
• Radiation Oncologist
• Symptom management
• Enterostomal therapist
• Other specialists (eg. Nutritionist)

Review Treatment Options: Discussed and Decided
(Surgery, Radiation, Chemotherapy—alone or in combination)

Information Sessions Offered: Surgery, Chemotherapy and/or Radiation

Surgery

Radiation followed by Surgery

Radiation and Chemo followed by Surgery

Surgery followed by Chemo and/or Radiation

No Surgery Will have Chemo and/or Radiation

No Surgery
No Chemo
No Radiation

Post-surgery patients will:
• review the pathology with surgeon
• have possible referral/follow-up with oncologists
• be informed about future monitoring and colonoscopy

Non-surgical patients will be followed-up with
Medical/Radiation Oncologist and/or with Primay Care Provider.

Discharged to Primary Care Provider/
Wellness Beyond Cancer Program

This process map is to provide rectal cancer patients, their families and caregivers with a general understanding of the patient’s journey. There may be some variation depending on the patient’s situation.
Sample questions to ask your surgeon

You may have your surgery in one of the Champlain LHIN hospitals. If surgery is being proposed for you, here are some sample questions you may wish to ask your surgeon before your surgery.

Questions

1. Where is the tumour located?
2. What is required before surgery? Do I need to have any other tests?
3. What are the potential benefits of surgery? What would happen if I did not have the surgery, or postponed the surgery?
4. What type of surgery will I be having?
5. What are the risks and side effects of the surgery?
6. How long will I be in the hospital after surgery?
7. What type of follow-up will be required with you? And where?
8. If other treatments are required, when will I be referred to the Cancer Centre?
9. How will surgery affect my sexual health?
10. Will I need an ostomy? Will it permanent or temporary?
11. Will I require any home support upon discharge from hospital?

How do I prepare for my surgery

- You will be given instructions on eating and drinking restrictions at your Pre-Admission Unit (PAU) visit.
- Walk for 30 minutes each day, if you can.
- Avoid tobacco for at least 14 days before surgery. Support is available. Smokers can have a higher chance of incision infection and lung problems after surgery.
- Contact the surgeon’s office for a medical certificate or if you have insurance forms that need to be completed.
- Skin prep: the evening before or the morning of your surgery, take a shower using regular soap and wash your hair. Do not use scented products.
Bowel prep: there are different types of bowel preparations and they are dependent on the type of surgery you are having. Your surgeon will order either: Pico salax, Colyte, fleet enemas and/or dulcolax tablets.

Remove all make-up, nail polish, body piercings and jewelry.

Bring the following to the hospital: shampoo, comb, toothbrush/paste, shoes/slippers, housecoat, scent free body lotion, deodorant, lip balm, razor, etc. If you have sleep apnea and use a machine at night, bring it to the hospital.

Your family will be able to visit you when you are settled into your bed on the surgical unit.

To learn more about what to expect if you need surgery, visit www.ottawahospital.on.ca/mySurgery for a virtual tour.

**Chemotherapy**

Not all patients require chemotherapy. In some cases, your medical oncologist may recommend that you have chemotherapy either before surgery to shrink the tumour (neoadjuvant) or after surgery to kill microscopic cancer cells (adjuvant therapy).

Chemotherapy is the treatment of cancer with medication. There are a number of chemotherapy drugs used to treat colorectal cancer. Although each chemotherapy drug works 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 colorectal cancer patient is different. How frequently the treatment is given will depend on the drugs being used and how well you tolerate the treatment. Individual patients respond differently to chemotherapy. Before starting chemotherapy, you will discuss with your medical oncologist and oncology nurse (PDN) the side effects that you may experience, how to prevent, manage or decrease them and the impact that they may have on your quality of life. The side effects for colorectal cancer chemotherapy can include diarrhea, hand and foot syndrome, nausea, vomiting and fatigue. Side effects of chemotherapy may differ depending on the kind of chemotherapy you have been prescribed. Typically chemotherapy drugs for colorectal cancer may cause hair thinning but very few patients will have total hair loss. An information session on chemotherapy is offered at The Ottawa Hospital Cancer Centre (TOHCC) before starting your treatment.

Chemotherapy can be given by pill or by injecting the drug into a vein (intravenous). Sometimes the chemotherapy recommended will require the insertion of a PICC
(Peripherally Inserted Central Catheter) or an implanted port ("port"). The PICC is a thin flexible tube that is inserted into a large vein in your arm and will remain in the vein for as long as it is needed. It can also be used to take blood samples. A port is a plastic disc with a flexible tube attached. It is inserted through a small surgical procedure into a large vein in the chest and sits just underneath the skin. Usually having either of these two devices is not painful and most people are able to function normally.

You can expect to receive your chemotherapy as an outpatient at the The Ottawa Hospital Cancer Centre and/or in your home through Chemotherapy Home Infusion Pump Program (CHIPP). Patients are rarely admitted to hospital for chemotherapy treatments. You will be given written information by the nurse at the Cancer Centre about the specific chemotherapy you will receive.

Length of chemotherapy treatment can vary. A treatment plan is developed for each patient. During chemotherapy, your medical oncologist and PDN nurse will monitor how you feel throughout your treatment. You may have frequent check-ups, scans and blood tests.

Chemotherapy can be given in conjunction with radiation therapy (see below). This decision will be made with you, your medical and radiation oncologists. When you have successfully completed your chemotherapy treatments a discharge plan will be discussed.

**Sample questions to ask your medical oncologist**

Not everyone with colorectal cancer receives chemotherapy; however, if it is being proposed for you, here are some sample questions you may wish to ask your oncologist before your treatment. Remember, it is your right to ask questions so that you are able to make the best decisions about your health care.

**Questions**

1. What are the potential benefits of this chemotherapy?
2. Are there other treatment options besides this treatment?
3. What would happen if I did not take chemotherapy, or postponed it?
4. Will I need more tests before my treatment begins?
5. Will I need a special intravenous line to receive the chemotherapy?
6. How often will the treatment be given?
7. How long will the whole course of chemotherapy last?
8. What are the risks and side effects of this chemotherapy and how will they be managed? For example, nausea, vomiting, hair loss, changes of appetite, fatigue.
9. Can I take other medicines or natural therapies during treatment?
10. Can I go to work while taking chemotherapy?
11. Will I have or need any home support while on chemotherapy?
12. What side effects are rare but of greater concern?

Radiation therapy

Radiation therapy is the treatment of cancer with radiation. Radiation beams are targeted to the affected area to kill cancer cells, shrink tumours and ideally prevent cancer cells from spreading or returning. It may also be used to reduce pain in advanced cancers. Depending on your medical situation, you may be offered chemotherapy and radiation at the same time (called concurrent chemo-radiation).

Before starting radiation therapy, you should discuss with your radiation oncologist the side effects that you may experience. The number of treatments varies from patient to patient. Each radiation therapy treatment usually lasts about 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 one hour for each radiation therapy treatment when scheduling transportation or other appointments. Take analgesics if lying on a table will be a problem (e.g. due to arthritis). You will know before you begin treatment how many treatments you will have.

Sample questions to ask your radiation oncologist

Not everyone with colorectal cancer receives radiation therapy; however, if it is being proposed for you, here are some sample questions you may wish to ask:

Questions
1. What type of radiation treatments will I be receiving?
2. What are the potential benefits of radiation?
3. Are there other treatment options for my type of colorectal cancer?
4. Will any chemotherapy be given during the time radiation treatments are given?
5. What would happen if I did not have, or have postponed, radiation treatments?
6. When will I start treatments?
7. How long will each treatment take?
8. How long will the whole course of radiation treatment be?
9. What are the short-term risks and side effects?
10. What are the long-term risks and side effects?

**Where will I receive care?**

Many patients may visit the The Ottawa Hospital Cancer Centre (TOHCC) for a consultation appointment and subsequent radiation and/or chemotherapy. Patients living in the west end of the city may have an opportunity to have their treatments offered at the Irving Greenberg Family Cancer Center (IGFCC) located on the grounds of the Queensway Carleton Hospital. In addition, the Community Oncology Program provides chemotherapy and some cancer care to patients living outside the city in various outlying communities. You will receive treatment closer to home if you live in an area that is served by this program. Appointments with your Oncologist may be at TOHCC, IGFCC or Cancer Assessment Clinic (CAC).

If you need to have treatments at TOHCC, we suggest that you attend the Navigating Cancer Care class. This class will provide you with information on what to expect at your first appointment. It will also discuss the role of team members and will provide you with information of various resources. Please contact 613-737-7700, ext. 70516 or ext. 25200 for information and to register.

You may be eligible to be on the Chemotherapy Home Infusion Pump Program (CHIPP). CHIPP is a program that allows you to receive all or part of your chemotherapy in the comfort of your own home, using a continuous infusion pump. At present, CHIPP is limited to a few areas across the region but plans to expand the program are underway.
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 will help arrange such services for you and also help you to obtain other services if necessary.

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

There are a variety of settings you will need to go to during your treatments. If you need treatment for your colorectal cancer, or for symptoms and conditions related to your cancer, you might be admitted to a hospital. If this is the case, the health care team at the hospital will provide the care that you need while you are in the hospital and help you make arrangements for you when you are discharged.

**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 virus and 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. If you are approached to participate in a clinical trial, the decision to participate is entirely yours.

If you are interested in participating in a local clinical trial, or would like more information on what clinical trials are offered at The Ottawa Hospital Cancer Centre, please speak to your oncologist or call the Clinical Trial office at 613-737-7700, ext. 70310.

To learn more about promising new cancer treatments and clinical trials in other locations, visit www.ontariocancertrials.ca.
How do I cope with my colorectal cancer?

A patient’s story: Heather Flamain

Frequently asked questions:

Q  What side effects can I expect from treatment?

Q  How can I cope with the physical symptoms?

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

Q  How do I manage my anxiety?

Q  Will I be able to do my regular daily activities?

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

Q  Loss of income

Q  What are the complementary therapies I should consider?
Heather Flamain
Age of diagnosis: 53
Diagnosis: Low Rectal Cancer
Treatment: Surgery, chemotherapy, radiation, T4N0MX

My journey began about three years ago when I went to my doctor to see what he thought about some back pain I was having, specifically in my tailbone area. He was at a loss to determine what was causing it so he prescribed Tylenol 3. I took them for the next year without much relief. The next step was cortisone shots which didn’t help much either.

At the same time I was dealing with the tailbone pain I experienced bleeding which we thought was from hemorrhoids. After several more doctor visits we decided it was time for a CT scan. The scan didn’t show anything so we scheduled an MRI of my lumbar spine, including my tailbone. The MRI results were not conclusive, and so nothing concrete was decided, and my pain and bleeding continued.

Finally I had a colonoscopy which showed a very large mass – about the size of a baseball – in my rectum. Next followed more tests to determine how invasive the tumour was. It was decided that all the bleeding I had been experiencing and the pain was due to the large size of the tumour.

To start treating the tumour aggressively I saw oncologists, a surgeon, the Symptom and Pain management team and started my first round of radiation and chemotherapy. At the end of these treatments my surgery was scheduled to remove the shrunken tumour (now the size of a kiwi).

I have to commend the cancer team in Radiology, Social work, Nutrition, Nursing, specialists and support staff. They were absolutely amazing. Being surrounded by many other patients facing the challenges made the process much easier to deal with. Lots of hugs and words of encouragement from the staff were extremely helpful.
The surgery went smoothly. It was determined before surgery that due to the location of the tumour in my rectum that I would need a permanent colostomy. I went home from the hospital six days after the surgery. I stayed with family to recuperate. The visiting nurses changed the dressing and provided me with much needed support. Six weeks after surgery I am getting used to my colostomy and started another six months of chemotherapy.

I would like to thank my primary team for their wonderful expertise and words of encouragement. My journey continues as I move into a new home in the New Year and feel confident that I am free of all cancer.
What side effects can I expect from treatment?

Individuals receiving surgery, chemotherapy or radiation therapy may have specific side effects from cancer treatment. Suggestions to cope with some of these can be found below. Additional information can also be found in the booklet, “Support* Knowledge* Hope: A Companion and Reference Guide for People with Colorectal Cancer”.

How can I cope with the physical symptoms?

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 helpful suggestions for you or refer you to a specialist in symptom management.

**Pain**

Pain can be managed through a variety of methods which includes medications and non-medicinal treatments. Your physician and the health care team will work with you to find the best dose and treatment plan to help you understand how to adjust the dose of medication depending on your needs. The amount of medication you need may vary from day to day. Many people fear the side effects of pain medication or fear that they will become addicted. Addiction almost never occurs in cancer patients. Many side effects of pain treatments can be easily managed.

Pain is not just physical. 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 counselling or support groups can help as well. You may inquire about a referral to the Psychosocial Oncology Program (PSOP) at 613-737-7700, ext. 70516 or ext. 25200.

**Nausea/Vomitting, Decreased Appetite and Weight Loss**

The following are tips to deal with some side effects from the chemotherapy. 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 important to increase your calories and proteins. 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.

- If you are feeling nauseated or your appetite is low, try eating 5 or 6 small meals per day rather than 3 standard meals. An empty stomach increases the feeling of nausea. Cold foods are better tolerated than hot foods which have a stronger aroma.

- Getting enough calories is important during treatment to maintain your weight and strength. Limit low energy foods and drinks, choose high protein foods and drinks instead.

- 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, peanut butter and legumes (beans). Protein drinks can help when your appetite is decreased.

- Drink plenty of fluids. A minimum of eight cups of fluid per day will prevent dehydration and help flush the toxicity of treatment and decrease side effects. Fluids can include water, juice, milk, broth, milkshakes, and other beverages. Beverages containing caffeine or alcohol 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 need more information about nutrition, the Canadian Cancer Society (CCS) has a booklet called *Eating Well When You Have Cancer—A Guide to Good Nutrition*. You can pick up this booklet at The Ottawa Hospital Cancer Centre or find it on the Canadian Cancer Society Web site www.cancer.ca.

**Diarrhea and/or frequent bowel movements**

A diet low in fiber or residue is recommended to help control diarrhea and frequent bowel movements. Ask your health care provider for a booklet called *Low Residue Diet* guide (P297). This guide provides a list of food groups that you can select from which have ‘binding properties’. A low residue diet is recommended for patients having chemotherapy, radiation therapy, or following bowel surgery, if you have a colostomy or ileostomy. Follow the advice from your health care team.

- For bowel incontinence, the pelvic winks are really the best exercise to do. Nutritionally speaking, a diet rich in fiber, especially soluble fiber could be helpful as well.
For diarrhea, apple sauce, bananas, boiled white rice or pasta and even cheese and peanut butter are great choices. Soluble fiber choices are also encouraged, including root vegetables such as carrots, squash, potatoes, and oatmeal are recommended. Metamucil, pectin and chia seeds or grounded seeds can also be effective as needed. Limiting concentrated sugars, caffeine, alcohol, raw fruits and vegetables is also recommended.

For frequent stools, the same as above are recommended, especially the high soluble fiber sources. Oat bran and barley can also be added to the list. To decrease stool frequency, Metamucil is very useful and effective and is gives more bulk to your stool consistency and helps decrease transit time.

For both diarrhea and frequent stools, proper hydration and electrolyte replacement should also be encouraged to help prevent dehydration. Taking extra salt and choosing food rich in potassium (bananas, potatoes, oranges and orange juice, tomatoes and tomato juice). A good oral rehydration solution to treat and prevent dehydration is mixing sport drinks diluted half with water and half with a ½ teaspoon of salt added for each litre.

**Constipation**

For constipation, proper hydration is also very important. A diet high in fiber and non-caffeinated fluids, is recommended to help prevent constipation. However, a high fiber diet is not encouraged if you are taking large doses of narcotics, as it tends to block and slow your bowel movements even further. Ask your health care provider for a booklet called *Nutritional guidelines to help increase your fiber intake* (P392). Follow the advice from your health care team.

For constipation and hemorrhoids, a high fiber diet is recommended, including whole grain bread, whole wheat pasta, brown rice, bran cereals, dried fruits, beans and lentils and a variety of fresh fruits and vegetables. Metamucil can be used as an effective fiber supplement.

**Sexual Health and Cancer**

Sex and sexuality are important parts of everyday life. It is difficult to predict how cancer and/or treatment will affect you. Many people may experience some changes due to surgery or treatment. It is important to know that sexual desire may decrease through treatments. These changes can be temporary while some may last for a longer period of time. They can be due to fatigue, surgery, body image, side effects of treatments, etc.
You may feel that you look different and may have a difficult time with your body image. Many people feel that it is difficult to adjust to the changes in their appearances. You may feel that your partner won’t find you attractive. It is important to talk to your partner about those fears and concerns and how it may impact sexual activity. This may help put both of you at ease.

The Canadian Cancer Society has a booklet that may help in giving you tips on different things to try: here is some information on how to prepare for sex during or after cancer treatment:

1. Talk openly with your partner about any fears you have about resuming sexual activity.

2. Let your partner know how you feel, when you are ready to have sex, what level of intensity you prefer, if he/she should do anything different and how he/she can help you to feel pleasure.

3. Be concerned about how your partner feels, as he/she may be worried about hurting you or appearing too eager.

4. Plan ahead. While this may lessen spontaneity, choosing the right time can help you deal with fatigue and pain.

5. Take it slowly. It may be easier to start with cuddles or a sensual massage the first few times rather than penetrative sex.

6. Be patient. Things may never be exactly as they were, but they will improve with time and practice.

Visit: www.cancer.ca for more information or to view this booklet.

If sexual health problems appear during or after treatments don’t hesitate to talk about them with your health care provider.

If you need help with coping with some of these changes or if you or your partner need counselling regarding your sexual health, please contact our Psychosocial Oncology Program at 613-737-7700, ext. 70516 or ext. 25200.
How do I deal with sexuality issues?  
(Self-esteem, body image, sexual relations)

**Self esteem**

Good self-esteem can be a challenge at the best of times. Very often self-esteem can be affected by body image. Colorectal cancer can further impact a person’s confidence in themself and their ability to cope. Try not to define yourself by the way your body looks or to blame yourself for getting colorectal cancer.

**Body image**

Our ‘body image’ perception is said to evolve throughout our lifetime. Like pain, body image is personal and difficult to describe. Changes to our physical appearance can occur due to surgical treatment (surgical scar or an ostomy) or chemotherapy (neuropathy – causing pain that can impact the use of the hands and feet). Some of you may feel that the altered body image is causing you personal distress. If this is happening to you, please contact PSOP for counseling.

**Sexual relations**

**intimacy**

Intimacy is the need or ability to experience emotional closeness with another human being and to have that emotional closeness reciprocated.

As you go through diagnosis and treatment, you may feel vulnerable and go through a wide range of emotions. Feelings of grief for their change in appearance can impact intimacy. Seek reassurance from partners and loved ones.
Communication with your partner

If communication with your partner has been good before your colorectal cancer diagnosis, it will probably continue to be through treatment and recovery. People often worry that their partners will not find them as sexually attractive and this will impact the stability of their relationship. The crisis of colorectal cancer can add to previous difficulties in the partnership.

Colorectal cancer does not come with a rule book and partners are learning and dealing in their own way with your cancer diagnosis and treatment. Sometimes partners can seem silent and detached, or conversely always trying to be positive. This may mask the fear of falling apart and not being able to provide the type of support a person may need. Partners may be experiencing anxiety and distress at levels similar to yours.

Sexuality

If a person has had a satisfying sexual relationship before colorectal cancer, with some adaptation this should continue. However, it is important to note that sexual desire can be impacted by emotion such as anxiety, sadness, fear, denial, depression and anger. Sexual desire can also be affected by treatment side effects such as skin changes, fatigue, weakness, radiation skin reactions, weight changes and colostomy/ileostomy bag. For some women, chemotherapy may cause vaginal dryness that can lead to painful intercourse. A water-based lubricant such as KY jelly or a moisturizer such as Replens may be helpful. For some men, treatment may impact their ability to have or maintain an erection. Counselling is available through PSOP or your primary care provider.

Fatigue

Fatigue is different from feeling tired. Many people who are living with colorectal 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 or calories, side effects from your treatments, 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.
- 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.
- 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.
- Eat and drink 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.

**Sleep tips: 10 steps to better sleep (by Mayo Clinic Staff)**

You’re not doomed to toss and turn every night. Consider simple tips for better sleep, from setting a sleep schedule to including physical activity in your daily routine.

Think about all the factors that can interfere with a good night’s sleep—from pressure at work and family responsibilities to unexpected challenges, such as layoffs, relationship issues or illnesses. It’s no wonder that quality sleep is sometimes elusive.

Although you might not be able to control all of the factors that interfere with your sleep, you can adopt habits that encourage better sleep. Start with these simple sleep tips.

**No. 1: Stick to a sleep schedule**

Go to bed and get up at the same time every day, even on weekends, holidays and days off. Being consistent reinforces your body’s sleep-wake cycle and
helps promote better sleep at night. There’s a caveat, though. If you don’t fall asleep within about 15 minutes, get up and do something relaxing. Go back to bed when you’re tired. If you agonize over falling asleep, you might find it even tougher to nod off.

**No. 2: Pay attention to what you eat and drink**

Don’t go to bed either hungry or stuffed. Your discomfort might keep you up. Also limit how much you drink before bed, to prevent disruptive middle-of-the-night trips to the toilet.

Nicotine, caffeine and alcohol deserve caution, too. The stimulating effects of nicotine and caffeine—which take hours to wear off—can wreak havoc with quality sleep. And even though alcohol might make you feel sleepy at first, it can disrupt sleep later in the night.

**No. 3: Create a bedtime ritual**

Do the same things each night to tell your body it’s time to wind down. This might include taking a warm bath or shower, reading a book, or listening to soothing music—preferably with the lights dimmed. Relaxing activities can promote better sleep by easing the transition between wakefulness and drowsiness.

Be wary of using the TV or other electronic devices as part of your bedtime ritual. Some research suggests that screen time or other media use before bedtime interferes with sleep.

**No. 4: Get comfortable**

Create a room that’s ideal for sleeping. Often, this means cool, dark and quiet. Consider using room-darkening shades, earplugs, a fan or other devices to create an environment that suits your needs.

Your mattress and pillow can contribute to better sleep, too. Since the features of good bedding are subjective, choose what feels most comfortable to you. If you share your bed, make sure there’s enough room for two. If you have children or pets, set limits on how often they sleep with you—or insist on separate sleeping quarters.

**No. 5: Limit daytime naps**

Long daytime naps can interfere with nighttime sleep—especially if you’re struggling with insomnia or poor sleep quality at night. If you choose to nap during the day, limit yourself to about 60 minutes and make it during the mid-afternoon.
If you work nights, you’ll need to make an exception to the rules about daytime sleeping. In this case, keep your window coverings closed so that sunlight—which adjusts your internal clock—doesn’t interrupt your daytime sleep.

**No. 6: Include physical activity in your daily routine**

Regular physical activity can promote better sleep, helping you to fall asleep faster and to enjoy deeper sleep. Timing is important, though. If you exercise too close to bedtime, you might be too energized to fall asleep. If this seems to be an issue for you, exercise earlier in the day.

**No. 7: Manage stress**

When you have too much to do—and too much to think about—your sleep is likely to suffer. To help restore peace to your life, consider healthy ways to manage stress. Start with the basics, such as getting organized, setting priorities and delegating tasks. Give yourself permission to take a break when you need one. Share a good laugh with an old friend. Before bed, jot down what’s on your mind and then set it aside for tomorrow.

**No. 8: Deep breathing**

Lie on your back while in bed. Place your hand on your belly and start to engage in some deep breathing. Observe the sensations in your torso as you breathe in and out. Try to lengthen your inhale and your exhale. Try to keep your attention on your breath and the sensations in your body as you inhale and exhale. Do this for 10 to 15 minutes. You may actually drift off to sleep.

**No. 9: Meditation and mindfulness**

Sitting comfortably in a chair or on your bed, close your eyes and observe the thought in your mind. Try to slow down those thoughts and focus on them one at a time. Acknowledge and label each thought. Explore it for a bit and then see if you can put it aside. Continue to do this with each thought until you have briefly explored them all and have put them aside for the night. If there are particular thoughts which are more concerning, write them down on a note pad, explore it a bit more in writing and come back to it the next day.

**No. 10: Gentle yoga**

Engage in a gentle yoga practice for 10 to 30 minutes with a focus on forward bends and restorative postures. Explore the yoga program at the Cancer Centre for more ideas and guidance.
**Perineal strengthening exercises**

**Anal winks:**
These exercises may be performed anywhere. For example, they may be done while you are driving or watching television. They usually don’t take time out of your busy day.

**How to do them:**
Tighten your anus as if you are refraining from expelling gas or urine. Hold as tight as you can for 20 to 30 seconds, relax for 20 seconds and repeat 20 times a day. In addition to the anal winks you may squeeze your buttocks. This may provide additional pelvic floor strength. The overall goal is to improve your ‘squeeze’ pressures. Long term, an increase in external sphincter control can improve your resting anal tone, which is while you are walking or sleeping.

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**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.
- Seek support from family and friends. Have a friend or family member accompany you to treatments.
- Listen to your body. Expect to feel tired and make plans to rest frequently.
- Exercise daily, in whatever way you are able.
- Eat well.
- Do things to enjoy life. Having a treat to look forward to may improve your sense of wellbeing.
- Talk to someone who has *been there*. It might be a big help and also lessens the stress on your family. Joining a colorectal cancer support group allows you to talk to someone that has the same experiences, concerns and lifestyle changes. For information about local support groups, see Section 10.
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 companion who has a calming influence with you to treatment. Choose the sort of person who will be most helpful to you.
- Remember that treatment is temporary and will come to an end. Social Workers are available in the hospital and Cancer Centre to meet with you on an individual or family basis to help you with coping strategies.
- 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 support.

Will I be able to do my regular daily activities?

For many people, routines give 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.

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.

Work Issues

The thoughts of trying to juggle a busy job, doctor’s appointments, treatment schedules and family commitments can be overwhelming. Many people with colorectal cancer may decide to take sick leave following their diagnosis. 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 working 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 around 4 weeks after your surgery. At that time you will be able to discuss with your surgeon if other treatments are required, and timing of returning to work.

**Can I work while I have chemotherapy or radiation therapy?**

Some people are able to work throughout their treatments. However, there may 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 can result in being very tiring. Maintaining open discussion with your employer may help you work out the best arrangement during your treatments 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 insurance or Employment Insurance Benefits while I am getting treatment?” Social workers can give you information and guidance. They can inform you about community support for finances, extra help at home, transportation assistance to treatments, power of attorney and will making. Contact the PSOP program for a referral at 613-737-7700, ext. 70516 or ext. 25200.

**What are the complementary therapies I may consider?**

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. It is important to tell your oncologist, nurse, and pharmacist that you are using complementary therapy.

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. 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.

**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.

**Relaxation Techniques**

Relaxation techniques can help to decrease the anxiety and stress. These methods help you relax, working with the mind and/or the body. They are techniques that can be easily learned. The basis for all relaxation is focusing on breathing. Some examples 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.

**Meditation** – Meditation is a method of relaxation from ancient times. Meditation is clearing of the mind by focusing on one thing at a time, whether it is breathing, counting or repeating one word.
**Progressive muscle relaxation** – A technique used to relieve tension and stress by systematically tensing and relaxing successive muscle groups.

**Therapeutic touch** – A modality in which the practitioner uses hand motions, but not direct physical contact, in an effort to balance and modulate the energy flow through and around your body.

**Reiki** – A Japanese technique in which the practitioner places his hands on or near the person receiving treatment, with the intent to transmit *ki*, believed to be life-force energy.

**Healing touch** – A modality that uses gentle touch in an effort to balance physical, mental, emotional and spiritual needs.

**Sound/music** – The use of music and musical elements in an effort to promote, maintain and restore mental, physical, emotional and spiritual health.
How to maintain a healthy lifestyle?

A patient’s story: Chris Flemming

Frequently asked questions:

Q What can I do to promote my overall health?

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

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

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

Q What is the Wellness Beyond Cancer program?
**Chris Fleming**
Age of diagnosis:  Age 56  
Diagnosis:  T2, N0 rectal cancer  
Treatment:  Radiation, surgery  

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**Chris Fleming is a colorectal cancer survivor who has learned cancer can be beaten.**

I was encouraged by my wife to have a colonoscopy. I didn’t even know what the word meant - and it proved to be a life saving event. I was 56 years old with no symptoms to suggest I had any health problems and no family history of cancer. However, one of the husbands of a member of my wife’s bridge group had heard it was important for anyone over 50 to have a routine colonoscopy and so, again with no symptoms or family history he went in and they found a small tumor. Clearly, after that everyone in the bridge group and their spouses went in for their colonoscopy.

Of that group I was the only one found to have cancer. The gastroenterologist did the procedure and announced “I’m surprised but Chris I think that we have a cancerous tumor here”. Before I could even absorb what he said he continued “… and this is good news”.

It turned out he was totally correct. The tumor was found so early that it was easily removed soon after and had not spread; so full recovery was expected.

For those who face the prospect of having cancer it is a life altering moment one that you are never ready for and you are first totally unaware of what you face ahead. You quickly share your news and fears with your friends and family and then start to deal with this new reality. All of us who have faced cancer soon learn we are fortunate to be in Ottawa and able to be “cared for” by the people and procedures in place at The Ottawa Hospital Cancer Centre. Like many many others I found the nurses, doctors and support staff so amazingly skilled in providing information to help assess what I faced. They provided comfort to both me and my wife helping us through the many trying times when we were uncertain about our future and the ongoing care needed to ensure the best possible treatment.
While your life is altered and you will never be the same following your diagnosis, I believe I’m a better person for having to learn to face the risk and to have realized how much strength can come from your family, friends and your new “support team” at the hospital. The people who choose to be health care providers are impressive for their knowledge and dedication to helping others—strangers who they willingly work hard for because they know how important their work is.

Clearly cancer can be beaten. Colorectal cancer, in fact is one of the many kinds that can be treated and full recovery is possible.

Knowing this will help anyone facing the uncertainty of their future and the many disciplines of the staff of the hospital will rally with you to help get you and your family through this. I have lived with my new reality for almost 3 years now and I am still amazed how often a sense of gratitude overwhelms me as I think about these last few years and remember how fortunate I am to have been treated by The Ottawa Hospital Cancer group.
What can I do to promote my overall health?

Adopting healthy lifestyle choices is always beneficial in helping you through your treatment experience. The following suggestions may help you stay as healthy as possible.

- 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. Start slowly.

- Make a habit of walking every day, 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 recovery. Keeping well hydrated and nourished will help you to maintain your strength and energy, and 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 treatments you are having.

- Try to limit red meat to 18 oz per week and avoid processed luncheon meat if you can.

- Limit alcohol intake, particularly during treatment to one drink daily (for women) and 2 drinks daily (for men).

What is the role of my primary care provider in my overall general health?

The role of your primary care provider or nurse practitioner (NP) is very important during the course of your treatment. They 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 primary care provider. Your primary care provider can serve as a vital link between you and your colorectal 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 primary care provider. Although you can feel overwhelmed with numerous appointments, it is important to remember to attend to all areas of your health.

Your primary care provider will continue treating your other health issues, e.g. diabetes, cardiac; and will refill medications they have previously prescribed. Your oncologist or surgeon will treat you for health issues related to your cancer. Any prescriptions for cancer related medications will be prescribed by the oncologist or surgeon.

Finding a Primary Care Provider

If you do not have a primary care provider, you might want to try some of these strategies:

■ Ask around. Ask a friend or family member if their doctor is accepting new patients.

■ Contact ‘Health Care Connect’. This is a government program which helps people find a primary care provider. The program refers people to doctors and nurse practitioners who are accepting new patients. To register for the Health Care Connect program, call 1-800-445-1822. Or for more information, visit the MOHLTC Web site at: http://www.health.gov.on.ca/ms/healthcareconnect/public/index.html.

■ Connect with a Community Health Centre (CHC) in your area. CHC's provide primary health care and give prevention programs. Keep in mind that most centres only give services to people who live within the community or neighbourhood. You can find a list of CHC’s in Ontario at the Web site of the Ontario Ministry of Health and Long-Term Care: http://www.health.gov.on.ca/english/public/contact/chc/chcloc_mn.html.

■ Scan local newspapers. When doctors are new to an area they will sometimes advertise that they are accepting new patients. The same goes for those who are just starting a new practice.

How will I feel at the end of my treatment?

Although people look forward to the time treatment is over, it can also be a time of anxiety and concern, sometimes depression. During treatment, there was frequent, perhaps daily contact with the health care team. Although treatment may have
been demanding, at least, *something* was being done to fight the cancer. Now that treatment is over, as well as the frequent attention of the health care team, many people worry that the cancer may return.

These feelings are normal and to be expected.

You may experience a period of adjusting, physically and psychologically. Fatigue can be a problem. Learn to pace yourself. You may have to begin to re-define what is “normal” in your life. Priorities may change. Do the things you enjoy, focusing on the things you “want” to do, not on what you “should” do. Attending a support group with others going through a similar situation can decrease the depression and loneliness, by providing a place to talk about your concerns. It is important to develop and maintain good health habits: eating properly, getting adequate sleep, and exercising.

You may have concerns about returning to work. Because your energy may be depleted, take time to recover physically and emotionally before trying to adjust to work stress. Consider working part-time at first. Ensure the demands of your job are realistic for what you can do. Before changing employers, check the details of the insurance and disability benefits package. You may not be covered for pre-existing conditions.

Family life, and roles within your family may have been affected. Discuss your experience and fears openly with family. Recognize that you have been through a hard time. If you need additional support, ask for help from professionals such as social workers, nurses, clergy, psychologists, and psychiatrists.

**Cancer Survivorship**

By 2017, it is expected that 83,200 Ontarians will be diagnosed with cancer in a single year. At the same time, improvements in detection and treatment are resulting in a greater number of Ontarians living with cancer. By 2017, it is expected there will be 400,000 Ontarians living with cancer.

Although there are many definitions of cancer survivorship, many who work in cancer programs consider survivorship to be the recovery phase, or after the treatment is complete.
The Ottawa Hospital Cancer Program is committed to providing support and care to people from the time of diagnosis to end of treatment. This includes care and support for people at the end of their cancer treatment. To ensure people receive the best possible care at the end of their treatment, the “Wellness Beyond Cancer Program” (WBCP) was established.

**What is the Wellness Beyond Cancer Program?**

The WBCP is a multidisciplinary team of health care providers who ensure that people, at the end of their active cancer treatment, are aware of their individual needs and have access to appropriate follow-up care required to best meet their needs. Our team of experts will help develop your treatment care plan.

**When and how are individuals referred to the program?**

Your oncologist will refer you to the program once you have completed your treatment. Your oncologist, with you, will determine who the most appropriate health care provider is to lead your ongoing oncology medical care. The decision depends on several factors, including the type and stage of disease and treatment side effects you may have experienced. The WBCP offers three scenarios for follow up:

a) Discharge to the Primary Care Provider

b) Discharge to the WBCP Nurse Practitioner, including shared care with the Primary Care Provider

c) Continued care by a surgical, radiation or medical oncologist, including shared care with the Primary Care Provider
Regardless of who follows you for your ongoing medical care, the goal will be to return you to the care of your Primary Care Provider. If your ongoing oncology care remains at the cancer centre with a Nurse Practitioner or an Oncologist, it is important that you continue to be seen regularly by your PCP to ensure you receive care necessary to keep the rest of you healthy.

When you are referred to the WBCP, you will be asked to complete a needs assessment to identify your individual personal needs. The needs assessment is electronically entered by one of our WBCP team members. Needs of three out of five or greater will automatically enter your Wellness Plan. The Wellness Plan includes your treatment summary, cancer team, recommended surveillance, and summarizes your self identified needs. A discharge letter and the Wellness Plan will be sent to your Primary Care Provider. You will receive a copy as well for future reference.
You will be invited to attend two group sessions: a generic survivorship class and a colorectal specific education class. Primary Care Providers have access to the WBCP phone number to call with any questions and to quickly refer you back into the Cancer Center if it is necessary. See TOH Web site for links.

**Your individualized wellness plan**

As time goes by, it may be difficult for you to remember all the details of your diagnosis and treatment. Also, this information will be valuable to the doctors who care for you throughout your lifetime. A “Wellness Plan” or “treatment summary” is a report that outlines your diagnosis, the treatments you received and follow-up recommendations in one document. It describes how often you should have a check-up with your Primary Care Provider and what tests they can arrange for you in the future.

**Importance of follow-up care**

Participating in your follow-up care is very important to regain physical and emotional health. Cancer survivors feel in control when they participate in their care as they transition back to their everyday lives. The first goal of follow-up care is to watch for a recurrence of cancer. Your doctor can identify and address any health issues caused by cancer or by its treatment.

**Tips for your visit to your health care team:**

- Prepare a list of questions.
- Bring a friend or family member with you to take notes during the appointment.
- Report any new or different symptoms to your doctor.
- Repeat instructions back to your health care team to make sure you have the right information.
- Speak up: Before you leave your appointment, make sure you address any questions or concerns.
- Keep a journal or a notebook to record your medical history in your own words and for your own use.

For more information on the Wellness Beyond Cancer Program, please call us at 613-737-7700, ext. 70256 between the hours of 8 a.m. to 4 p.m. Monday through Friday.
**Key local resources**

- The Ottawa Hospital Cancer Program Web site: (www.ottawahospital.on.ca/cancer)  
  – Support and Follow-up Section
- The Canadian Cancer Society: www.cancer.ca
- The Maplesoft Cancer Survivorship Centre: www.ottawacancer.ca
- Ottawa Integrative Cancer Centre: www.oica.ca

**Other Helpful Web sites:**

- Cancer Care Ontario: www.cancercare.on.ca
- Livestrong: www.livestrong.org
- National Coalition For Cancer Survivorship: www.canceradvocacy.org/
- BC Cancer Agency: www.bccancer.bc.ca/PPI/RecommendedLinks/coping/survivorship.htm
- American Cancer Society: www.acscsn.org/
- Oncolife: www.oncolink.org/oncolife
- Princess Margaret Hospital: www.survivorship.ca/
- Colorectal Cancer Association of Canada: www.colorectal-cancer.ca
SECTION 7

What are the issues for people with advanced colorectal cancer?

A family member’s story: Jean Luc Gingras

Frequently asked questions:

Q  What is palliative care?
Q  How do I plan for end of life care?
Q  What is DNR (Do Not Resuscitate)?
Jean Luc Gingras  
Spouse of Lise Gingras  
Age of wife at diagnosis: Age 59  
Diagnosis: metastatic rectal cancer  
Treatment: radiation therapy and chemotherapy

Lise and I have been married 37 years and have three children. In September 2005, Lise was diagnosed with “stage IV” colorectal cancer. There had been no warning signs prior to her medical appointment, only some minor discomfort during her bowel movements, which led her doctor to refer her to a specialist. When I was asked, as a spouse of a patient, if I had some thoughts I could pass on to help others cope with the impact of cancer I immediately thought how important it is not to have to go through it alone. It became evident right from the moment this terrible news was announced to us that we would have to fight this cancer as a couple, as a team. I encourage anyone with cancer to get support immediately, whether it is from a spouse, family or friends. No one should go through this alone. As the husband and caregiver to Lise, I understood the importance of giving her my constant support. The doctors and nurses are there to try to cure or control the cancer and relieve some of the pain associated with it, but I’ve learned that the support from someone close will help immensely in combating the daily torments of a cancer patient.

We have had to adjust our lives since Lise was diagnosed; coping with our feelings, quitting our jobs, changing responsibilities at home. I drive her to all her appointments and have accompanied her in all her chemotherapy and radiation treatments. I must add also that we get a lot of support from our children; we know it is hard for them as well but they are always there supporting us. Managing the pain is very important. I assist Lise the best I can in selecting the right medication for the different symptoms as they occur. We also rely on a very professional team that has supported us immensely. We are very touched by the devotion and professionalism of all the health care team that have cared for Lise.

When Lise is up to it, we take time away from home for a change in environment. We have had to adapt to the treatments. There are times when the effects of the therapies are more severe and I know Lise needs a lot of rest. In essence, due to the pain, the stress, the medications and personal discomforts, Lise is constantly in need of support.

Lise knows I love her and that I will always be there for her.
What is palliative care?

Palliative care strives to improve the quality of life of patients and their families dealing with problems related to serious illnesses such as cancer. Palliative care aims to prevent and relieve physical, psychological, emotional and spiritual symptoms.

Your doctor can ask the Palliative care and symptom management team to be involved at any point in your illness. Radiation and chemotherapy can also be used to palliate or relieve symptoms you may be having. 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 for as long as possible. When you are facing advanced colorectal cancer, you may continue to be cared for by your oncologists and family physician. As well, the palliative care team may also become involved in your care.

The palliative care consult team consists of physicians, nurses, social workers and other health care professionals that work with the oncology team. The team can help link up services in your community.

If you require the services of the palliative care team your health care provider can request a consult to the team or have you booked into one of the Palliative Care Clinics.

Should you require any further information you can ask a member of your health team.

How do I plan for end of life care?

A diagnosis of advanced colorectal 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 so 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. Usually, it means organizing your personal life: legal
papers (Power of Attorney, Will) income information, insurance policies, financial information such as investments or loans and making sure that the right people know how to access this information. Ensuring 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 end of life care in advance can also give you a sense of control. Discussion with your physician teams and with your family and friends on how you want your care to be carried out can relieve loved ones 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.

**What is DNR (Do Not Resuscitate)?**

Part of planning how you wish to be cared for includes discussing what you would like to happen should you stop breathing or your heart stop beating. A Do Not Resuscitate (DNR) order is a doctor’s written order instructing your health care providers not to attempt cardiopulmonary resuscitation (CPR). CPR includes all the medical efforts that would occur in order to restart the heart if it stops beating or you stop breathing, with a machine.

If you have already thought about this aspect of your care, you may need to bring the topic up with your doctor. On the other hand, your doctor may bring this topic up with you as part of creating your treatment plan. The decision about whether you want to have CPR should be made together with your doctor, your health care team, and with the important people in your life. You will need to know about the options available to you. As well, you will need to consider what your preferences are for care at the end of life.

It is important to remember that whether you have decided that you want resuscitation or not, all other active treatment will be continued. Your symptoms will continue to be managed, any conditions or complications that arise will be treated, and your care team will still be focused on maintaining or improving your present condition. It is important to know that you can change your decision at any time.
Support and Information Resources at The Ottawa Hospital, the Cancer Centre and in the community

- Information and Support Services
- Medical, Counselling and Home Care Resources
- Programs
- Lodging and Transportation
- Financial
- Legal Issues
- Books and Web sites
Information and Support Services

The Ottawa Hospital Cancer Assessment Clinic (CAC), 7NE, General Campus

The Ottawa Hospital Ages Cancer Assessment Clinic (CAC) is located in the main building on Smyth Road at the General Campus, on the 7th floor. This clinic provides care to patients undergoing assessment and diagnosis for colorectal, prostate and lung cancer. The clinic is open Monday to Friday from 8 a.m. to 4 p.m. The reception main phone number is 613-737-8501; to reach a member of the colorectal team press option 2.

The CAC is a gateway to cancer care with coordination provided throughout the system. The CAC streamlines referral process to specialists and diagnostic testing. Care is provided by a multi-professional team including nurses, clerical staff, surgeons, radiation oncologists, medical oncologists and social workers and dieticians. The team provides disease information and educational material. Nurses provide coordination of care, telephone support and are a primary contact for patients and families. Social workers counsel newly diagnosed cancer patients and their families. Your contact with the multi-professional team will allow you to be better informed about your medical situation and treatment options. In consultation with the team, you can make the best decision regarding treatment for you.

The Ottawa Hospital Cancer Centre (TOHCC) and Irving Greenberg Family Cancer Center (IGFCC)

TOHCC is the cancer treatment centre for Eastern Ontario. TOHCC has two campuses: the General Campus is at The Ottawa Hospital, 503 Smyth Road; and the Irving Greenberg Family Cancer Centre, is at the Queensway Carleton Hospital site on Baseline Road. These facilities are open Monday to Friday from 8 a.m. to 4 p.m. The main number is 613-737-7700.

For problems or emergencies during Cancer Centre hours; phone the main number and ask for your nurse’s extension. For emergencies that are related to your cancer treatment, after hours or on weekends and holidays, call 613-737-7700 and wait for TOH switchboard. You will be asked to leave a message including your name and phone number, the name of your oncologist, and if you would like to speak to the Oncologist “on call”. If your concerns are not related to your cancer or treatment, please call your family physician first. In an emergency situation,
please go to your nearest Emergency Department or call 911 for assistance. If you have a community nurse through the Community Care Access Centre (CCAC), they are also a good resource for information and advice related to your cancer treatment.

In addition to the medical care given, many **other health care professionals and services** are available at no cost, including the following PSOP members:

- **Social workers** provide individual and family counseling, offer patient support groups and education sessions and help with practical issues such as access to medication coverage, transportation, financial support and convalescent care. These services are available to all cancer patients and their families seen at the Cancer Centre. You can talk to your nurse or oncologist about a referral to the program or you can call directly at 613-737-7700, ext. 70516 or ext. 25200 (IGFCC).

- **Registered dietitians** give nutritional counseling to specific persons with colorectal cancer. Patients may be at risk for developing a bowel obstruction before they have had surgery to remove the tumour or possibly have diarrhea, nausea/vomiting, taste changes or other side effects of radiation and chemotherapy. These services are available to cancer patients seen at the Cancer Centre. You can talk to your nurse or oncologist about a referral to the program or you can call directly at 613-737-7700, ext. 70516 or ext. 25200 (IGFCC).

- **Physiotherapists** provide physical assessment. They also help to manage pain, increase movement and mobility to maximize function as well as educate on self-management. This service is available to cancer patients seen at the Cancer Centre. You can talk to your nurse or oncologist about a referral to the program or you can call directly at 613-737-7700, ext. 70516 or ext. 25200 (IGFCC).

- **Psychologists** provide a psychological assessment, treatment recommendations and may also provide psychotherapy. This service is available to cancer patients seen at the Cancer Centre. You can talk to your nurse or oncologist about a referral to the program or you can call directly at 613-737-7700, ext. 70516 or ext. 25200 (IGFCC).

- **Psychiatrists** assess and treat individual who needs psychotherapy and medications. This service is available to cancer patients seen at the Cancer Centre. You can talk to your nurse or oncologist about a referral to the program or you can call directly at 613-737-7700, ext. 70516 or ext. 25200 (IGFCC).

- **Palliative Medicine Clinic** – the goal of palliative care is to improve the quality of life for cancer patients and their families. Palliative care physicians and nurses provide help with pain and symptom management. Referral is required.

- **Enterostomal therapy** – Lists for your community resources or suppliers are available through your local CCAC team.
The Ottawa Hospital Web site – 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 receiving treatments for cancer.

Online are a number of booklets produced by the Ottawa Hospital Regional Cancer Centre such as:

1. The Ottawa Hospital Cancer Patient Information Booklet
2. Chemotherapy Patient Information Booklet
3. Radiation Therapy Patient Information Booklet
4. Coping… with loss of income and other financial issues

Colorectal Cancer Association of Canada

The Colorectal Cancer Association of Canada provides support for people living with colorectal cancer, their families and caregivers. Through their Web site www.ccac-accc.ca you can be linked to on-line resources including clinical trials information, journal articles and media reports. Through the toll free information line 1-877-502-6566 you can find out about programs and services. In addition the CCAC is involved in education awareness and advocacy.

Canadian Cancer Society

The Canadian Cancer Society offers a wide range of services to cancer patients. These services include transportation, emotional support, information, cloth hats, wigs, smoking cessation, etc. In some areas, the Canadian Cancer Society runs support groups. The Canadian Cancer Society has the following offices in Ottawa and surrounding areas:
<table>
<thead>
<tr>
<th>Canadian Cancer Society Unit Office</th>
<th>Phone Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ottawa Unit</td>
<td>613-723-1744</td>
</tr>
<tr>
<td>Lanark, Leeds and Grenville Unit (Brockville, Carleton Place, Gananoque,</td>
<td>1-800-367-2913 or 613-267-1058</td>
</tr>
<tr>
<td>Perth and Smiths Falls)</td>
<td></td>
</tr>
<tr>
<td>Renfrew County Unit (Arnprior, Deep River, Eganville, Pembroke, Petawawa</td>
<td>1-800-255-8873 or 613-735-2571</td>
</tr>
<tr>
<td>and Renfrew)</td>
<td></td>
</tr>
<tr>
<td>Stormont, Dundas, Glengarry and Prescott Russell Unit (Cornwall, Hawkesbury</td>
<td>1-800-669-4181 or 613-932-1283</td>
</tr>
<tr>
<td>and Russell)</td>
<td></td>
</tr>
<tr>
<td>Québec Division (Gatineau)</td>
<td>819-777-4428</td>
</tr>
</tbody>
</table>

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.

The Canadian Cancer Society also provides the following national programs:

- **Canadian Cancer Society Peer Support Program**
  The Peer Support Program will connect you by phone with someone who has experienced the same or similar cancer. For more information, phone 1-800-263-6750. To connect with peer support line, go to www.cancerconnection.ca.

- **Cancer Information Service**
  This is a free telephone information service, offered in English and French to answer questions about cancer and its treatment, prevention and early detection, drugs and clinical trials, complementary therapies, etc. For more information, phone 1-888-939-3333.
Support Groups

Colorectal Cancer Support Group Ottawa, Ontario

Monthly meetings to provide support and information for those living with colorectal cancer, their families, friends and caregivers. The group meets the second Tuesday of each month from 7 p.m. to 9 p.m. Location: Maplesoft Cancer Survivorship Centre, 1500 Alta Vista Drive, Ottawa. Free parking. For information, please e-mail to www.pbednarp@magma.ca or call 613-257-1884.

The United Ostomy Support Group, Ottawa

This is a volunteer, charitable organization dedicated to assisting people who have or will have bowel or urinary tract diversions by providing peer support, education services and support to the family unit. Information meetings are on the third Thursday at 7:30 p.m. of each month September to November, January to May (December and June may be on another date). For information, please call 613-447-0361. The meetings are held at: Canada Care Medical Building, 1644 Bank Street at Heron Road, Ottawa, ON. www.ostomyottawa.ca

Support Groups and Education Sessions at The Ottawa Hospital Cancer Centre/The Psychosocial Oncology Program

Education Sessions:

- **Breathe**
  Offered to those diagnosed with cancer and suffering from shortness of breath in their everyday activities. Join us to arm yourself with skills to help yourself breathe better and with more comfort.

- **Financial Drop-in**
  Visit a PSOP social worker for a one-on-one consultation with a social worker that can help answer some of your financial concerns.

- **Lymphedema Education Class**
  For anyone diagnosed with cancer that may be at risk for developing Lymphedema.

- **Navigating Cancer Care**
  For people newly diagnosed and their loved ones. Learn what to expect after a diagnosis of cancer and hear about the various resources available to you.
- **Nutrition Classes**
  Various classes are offered by TOHCC Registered Dietitians: Nutrition During Cancer Treatments, Nutrition After Cancer Treatments, Nutrition and Breast Cancer, Nutrition and Prostate Cancer.

- **Survivorship**
  For people having recently finished treatments and their loved ones. Learn what to expect as you finish treatments and hear about the various resources available.

- **Taking Care of Me**
  Psycho-educational group intended for people with cancer. Learn how to reduce stress and cope in healthy ways through behaviour modification, nutrition and exercise.

  - Nutrition during cancer treatment
  - Nutrition after cancer treatment

**Support Groups:**

- **Caregiver Support Group**
  A group for family members whose loved one has cancer. Duration: Ongoing.

- **Connections 18 to 35**
  A support group for those with cancer aged 18-35 years of age, who are coping with special problems regarding relationships, self-image, education, career and lifestyles changes.

- **Coping with Cancer Stress:** A 6-week classroom-style course for men and women with cancer, and their loved ones, particularly those who are newly diagnosed. Learn methods of coping with the emotional aspect of cancer as well as stress-management techniques.

- **Embrace Life**
  For patients diagnosed with life threatening cancer as well as their caregivers who are facing the end of life process and have questions about end of life issues. A group for family members whose loved one has cancer. Duration: Ongoing.

- **Yoga Thrive**
  Gentle, therapeutic yoga program for people with cancer. Duration: 7 weeks.

For more information about any of these sessions or to register, contact 613-737-7700, ext. 70516 or ext. 25200.
Hospices

Hospices provide support and care for people diagnosed with a life-threatening illness, and for their families. Both Ottawa Hospice programs offer home support and day hospice. The Hospice at Maycourt also offers an in-patient unit. There are no costs associated with these services.

- Hospice at Maycourt, 114 Cameron Ave., tel. 613-260-2906
  www.hospicemaycourt.com

- Friends of the Hospice Ottawa, tel. 613-838-5744
  www.friendsofhospiceottawa.ca

- A palliative outreach program for francophones “Une fleur a la main” provides volunteers for home support/respite. For information, phone 613-241-1266.

Medical, Counselling and Home Care Resources

Medical

Fertility Resources in Ottawa

- The Ottawa Fertility Centre – Phone 613-686-3378
  – Sperm Cryopreservation Storage
  – IVF Fertilization Treatment Cycle
  – Embryo Cryopreservation Storage

- Fertile Future
  – 19 Woodson St., Ottawa
  – 1-877-Hope066
  – www.fertilefuture.ca

- Dr. Weis – Phone 613-236-6772
  – Sperm Cryopreservation

- Dr. Barwin – Phone 613-728-5104
  – Sperm Cryopreservation

Film Library

Copies of your CTs, MRIs, x-rays and radiological records are kept at The Ottawa Hospital Film Library. Since 2002, CTs and MRIs are put on CDs. If you need a CD with a copy of your CT, MRI, PET Scan or x-ray, ask your physician to make the request.
If the receiving physician (even if they reside outside Canada) sends a request by fax, there is no charge to the patient. If the patient initiates the request, there is a charge.

If the record you require is (1) not a CT or MRI or (2) dates before 2002, you will need a copy of the actual radiological film. If the films are to be reviewed by another physician within Canada, the films can be loaned. If the films are being sent out of the country, copies will be made, for which there is a charge. Payment must be made in advance. The films can be ordered over the phone by giving a credit card number. Call the film library at the campus of the hospital where the films were taken.

The direct phone numbers for The Ottawa Hospital Film Library are:

<table>
<thead>
<tr>
<th>Campus</th>
<th>Telephone</th>
<th>Fax</th>
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</thead>
<tbody>
<tr>
<td>General</td>
<td>613-737-8502</td>
<td>613-739-6593</td>
</tr>
<tr>
<td>Civic</td>
<td>613-761-4333</td>
<td>613-761-5321</td>
</tr>
</tbody>
</table>

**Counselling**

**Professional Counsellors**

Sources for professional Counselling include:

<table>
<thead>
<tr>
<th>Source</th>
<th>Contact Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer Assessment Centre (CAC) Social Worker</td>
<td>613-737-8501, option 2</td>
</tr>
<tr>
<td>Hospital Social Workers while admitted to hospital</td>
<td>Phone your hospital’s main switchboard and ask for the Social Work department</td>
</tr>
<tr>
<td>Psychosocial Oncology Program (PSOP)</td>
<td>613-737-7700 ext. 70516, 70148 or 25200</td>
</tr>
<tr>
<td>Employee Assistance Program</td>
<td>Contact Human Resources at your place of employment</td>
</tr>
<tr>
<td>Community Care Access Centre</td>
<td>Ask your Case Manager 613-745-5525</td>
</tr>
<tr>
<td>Private Counsellors</td>
<td>See the yellow pages of your telephone book</td>
</tr>
<tr>
<td>Wellness Beyond Cancer Program</td>
<td>613-737-8899, ext. 70256</td>
</tr>
</tbody>
</table>
**Home Care Resources**

Sometimes when people have a diagnosis of a colorectal tumour, they require extra help at home. The following are some of the community services that may be able to assist. If you need help accessing any of these community services, contact your Social Worker.

**Community Care Access Centre (CCAC)**

Community Care Access Centre is funded by the Ontario Ministry of Health and Long-Term Care. CCAC can arrange in-home services such as nursing, physiotherapy, occupational therapy, nutritionist, social worker, speech therapist, and, in some instances, a home support worker to assist with personal care. If you meet the criteria for services, ask your nurse or physician to make that referral for you. You can also contact CCAC yourself. A CCAC case manager can meet with you at the Cancer Centre to talk about what you may need. Your case manager will see you if you are admitted to hospital and will reassess your needs before you are discharged.

<table>
<thead>
<tr>
<th>City or Region</th>
<th>Telephone</th>
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</thead>
<tbody>
<tr>
<td>Ottawa</td>
<td>613-745-5525, 1-800-538-0520</td>
</tr>
<tr>
<td>Leeds, Grenville Counties (Brockville)</td>
<td>613-345-0060, 1-800-267-4403</td>
</tr>
<tr>
<td>Lanark County (Perth, Smiths Falls, Carleton Place)</td>
<td>613-283-8012, 1-800-267-6041</td>
</tr>
<tr>
<td>Renfrew County (Pembroke, Renfrew, Arnprior)</td>
<td>613-732-7007, 1-888-421-2222</td>
</tr>
<tr>
<td>Stormont, Dundas, Glengarry, Prescott, Russell Counties (Cornwall, Winchester, Hawkesbury)</td>
<td>613-936-1171, 1-800-267-0852</td>
</tr>
</tbody>
</table>

Information about the Ottawa CCAC is also available on the Web site at www.champlain.ccac-ont.ca or phone 613-745-5525 or 1-800-538-0520.

Your hospital or Cancer Centre social worker can provide information on other community resources that provide services in the home.
- **Personal emergency response systems**, which link individuals to 24-hour emergency assistance. There is a cost for this system.

- **Meals on Wheels**: a program that delivers hot meals (some programs also have a frozen food plan) to individuals unable to prepare meals at home. There is a cost.

- **Senior Home Support Programs**: These agencies provide a variety of services, including homemaking, transportation, escorts, sitters, and friendly visitors. Every agency may not be able to provide all services. They have reasonable rates for home help and transportation.

- **Telephone Assurance Program**: The program provides a daily telephone call to senior citizens and handicapped people who live alone to make sure all is well.

**Ontario Works/Ontario Disability Support Program**

Ontario Works/Ontario Disability Support Program may be able to provide financial assistance for home support help and child care for people on either of these programs. Discuss this with your worker if you are already receiving these benefits.

**Private Homemaker Services and Nursing Registries**

If you wish to hire privately, or have extended health insurance that covers private-duty nursing; look in the yellow pages of the Telephone Directory under “Nurses”. If you plan to claim on your insurance, make sure you receive this prior to setting up.

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**Programs**

**Medical equipment**

**Assistive Devices Program (ADP)**

The Ontario Ministry of Health and Long-Term Care runs a program to help people who have physical disabilities get needed medical equipment and supplies such as: ostomy supplies, hearing aids, mobility devices, and communication devices. The amount of financial assistance given varies with the type of equipment.

*For Ontario residents who have a permanent colostomy, ileostomy, urostomy, ileal conduit or continent pouch reservoir, be sure to apply for an annual ostomy grant through ADP.*

For more information, call 1-800-268-6021, or visit: www.health.gov.on.ca.
**Loan Cupboards**

Many communities have loan cupboards that offer medical equipment, at a nominal charge, for limited time periods. For further information, contact a hospital or a Cancer Centre social worker or your local CCAC.

**Quality of life**

**Look Good … Feel Better Program**

The Look Good…Feel Better program offers free workshops about facial skin care, makeup and options for hair loss for women who are receiving cancer treatment. The workshop is offered twice a month. Pre-registration is required. If you wish to register or need more information, call 613-737-7700, ext. 10315.

**Victoria’s Quilts Canada**

Victoria’s Quilts offers handmade quilts to cancer patients. If you wish to request a quilt, call 613-843-9212 or visit the Web site @ www.victoriasquiltscanada.com.

**Smoking Cessation Programs**

Smoking is detrimental to your health. There are programs to help you quit.

- The University of Ottawa Heart Institute sponsors the Heart Check Smoking Cessation Program at The Ottawa Hospital, Civic Campus. This six-step program is for adults who require a combined medical and behavioral approach for quitting. For further information, phone 613-761-4753.

- Canadian Cancer Society’s Helpline provides information, advice, and support. There is no charge. For more information, phone 1-877-513-5333.

- For information on other programs, see the following table:

<table>
<thead>
<tr>
<th>City or Region</th>
<th>Facility</th>
<th>Telephone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ottawa</td>
<td>Public Health Info Line (Smoking Cessation Program)</td>
<td>613-580-6744 ext. 24179</td>
</tr>
<tr>
<td>Renfrew County &amp; District Health Unit</td>
<td>Health Info Line</td>
<td>613-735-8666 ext. 547 or 1-800-267-1097 ext. 547</td>
</tr>
</tbody>
</table>
Lodging and Transportation

Lodging

- The Maurice Grimes Lodge, Civic Campus of The Ottawa Hospital Cancer Centre, provides accommodation for out-of-town patients requiring assessment or treatment at the Cancer Centre. It is open Monday to Friday. For more information, phone 613-725-6328.
  Criteria for admission to the lodge includes:
  1. A registered Cancer Centre patient.
  2. Live more than 40 km outside of Ottawa.
  3. Be able to manage stairs.

- Rotel, 411 Smyth Road, provides inexpensive accommodation for out-patients, and for friends and relatives of in-patients at Ottawa area hospitals. For more information, phone 613-733-1412.

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

- Some hotels can also offer long-term accommodations. Contact PSOP for assistance.

Transportation to medical appointments

If family or friends are unable to assist you with transportation to medical appointments, the following are some options.

- Canadian Cancer Society volunteers may be able to provide transportation to Cancer Centre. Call your local Cancer Society Unit Office. For phone numbers, please refer to the table in the previous section on the Canadian Cancer Society.
**Canadian Cancer Society – Volunteer Driver Transportation Program**

<table>
<thead>
<tr>
<th>FIRST register by calling 613-723-1744 ext. 3626</th>
</tr>
</thead>
</table>

**Once you have registered, this is how you request a ride:**

Call 613-723-1744, ext. 3613 or 1-855-380-7484 ext. 3613 and leave all of the following information:

a. Your name and phone number.
b. Time/s, date/s, location/s of your cancer treatment/s.
d. Specify whether it’s a one-way drive to/from the Lodge/QCH or a round-trip.
e. Approximate time you will be ready to leave the hospital.
f. Are you bringing a medically required escort?
g. Are you bringing a walker or portable medical device (e.g., portable oxygen)?

**Lanark Leeds and Grenville:**

- To register call 613-267-1058 or 1-800-367-2913
- To book a ride call 613-723-1744 ext. 3613 or 1-855-380-7484 ext. 3613

**Renfrew County:**

- To register call 613-735-2571 or 1-800-255-8873
- To book a ride call 613-723-1744 ext. 3613 or 1-855-380-7484 ext. 3613

**S.D.G. & Prescott-Russell:**

- To register or book a ride, call 613-932-1283 or 1-800-669-4181

*The offices are closed on weekends and on statutory holidays—ensure that your travel arrangements are planned well in advance!* If you need to cancel a drive at last minute, call 613-723-1744, ext. 3610 ASAP.

At lease 3 business days’ notice is required or you may not be accommodated.

To book a trip the following:

<table>
<thead>
<tr>
<th>Monday</th>
<th>by</th>
<th>Wednesday by 3 p.m.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tuesday</td>
<td>by</td>
<td>Thursday by 3 p.m.</td>
</tr>
<tr>
<td>Wednesday</td>
<td>by</td>
<td>Friday by 3 p.m.</td>
</tr>
<tr>
<td>Thursday</td>
<td>by</td>
<td>Monday by 3 p.m.</td>
</tr>
<tr>
<td>Friday</td>
<td>by</td>
<td>Tuesday by 3 p.m.</td>
</tr>
</tbody>
</table>
Senior Home Support Programs may be able to provide transportation. There is a fee for this service. Check with the Senior Support Program in your local community.

If you are on the Ontario Works or Ontario Disability Support Program, contact your worker to determine if you are eligible for any financial assistance for transportation expenses.

For the Ottawa Region only:

Para Transpo provides special transportation for disabled persons who cannot board a conventional bus. For information on the application process, phone 613-244-1289. For bookings after you are registered, phone 613-244-7272.

Parking

Passes are available on daily, weekly or monthly basis. You may purchase your pass at any campus. If you cannot pay for parking, please contact your social worker.

For more information, contact:
The Ottawa Hospital: 613-737-5555, ext. 14281
Queensway Carleton Hospital: 613-721-4700, ext. 2679

For other hospitals, refer to your local telephone directory.

Physically disabled parking permits

The Ministry of Transportation of Ontario issues Disabled Parking Permits. The application can be picked up at any Private License Bureau or from a hospital, Cancer Centre social worker or PSOP.

Financial Information

A) Replacing Lost Income – Options for Patients
B) Replacing Lost Income – Options for Caregivers
C) Paying for Prescription Drug Cost
Loss of income

Whether you are living with cancer, or acting as a caregiver to a person with cancer, your income can be affected through unexpected expenses or time away from work. This section discusses the options.

A. Replacing lost income – options for patients

Some people who have cancer may be unable to continue to work either temporarily or permanently. The resulting loss of income can cause additional stress to an already stressful situation. Options you can explore to replace lost income are discussed below.

1. Taking leave from your place of employment
   Talk to Human Resources personnel at your place of employment about your coverage for sick leave, vacation leave, and short or long-term disability.

2. Employment Insurance Sickness Benefit
   This is a federal program accessed through Service Canada. Sickness benefits are paid up to 15 weeks.
   - **Eligibility:** 600 hours of insurable employment in the last 52 weeks, or since the start of the last Employment Insurance (EI) claim. Some exceptions are allowed.
   - **How Much:** Most claimants receive approximately 55% of their earnings. If you are a low-income family with children, you could receive a higher rate.
   - **When Benefits Start:** There is a two-week waiting period. However, if you get paid sick leave from your employer or group insurance benefits, you may not have to wait. The claim can take four to six weeks to process. Ontario Works (Social Services) may assist in the interim.
   - **To Apply:** Application forms are available from a Social Worker, PSOP (Coping with loss of income and other financial issues blue booklet) or at a Service Canada centre.

For more information on the Employment Insurance Sickness Benefit, contact your local office. For phone numbers and addresses, look in the blue pages of the telephone directory, or see their web page: www.servicecanada.gc.ca.
3. **Canada Pension Plan (CPP) or Quebec Pension Plan (QPP) Disability Benefit**

**CPP Disability Benefit**
The CPP Disability Benefit is a federal program run by Service Canada, Income Security Programs. Qualification for this program is based on medical need, not financial need.

- **Eligibility:** The applicant must be: between the ages of 18 and 65; have enough CPP contributions and have a disability that is “severe and prolonged”.
- **How Much:** Dependent on contributions to the plan. Call 1-800-277-9914 to determine the amount for which you might be eligible. Benefits are taxable.
- **Disabled Contributor’s Child Benefit:** Dependent children may be eligible for benefits if they are less than age 18 years, or are between 18 and 25 and attending school full time.
- **When Benefits Start:** Benefits start in the fourth month after you are deemed to have become disabled. You can receive up to twelve months of retroactive payments.
- **To Apply:** Application forms are available from a Social Worker or from Service Canada.

For more information on the Canada Pension Plan, call 1-800-277-9914, or see their Web page: www.servicecanada.gc.ca.

**QPP Disability Benefit**
The QPP Disability Benefit is similar to CPP Disability Benefits. If you have contributed only to the QPP, or if you contributed to both plans but reside in Quebec, you should contact: La Régie des rentes du Quebec at 819-772-3049, or 1-800-463-5185.

4. **Ontario or Quebec Social Assistance**

**Ontario Works**
This program is for people who need financial assistance to pay for day-to-day living expenses such as food, housing, and utility costs.

- **Eligibility:** It is based on a financial needs test. People applying for the Ontario Disability Support Program (ODSP) are allowed higher levels of assets.
- **How Much:** Depends on various factors. An Ontario Drug Benefit Card is provided.
Extra financial help is available for special dietary needs, medical transportation, dental and vision care for children, and the balance for medical equipment or prostheses not covered by the Assistive Devices Program.

To Apply: Phone the local office of Ontario Works.

<table>
<thead>
<tr>
<th>City or Region</th>
<th>Telephone</th>
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</thead>
<tbody>
<tr>
<td>Ottawa</td>
<td>613-560-6000 (ask for intake)</td>
</tr>
<tr>
<td>Lanark County (Smiths Falls, Perth, Almonte, Carleton Place)</td>
<td>613-267-4200, 1-866-878-9588</td>
</tr>
<tr>
<td>United Counties of Leeds/Grenville (Brockville)</td>
<td>613-345-4101, 1-800-267-8146</td>
</tr>
<tr>
<td>Renfrew County (Renfrew, Pembroke, Arnprior)</td>
<td>613-433-9846, 1-888-281-7526</td>
</tr>
<tr>
<td>Stormont, Dundas, Glengarry County (Cornwall)</td>
<td>613-933-6282</td>
</tr>
<tr>
<td>Prescott, Russell County</td>
<td>613-675-4642, 1-800-667-9825</td>
</tr>
</tbody>
</table>

**Quebec Social Assistance**

For information on financial resources, contact your local CLSC:

<table>
<thead>
<tr>
<th>City or Region</th>
<th>Telephone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hull Sector</td>
<td>819-770-6900</td>
</tr>
<tr>
<td>Gatineau Sector</td>
<td>819-561-2550</td>
</tr>
<tr>
<td>Aylmer Sector</td>
<td>819-684-2251</td>
</tr>
</tbody>
</table>
5. **Ontario Disability Support Program (ODSP)**

This program is based on medical needs as well as financial needs. An application for ODSP goes through a medical determination process by the Disability Adjudication Unit in Toronto.

- **Eligibility:** The applicant must “have a substantial health condition expected to last more than 1 year”. ODSP allows you to have more assets than what is allowed by Ontario Works.

- **How Much:** Depends on various factors. Amount received is higher than what is received under Ontario Works. An Ontario Drug Card is provided.

- **When Benefits Start:** Application process can take up to four months or longer. If you do not have other income, apply for Ontario Works in the interim.

- **To Apply:** Ontario Works and ODSP (for phone numbers, see 4 above).

For more information on ODSP, contact your local office, or see their Web page: www.mcss.gov.on.ca/CFCSEn/programs/IES/OntarioDisabilitySupportProgram/default.htm.

You can call ODSP directly:

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<th>City or Region</th>
<th>Telephone</th>
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<tr>
<td>Ottawa</td>
<td>613-234-1188</td>
</tr>
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<td>Lanark County</td>
<td>613-283-1165, 1-800-267-7911</td>
</tr>
<tr>
<td>Leeds-Grenville County</td>
<td>613-345-1200, 1-800-267-0834</td>
</tr>
<tr>
<td>Stormont, Dundas, Glengarry County</td>
<td>613-932-3381, 1-800-565-5374</td>
</tr>
<tr>
<td>Prescott, Russell County</td>
<td>613-632-1171, 1-800-565-4431</td>
</tr>
<tr>
<td>Renfrew County</td>
<td>613-735-1073, 1-800-267-0112</td>
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6. **Private Retirement Plans/CPP/QPP Retirement Plans**

Some people may choose to take early retirement. Talk to Human Resources personnel at your place of employment.
7. Other Sources of Financial Assistance

1. **Specific disability insurance**
   Check to see if you have disability insurance on your mortgage, your line of credit, etc.

2. **Essential Health and Social Support (EHSS)**
   In Ottawa, you can call Social Services at 613-560-6000, for financial assistance (for those of low income) and provide for:
   - Trillium Prescription Drug Plan Deductible
   - Dental and vision care for children and adults
   - Medical transportation
   - Mobility aids
   - Assistive Devices Program top-up
   Outside of Ottawa, call Social Services in your local municipality to determine whether they provide any financial assistance.

3. **Gas mileage**
   Patients who live 40 km or more from a Regional Cancer Centre are eligible for income tax deductions for their mileage. Patients who live 80 km or more from a Regional Cancer Centre can claim for accommodations and meals.
   To get information, visit the Canada Revenue Agency Web site www.cra.gc.ca/travelcosts..

4. **Disability Tax Credit (Revenue Canada–Taxation Office: Form T2201)**
   The Disability Tax Credit is a non refundable tax credit that reduces the amount of federal income tax you pay. Apply if you “have a severe and prolonged (at least 12 months) mental or physical impairment such that you are markedly restricted in your ability to perform one or more basic activities of daily living.”

B. Replacing lost income – options for caregivers

The following are some options to replace income lost due to caregiving responsibilities.

1. **Taking leave from your place of employment**
   Talk to Human Resources personnel at your work to determine if you are eligible for sick leave, personal leave or vacation leave.
2. **Employment Insurance Compassionate Care Benefits**
   This program provides a maximum of six weeks of benefits to “eligible workers who have to be absent from work to provide care to a family member who has a serious medical condition with a significant risk of death within 26 weeks (6 months)”. To qualify, you will need a medical certificate from the physician treating the gravely ill family member. You will also need a Record of Employment (ROE) from your employer. You can share the six weeks of compassionate care benefits with other family members so long as they also (1) meet the eligibility criteria and (2) apply for the benefits. For further information, 1-800-206-7218, or visit www.servicecanada.gc.ca.

3. **Tax Savings**
   For information on the Medical Expense and Disability Tax Credits and Attendant Care Expense Deduction, call 1-800-959-8281 or visit http://www.cra-arc.gc.ca/E/pub/tp/it519r2-consolid/README.html. PSOP is also available to help you look for resources in your community.

---

For more information on financial assistance, the Social Workers at The Ottawa Hospital will gladly assist you.

or

Although the Canadian Cancer Society does not provide financial assistance, it does have information on 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.


---

C. **Paying for prescription drug costs**

1. **Drug Insurance Plan**
   If you are covered by a drug insurance plan at work or privately, check any limitations that your plan might have, for example: partial or total coverage for drugs, maximum amounts each year, and exceptions to the coverage.
2. **Ontario Drug Benefit (ODB) Program**
   If you are an Ontario resident with a valid OHIP Number, you are eligible for coverage if you are: 65 years or older; receiving professional services under the CCAC program; receiving social assistance through the Ontario Works or Ontario Disability Support programs or a resident in a long-term care facility. There is a co-payment charge for each prescription.

3. **Trillium Drug Program**
   The Trillium Drug Program is designed to help individuals and families who spend a large portion of their income on prescription drugs. There is a deductible, based on the number of people in your family, and your family’s net income. To help you calculate your deductible, a chart is included in the application form. Once you have spent your deductible on prescription drugs, you will receive coverage for drugs listed on the Ontario Drug Benefit Formulary list.

   Sometimes Ontario Works (Social Services) can help with the deductible expenses. In Ottawa call 613-560-6000.

   You can apply for the Trillium Drug Program if your private insurance plan does not cover all the costs of your prescription drugs.

   Once you are eligible, there is a co-payment charge for each prescription.

   Application forms are available from your pharmacist, hospital or Cancer Centre Social Worker, from the Ministry of Health and Long-Term Care – Trillium Drug Program at 1-800-575-5386, or at www.gov.on.ca/health. For more information, see the Ministry of Health and Long-Term Care’s Web page: www.gov.on.ca/health.

4. **Questions on Reimbursement**
   For a guide to reimbursement for prescription medications in Canada, see the Web site: www.drugcoverage.ca.
Legal Issues

Every adult, regardless of age or health, should complete a Power of Attorney and make a will.

Power of attorney

A Power of Attorney is valid only when you are living. There are two types of Power of Attorney:

1. Continuing Power of Attorney for Property allows you to name a person(s) to manage your financial affairs on your behalf, under specified conditions.

2. Power of Attorney for Personal Care allows you to name a person(s) to make decisions about your personal care, should you become mentally incapable. Personal care includes decisions about health care, living arrangements, food, clothing, and safety. You can give verbal or written instructions, conditions, and restrictions to the person you have named. The most common type of instructions is to decline artificial life support in the event of a terminal disease.

When you are planning to do a Power of Attorney, make sure you ask the person you want to manage your affairs or make decisions on your behalf, to make sure they are willing to take on this responsibility. When you have done the paperwork, let this person know, and tell them where it is kept.

To do a Power of Attorney

1. Contact a lawyer

   OR

2. Go to the Ministry of the Attorney General Web site at www.attorneygeneral.jus.gov.on.ca/html/PGT/powkit.htm, or contact a hospital social worker, to obtain the “Ontario Ministry of the Attorney General” booklet which has information and the Power of Attorney forms. Using this booklet, you can do both the Power of Attorney for Property and Power of Attorney for Personal Care, at no expense.
**Will**

A *Will* takes effect only upon a person’s death. The purpose of a will is twofold. It states your wishes for the distribution of your assets, and it names the person (the executor) to carry out this distribution. There are two types of wills: “formal wills” and “holographic wills”.

1. *A formal will* is usually prepared by a lawyer, but a will form can be purchased from a stationary store. For this type of will, the client signs it in the presence of two witnesses (beneficiaries and their spouses should not be witnesses).

2. *A holographic will* is prepared without a lawyer’s help. To be binding, a holograph will must be entirely in the person’s handwriting, with no printing or typewriting anywhere on the document and must end with the signature of the testator (the person making the will). This type of will does not need to be witnessed, but a witness is a good idea.

When you are planning to write a will, make sure you ask the person you want to be your executor, to make sure they are willing to take on this responsibility. When you have done the paperwork, let this person know, and tell them where it is kept.

**Books**

**Books for colorectal cancer patients and their families**

Topics include information about what colorectal cancer is, treatment options, coping with side effects, etc.

- **ABC of colorectal cancer. 2nd ed.**
  Annie Young (ed)

- **Bowel cancer: the essential guide**
  Ian Eustace
  Need2Know, 2011 (ISBN 1861441347)

- **Colon & rectal cancer: from diagnosis to treatment. 2nd ed.**
  Paul Ruggieri.
Books for coping with cancer

These resources are to help you cope with the side effects of colorectal cancer and its treatment. Topics include pain, fatigue, nutrition, etc.

- **100 questions and answers about cancer symptoms and cancer treatment side effects**
  Joanne Frenkel Kelvin
  Jones & Bartlett, 2004 (ISBN 0763726125)

- The Cancer fighting kitchen: nourishing, big-flavor recipes for cancer treatment and recovery.
  Rebecca Katz.

- The Chemotherapy survival guide. 3rd ed.
  Judith McKay.

Books 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
health care team and how to handle the stress and challenges of care giving.

- **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)

- **Partners in healing: simple ways to offer support, comfort, and care to a loved one facing illness.**
  William Collinge.
  Trumpeter, 2008 (ISBN 9781590304150)

- **When a parent is sick: helping parents explain serious illness to children**
  Joan Hamilton.

**Books for palliative and end of life care**

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

- **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.**

- **Handbook for mortals: guide for people facing serious illness**
  Joanne Lynn and Joan Harrold

**Books on complementary therapies**

The Whole-body workbook for cancer: a complete integrative program for increasing immunity and rebuilding health.
Dan Kenner.

Pamphlet

Colorectal cancer: understanding your diagnosis
Canadian Cancer Society, 2011
Sexuality and Cancer
Canadian Cancer Society, 2012
Can also be printed from the Canadian Cancer Society’s Web site at www.cancer.ca or from the Cancer Information Service at 1-888-939-3333. Versions in other languages are available on the Web site.

Where to Start sheets for patients may be helpful:
www.ottawahospital.on.ca/wps/portal/Base/TheHospital/EducationAndLearning/PatientFamilyLibraries. For inquiries, please call 613-737-7777 ext. 70107.

CDs

Beginning your healing journey: an active response to the crisis of cancer (workbook and CDs)

Health journeys: cancer: guided imagery

The Ottawa Hospital patient and family libraries have a large collection of relaxation, meditation and guided imagery DVDs and CDs.

Web sites

Web sites for colorectal cancer information

Canadian Cancer Society – www.cancer.ca
Information about cancer treatment and support services in the community.
(English and French with some information in Chinese, Farsi, Punjabi and other languages.)
Cancer Care Ontario’s colorectal cancer screening information - www.cancercare.on.ca/index_colorectalScreening.htm.

Colorectal Cancer Association of Canada – www.ccac-accc.ca
Information, support and advocacy for patients and families. English and French.

Ontario Cancer Trials – 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 trials taking place in Ontario and find out more about what clinical trials are.

United Ostomy Association of Canada Inc. – www.ostomycanada.ca
This site is designed to provide information about UOAC and its services. There are explanations about what an ostomy is with some definitions and terminology, frequently asked questions about ostomies, and a list of manufacturers of ostomy products.

American Cancer Society – www.cancer.org

Colorectal Cancer Alliance (U.S) – www.ccalliance.org

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. Link directly to the colorectal cancer information page at www.nlm.nih.gov/medlineplus/colorectalcancer.html.

The Patient Information Web site of the American Society of Clinical Oncology (ASCO) – www.plwc.org
This Web site 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 Web site has been approved by American oncologists (cancer specialists).

The National Cancer Institute coordinates the U.S. federal government’s cancer research program. The Web site has information for patients and health care professionals on all aspects of cancer prevention, treatment, coping, etc. and includes information on cancer clinical trials taking place around the world. Link directly at: www.cancer.gov/cancertopics/types/colon-and-rectal.
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 the main cancer and treatment-related side effects such as fatigue, anorexia, pain, depression, neutropenia and cognitive dysfunction.

Web sites for Fertility Information

www.fertilehope.com
www.fertilehope.com
www.conceive.org

Web sites for palliative and end of life care

- **Ottawa Hospice Palliative Care Network** – 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 Web site 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)** – www.growthhouse.org/
  Growth House, Inc. Provides a portal to international resources for life-threatening illness and end of life care.

## Terminology / Glossary

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<td><strong>Abdomen</strong></td>
<td>The part of the body below the ribs and above the pelvis.</td>
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<td><strong>Adjuvant therapy</strong></td>
<td>Therapy given after surgery to reduce the chance that the cancer will come back.</td>
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<tr>
<td><strong>CEA (carcinoembryonic antigen)</strong></td>
<td>A blood test that may be used to monitor how treatment is working or may provide clues about whether cancer has returned. It is a tumour marker for colon cancer.</td>
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<td><strong>Chemotherapy</strong></td>
<td>Treatment with drugs for the purpose of killing cancer cells.</td>
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<td><strong>CHIPP</strong></td>
<td>Chemotherapy Home Infusion Pump Program.</td>
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<tr>
<td><strong>Clinical Trials</strong></td>
<td>A study done to determine whether or not a new treatment is safe and effective and how it compares to other treatments.</td>
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<td><strong>Colon</strong></td>
<td>Also called the large bowel, leads from the small bowel or intestine to the rectum and is about 150–180 cm (5–6 feet) long.</td>
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<td><strong>Complementary therapies</strong></td>
<td>Are often used to decrease symptoms and to enhance the quality of a person’s life along with conventional medical care.</td>
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<td><strong>Enterostomal Therapy (ET) Nurse</strong></td>
<td>A specially trained nurse who can help you by offering counselling prior to surgery and education on the care of a stoma after surgery, should you have one.</td>
</tr>
<tr>
<td><strong>Familial Adenomatous Polyposis (FAP)</strong></td>
<td>An inherited disease that causes the growth of numerous polyps in the colon and rectum with a very high chance of developing colorectal cancer.</td>
</tr>
<tr>
<td><strong>Hereditary Nonpolyposis colorectal cancer (HNPCC)</strong></td>
<td>An inherited disease that causes an increased risk of colorectal cancer and sometimes other cancers.</td>
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<td><strong>Minimally invasive surgical resection</strong></td>
<td>Also called a laparoscopic colon resection where tube-like instruments (trochars) are passed through smaller incisions and the abdomen is filled with air, which helps your surgeon view the abdominal cavity. A camera is passed through the tube that is placed in the incision near your belly button so the surgeon is able to work inside your abdomen without making a larger incision.</td>
</tr>
<tr>
<td><strong>Open approach surgical resection</strong></td>
<td>Traditional surgery where an incision is made in your abdomen.</td>
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<td><strong>Palliative care therapy</strong></td>
<td>Therapy given to control symptoms and improve quality of life, rather than to cure.</td>
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<td><strong>Polyp</strong></td>
<td>A growth found within the lining of the colon.</td>
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<td><strong>Radiation Therapy</strong></td>
<td>The use of high doses of x-rays to kill cancer cells.</td>
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<td><strong>Rectum</strong></td>
<td>Is the last 15 cm (6 inches) of the large bowel leading to the anus.</td>
</tr>
<tr>
<td><strong>Side effects</strong></td>
<td>Unintentional effects of a treatment on a patient.</td>
</tr>
<tr>
<td><strong>Stoma</strong></td>
<td>Opening in the abdomen that connects the colon to the outside of the body.</td>
</tr>
<tr>
<td><strong>Tumour</strong></td>
<td>An abnormal growth of tissue. Tumours may be either benign (not cancer) or malignant (cancer).</td>
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Donations

If you would like to contribute to Colorectal Cancer Information Guide and Personal Record’s ongoing distribution throughout the Champlain LHIN, you can send a donation to The Ottawa Hospital Cancer Foundation with this completed form.

**DONATION**

Please accept this donation in the amount of $ ____________ to use towards the funding of “Colorectal Cancer Information Guide and Personal Record”.

Name _______________________________________________________________

Street Address ____________________________________________ Apt. __________

City __________________________ Prov. ______ Postal Code _________________

Telephone ___________________________________________________________

Tax receipts will be issued for donations of $10 or more.
Tax receipt requested:  □ Yes   □ No