OVARIAN
CANCER
CANADA

UNDERSTANDING OVARIAN CANCER

A comprehensive patient guide

LAND ACKNOWLEDGEMENT

The many collaborators who shared their time and expertise to develop this guide live and work across Turtle Island, on the lands that we now collectively call Canada. We recognize and respect that these are the traditional lands of many diverse First Nations, Inuit, and Métis communities. We commit to doing all we can to encourage the culturally safe care of those affected by ovarian cancer, and to use our unique position as a health charity to respond to the calls to action outlined in the Truth and Reconciliation Commission. Specifically:

- We acknowledge that the current state of Indigenous health in Canada is the direct result of previous Canadian government policies.

- We support efforts to close the gaps in health outcomes between Indigenous and non-Indigenous communities, with particular consideration given to the availability of appropriate health services.

- We recognize, respect, and will work to address the distinct health care needs of all Indigenous peoples, specifically those with (or at risk for) ovarian cancer.

- We celebrate the value of Indigenous healing practices and encourage healthcare providers to consider how to safely, effectively, and respectfully integrate these practices into ovarian cancer care.

- We encourage healthcare providers to collaborate with Indigenous healers and Elders, when requested by Indigenous patients.

- We will engage in ongoing skills-based training in cultural safety, intercultural competency, and anti-racism, and call on all others in the scientific and clinical ovarian cancer community to join us.

Understanding Ovarian Cancer

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Ovarian Cancer Canada extends our thanks to the dedicated people with ovarian cancer, healthcare providers, and experts who helped develop this guide for the ovarian cancer community.

Ovarian Cancer Canada resources like this guide are enabled by the generosity of the community. We are sincerely grateful and welcome your support and participation.

DISCLAIMER

All information in this guide has been reviewed by qualified scientists and health professionals. To the best of *Ovarian Cancer Canada*'s knowledge, it is an accurate representation of the available information at the time of printing. As new knowledge about ovarian cancer continues to develop, *Ovarian Cancer Canada* cannot guarantee, and does not assume legal responsibility for the accuracy or completeness of the information contained herein. This guide is not a substitute for medical advice from a qualified medical or other health professional.

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TABLE OF CONTENTS

CHAPTER 01

CHAPTER 02

CHAPTER 03

CHAPTER 04

CHAPTER 05

CHAPTER 06

CHAPTER 07

TABLE OF CONTENTS CONT.

CHAPTER 08

CHAPTER 09

CHAPTER 10

CHAPTER 11

CHAPTER 12

CHAPTER 13

CHAPTER 14

APPENDICES

CHAPTER 01

INTRODUCTION

INTRODUCTION

Understanding Ovarian Cancer was developed to support and inform you throughout your ovarian cancer experience. Many people contributed to *Understanding Ovarian Cancer*, including those whose lives have been affected by ovarian cancer and who have experienced what you are going through now. Leading scientists, doctors, nurses, and other professionals also shared their valuable knowledge, expertise, and advice. Each chapter will walk you through information that these communities believe will be helpful to you as you navigate the ovarian cancer experience. Additional chapters within this guide provide support and information for those experiencing a recurrence. We hope this guide provides you with valuable support during a time when you may need it most.

When diagnosed with ovarian cancer, you may experience many different emotions. Uncertainty, shock, confusion, anger, and fear are some common reactions. Maybe you are experiencing these and many other feelings all at the same time. It can be difficult to think clearly when you are also asking yourself, “Why did this happen? “What is going to happen next?” “Am I going to be okay?” These are all understandable responses to being diagnosed with ovarian cancer.

There are others who have been through exactly what you are experiencing. The road ahead will not always be easy, and you may need to make difficult decisions, but there is information and support available. We are here for you. Please reach out to *Ovarian Cancer Canada* to discuss your unique questions and get the curated support that you need.

ABOUT *OVARIAN CANCER CANADA*

At *Ovarian Cancer Canada*, we reject the notion that ovarian cancer can't be eradicated. We are here to demand action, deliver change, and transform lives. We stand hand-in-hand with the people experiencing, affected by, or at risk of the disease.

We will not rest until women are able to live their lives freely, fully, and uninhibited by ovarian cancer.

THE MANY FACES OF OVARIAN CANCER

The information provided in this guide is intentionally general and will hopefully apply to as many people as possible. However, we all have our own unique experiences, preferences, and identities. Therefore, below you will find a list of resources that have been grouped based upon the unique needs and experiences of people in different communities. If there are specific resources or organizations that are not listed below, please connect with *Ovarian Cancer Canada* and let us know:

- Call: 1-877-413-7970
- Email: info@ovariancanada.org

Resources for People of Indigenous Ancestry

- National Collaborating Centre for Indigenous Health
- Aboriginal Health Access Centres
- Aboriginal Telemedicine
- Pauktuutit Inuit Women of Canada
- Ongomiizwin Indigenous Institute of Health and Healing
- First Nations Health Authority
- Sioux Lookout First Nations Health Authority
- Wabano Centre – Indigenous Centre for Excellence in Health

Resources for LGBTQIA+ communities

- Live Through This: The LGBTQ+ Cancer Charity
- National LGBT Cancer Network
- National LGBT Cancer Project
- FORCE: LGBTQIA+ and Cancer
- Cancer's Margins

Resources for people with neurodivergence

- The Autistic Health Access Project
- Thinking Person's Guide to Autism – Autistic with cancer: Six tips for navigating the medical system

Resources for people in remote + rural communities

- Virtual Hallway
- Ontario eConult Program
- Canadian Remote Access Framework for Clinical Trials

French language resources

- Un cancer en cadeau – Sophie Reis
- Guérir envers et contre tout : Le guide quotidien du malade et de ses proches pour surmonter le cancer – Carl Simonton & al
- Anticancer N. éd. -David Servan-Schreiber
- Rémission radicale, survivre au cancer malgré les pires pronostics, Kelly Turner
- Les Aliments contre le cancer » de Richard Béliveau (remarque ici que Richard Béliveau a écrit plus qu'un livre, si tu veux fouiller la chose)
- Faim de vivre » de Jérôme Ferrer (utile pour ceux qui accompagnent)
- Association Québécoise des personnes atteintes du cancer à Québec
- OncoQuébec

BE YOUR OWN BEST ADVOCATE

You are your own best advocate. We hope that you feel empowered to speak to your medical team about your individual needs, preferences, and experiences. This will help you feel more engaged and comfortable with the care you receive.

Depending on who you are, you may find some of the following conversation prompts helpful:

"I am not comfortable with some of the tests/procedures that you would like to do. Can we please discuss ways to address these discomforts?"

This prompt may be helpful for people who have experienced certain traumas, for example, a sexual assault. If you feel that your doctor is not able to provide you with safe and appropriate care, it is your right to ask to be referred to a different doctor, particularly one who specializes in trauma-informed healthcare.

"I do not identify as a woman. My gender identity is __________________________ and my pronouns are __________________________ . Please respect my gender identity as we move through this process together."

This prompt may be helpful for people who are trans, nonbinary, and/or gender queer. If you feel that your doctor is not able to provide you with safe and appropriate care, it is your right to ask to be referred to a different doctor, particularly one who specializes in LGBTQIA+ healthcare.

"Are there any culturally specific resources available to me? For example, an Indigenous Patient Navigator?"

This prompt may be helpful for members of communities who would like their traditional cultural knowledge respected and incorporated into their care.

"I learn best by ______________________________ . We have reviewed a lot of information today. Can you please summarize what we have discussed in a way that I will best understand?"

This prompt may be helpful for people with specific learning styles, and/or for people who are neurodivergent. If you learn best by listening, ask if you can audio record your appointment. If you learn best by reading, ask your doctor to write a short summary of your discussion. If you learn best by reflecting on information in a quiet space on your own time, tell your doctor that you will need some time to process the information before you can continue the conversation.

"I am worried about how long it may take, or how far I will have to travel, for my next appointment. Do you have access to e-referral, e-consult, or Virtual Hallway?"

If you live in a rural or remote area, there may not be a gynecologic oncologist in your region. This means you would have to travel to be seen by an ovarian cancer specialist. Many healthcare providers have access to electronic and virtual services, such as “e-consult”, “e-referral”, and “Virtual Hallway”. You can ask your doctor if they have access to these services that might facilitate an online appointment with a gynecologic oncologist.

> “Don’t dwell on or let statistics make you come to a conclusion about your prognosis. You are not a statistic but an individual.”
>
> –MARGARET

CHAPTER 02

WHAT IS OVARIAN CANCER?

A diagnosis of ovarian cancer can be very confusing and overwhelming. You likely have many questions. You may be asking yourself: “What is ovarian cancer?” “How does it spread?” “What does grade mean?” “What does stage mean?” This chapter will help you answer these important questions.

WHAT IS CANCER?

If you're like most people, there is a good chance you had never heard of ovarian cancer before your diagnosis. Before defining ovarian cancer, it is helpful to first understand what the word "cancer" means. Cancer is a collective term that describes a whole group of diseases in which abnormal cells divide out of control and can spread to other parts of the body. Typically, the cells in our body grow and divide in a controlled way, and as cells age and/or are damaged, they die and are replaced by new cells. These processes are needed to keep the body healthy. When a cell's genetic material is damaged or changed, mutations may be produced that affect the normal growth and division of cells. Cells that become cancerous can ignore signals to die when they are damaged and grow at a faster rate, resulting in the growth of a tumour.

WHAT IS OVARIAN CANCER?

Now that we understand the meaning of the word "cancer", let's look at ovarian cancer. Just like "cancer", ovarian cancer is an umbrella term that refers to a group of diseases. Ovarian cancers are cancers that originate at or near the ovaries. It is very important to understand that there are many types of ovarian cancers. If you do not know which type of ovarian cancer you have, be sure to ask your doctor.

WHAT ARE OVARIES?

Ovaries are small, almond-shaped organs and are an important part of the female reproductive system. Females have two ovaries, and they are found in the lower part of the abdomen, on either side of the uterus. The ovaries produce the female sex hormones (estrogen and progesterone) and produce eggs (ova).

Although the term, “ovarian cancer” makes it sound like all ovarian cancers originate in the ovaries, scientists and doctors have discovered that the majority of ovarian cancers actually begin in the fallopian tubes.

WHAT ARE THE FALLOPIAN TUBES?

The fallopian tubes are another important part of the female reproductive system. There are two fallopian tubes, and they connect the uterus to the ovaries. Following ovulation, the egg travels from the ovaries to the uterus through the fallopian tubes. These tubes are shaped like a funnel, with the narrow end attached to the uterus, and the wider end near the ovary. The wider (distal) end of the fallopian tube is covered in tiny finger-like projections called fimbriae, which are responsible for collecting the egg from the ovary and is where the most common type of ovarian cancer starts.

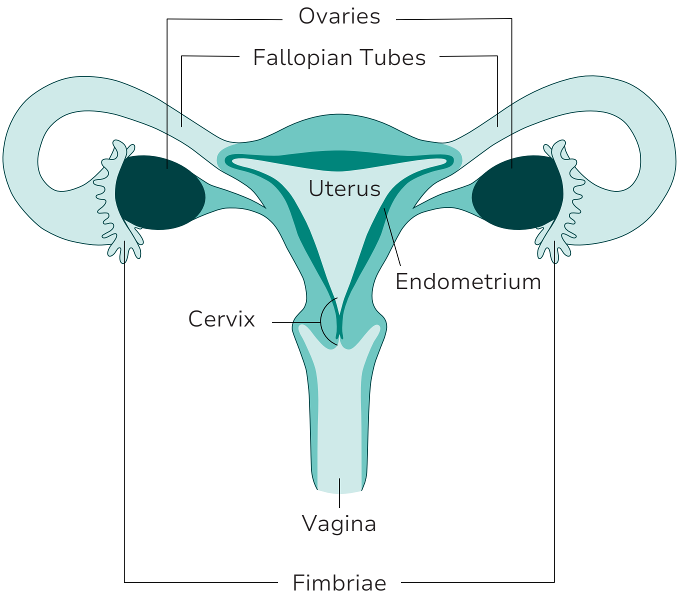


Figure 1: The female reproductive system

WHAT ARE THE DIFFERENT TYPES OF OVARIAN CANCERS?

Ovarian tumours can be benign (meaning that they are not cancerous) or malignant (meaning that they are cancerous). Malignant ovarian cancers can metastasize, meaning that they can spread to other parts of the body.

Ovarian cancers are many different diseases and are categorized into two broad groups, and further divided into types. Please see **Appendix 03**. These diseases are different from each other in many ways, including how they will respond to treatment. Again, this is why it is very important to understand which type of ovarian cancer you have. There are two broad categories of ovarian cancer:

1. Epithelial ovarian cancers
2. Non-epithelial ovarian cancers

WHAT ARE EPITHELIAL OVARIAN CANCERS?

Epithelial ovarian cancers are ovarian cancers that start in the cells that cover the lining (also called the epithelium) of the fallopian tubes or ovaries. These are the most common ovarian cancers, accounting for approximately 85-95% of all cases. There are many different types of epithelial ovarian cancers, all of which are their own unique disease:

1. **High grade serous ovarian cancer:** this is the most common type of epithelial ovarian cancer and accounts for approximately 70% of all cases. These cancers are typically diagnosed in later stages, for example in stage 3 or 4 (please see **pages 25–29** for information on staging).

   Most high grade serous ovarian cancers originate in the fallopian tubes. Therefore, the removal of the fallopian tubes is an effective preventative strategy, which is discussed in more detail on **pages 40–41**.

2. **Clear cell ovarian cancer:** this is the second most common type of epithelial ovarian cancer and accounts for approximately 10% of all cases. Clear cell ovarian cancer is associated with a history of endometriosis, which is a somewhat common and typically benign condition in which tissue similar to the lining inside the uterus (the endometrial lining) grows outside the uterus. This type of ovarian cancer is often diagnosed in early stages and therefore has a better prognosis.

3. **Endometroid ovarian cancer:** this is the third most common type of epithelial ovarian cancer and is similar to clear cell carcinoma because it is also associated with endometriosis and is typically diagnosed in early stages with a better prognosis. Endometroid ovarian cancer accounts for approximately 10% of all epithelial ovarian cancers.

4. **Low grade serous ovarian cancer:** despite the similar sounding names, low grade serous and high grade serous ovarian cancers are not linked. Low grade serous ovarian cancer accounts for approximately 5% of all epithelial ovarian cancers and typically affects younger people. It is characterized by slower growth and is more likely to be resistant to chemotherapy. Low grade serous ovarian cancer tends to be diagnosed in later stages, for example, in stage 3 or 4 (please see **pages 25–29** for information on staging).

5. **Mucinous ovarian cancer:** about 5% of epithelial ovarian cancer cases are mucinous tumours, which are large masses that are typically diagnosed at an early stage. The removal of these large masses is associated with a good prognosis.

6. **Undifferentiated:** in these cases, the cancer cells are undeveloped and therefore it is not possible to accurately classify ovarian cancer type.

WHAT ARE NON-EPITHELIAL OVARIAN CANCERS?

Non-epithelial ovarian cancers account for approximately 10% of all ovarian cancer cases. This class of ovarian cancers begin in the germ, sex cord and/or stromal cells of the ovary. Therefore, non-epithelial tumours are divided into two categories:

1. Germ cell tumours
2. Sex cord-stromal tumours

Similar to epithelial ovarian cancers, these categories can be broken down into further types that are distinct from one another. As these types of ovarian cancers are so rare, there are unfortunately no standard guidelines for clinicians to follow in these cases. However, these types of ovarian cancers tend to be diagnosed at earlier stages and therefore are associated with better outcomes.

WHAT ARE GERM CELL TUMOURS?

Germ cell ovarian cancers start in the germ cells, which are the cells in the ovaries from which eggs are formed. These tumours are more likely to involve just one ovary and tend to affect younger females in their twenties (but they can occur at any age). They are often found early and are very sensitive to chemotherapy, therefore the cure rate of germ cell ovarian cancer is high, even if the tumour has spread beyond the ovary.

There are three subtypes of germ cell ovarian cancers:

1. **Dysgerminoma:** this is the most common type of germ cell ovarian cancer and tends to grow very slowly. They are more likely to occur in adolescents and young females.

2. **Yolk sac tumour:** these are fast growing and are more likely to affect younger females (sometimes called "endodermal sinus tumours").

3. **Immature ovarian teratoma:** these are very rare and most likely affect females under age 20. In fact, these are the most common ovarian tumours in children.

WHAT ARE SEX CORD-STROMAL TUMOURS?

Stromal cell ovarian cancers, also called sex cord-stromal ovarian cancers, are very rare, accounting for 3-5% of all ovarian cancers. They begin in the cells that produce female sex hormones and that hold the ovaries together (the "structural cells"). As a result, the symptoms associated with stromal cell ovarian cancers are related to hormone production, including the appearance of facial hair, infrequent menstrual periods, menstruation after menopause, and a hoarse voice.

Sex cord-stromal tumours are often diagnosed early and treated with surgery. In some cases, however, chemotherapy may be given after the surgery.

Sex cord-stromal tumours can arise from the sex cord or stromal cells, and therefore, this category of ovarian cancers can be broken down even further:

- **Granulosa cell tumours:** these tumours can be either "adult-type" or "juvenile-type" and make up about 70% of all sex cord-stromal tumours (the adult-type is more common than the juvenile-type). A common symptom of granulosa cell tumours is abnormal bleeding. Most granulosa cells tumours are diagnosed early and treated with surgery. However, if the disease has spread (metastasized), then chemotherapy may also be used. Research has found that 95% of people with adult type granulosa cell tumours have a genetic mutation in the FOXL2 gene.

- **Sertoli-Leydig cell tumours:** these cells are named after the scientists who discovered them; Enrico Sertoli and Franz Leydig. Similar to granulosa cell tumours, these tumours tend to be found earlier and are treated with surgery. Some patients may also require chemotherapy. Research has found that about 60% of people with a Sertoli-Leydig cell tumor have a genetic mutation in the DICER1 gene, which also increases a person's risk for a type of childhood lung cancer called pleuropulmonary blastoma. Additionally, about 10-20% of people with a Sertoli-Leydig cell tumor have a genetic mutation in the FOXL2 gene.

BORDERLINE OVARIAN TUMOURS

These tumours are less likely to be cancerous (malignant) and tend to affect younger females. These tumours are only treated with surgery and tend to have a good prognosis. Borderline ovarian tumours have not been classified as ovarian cancer since 2000, however, in some cases, borderline ovarian tumours can evolve into low grade serous ovarian cancer.

ARE THERE ANY OTHER OVARIAN CANCERS?

Small cell carcinoma of the ovary (SCCO)

A very rare type of ovarian cancer, called small cell carcinoma of the ovary (SCCO), cannot be categorized into epithelial or non-epithelial ovarian cancer because it is unclear what type of cell this cancer originates from. This type of ovarian cancer accounts for only 0.1% of all cases of ovarian cancer. In fact, there are fewer than 500 cases of SCCO worldwide that have been documented in the scientific literature.

Small cell carcinoma of the ovary affects mostly younger women under age forty. The subtypes of SCCO include pulmonary, neuro-endocrine, and hypercalcemia.

The majority of people (60%) with SCCO also have above normal levels of calcium in their blood – a condition known as hypercalcemia. Most cases of SCCO are associated with mutations in the SMARCA4 or SMARCA2 genes.

At this time, there is no standard of care for SCCO, however, treatment tends to be very aggressive as this ovarian cancer is associated with poor outcomes. Given the toxicity that results from aggressive treatment and the poor outcomes of the treatment, scientists are investigating potential targeted treatment options.

In 2018, the International SCCOHT Consortium (small cell carcinoma of the ovary, hypercalcemic type) was founded to better understand this rare ovarian cancer and to ultimately improve outcomes: smallcellovarian.org/consortium.html

Mixed cell type tumours

In some rare cases, a person may be diagnosed with an ovarian cancer that originates from two or more types of cells. These cases are referred to as an ovarian cancer with mixed-cell types. This used to happen relatively frequently; however, research advancements have found that cases with a mixed-cell type are less common than originally thought. As scientists learn more about the features of the distinct ovarian cancer types, they can better distinguish (or recognize the differences) between them. Therefore, previously diagnosed cases of ovarian cancer with mixed-cell types may now be reclassified with our current scientific knowledge.

WHAT ARE THE “GRADES” OF OVARIAN CANCER?

The grade of a tumour refers to how abnormal the tumour cells look under a microscope. It is an indicator of how quickly a tumour is likely to grow and spread. The more the cancer cells look like normal cells, the more they will behave like normal cells. Knowing the grade of a cancer helps the medical team to determine how effective treatments may be.

- **Grade 1:** the cancer cells look similar to normal cells. These are referred to as "well differentiated cells". Grade 1 tumours tend to grow and multiply slowly and are usually the least aggressive.

- **Grade 2:** the cancer cells look less like normal cells. These are referred to as "moderately differentiated cells". These tumours tend to grow and spread faster than grade 1 tumours.

- **Grade 3:** the cancer cells have an abnormal appearance and do not look like normal cells. These are referred to as "poorly differentiated cells" or "undifferentiated cells". These tumours tend to grow rapidly and spread faster than grade 1 and 2 tumours.

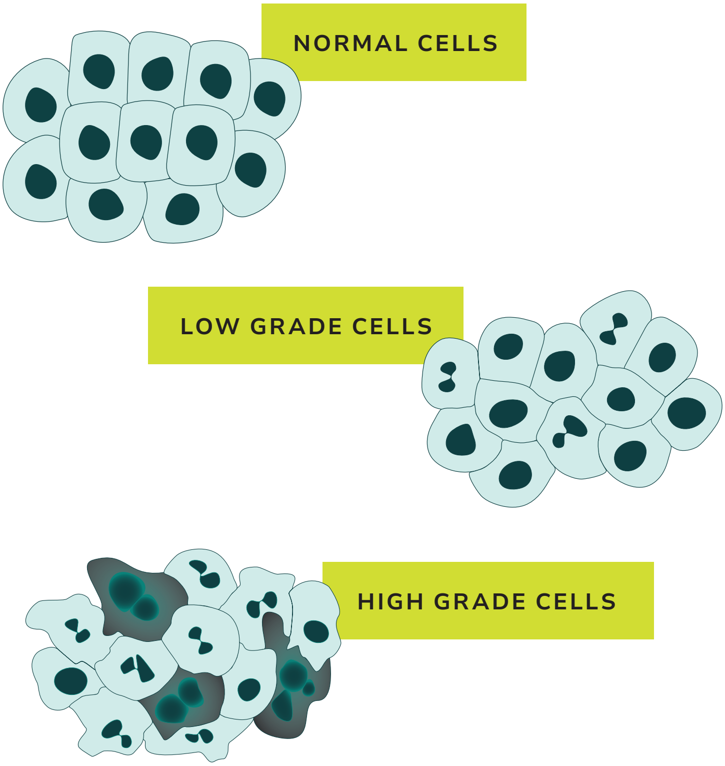


Figure 2: Diagram of normal cells, low grade cancer cells, and high grade cancer cells

WHAT ARE THE "STAGES" OF OVARIAN CANCER?

Staging is the process of finding out how much the cancer has spread in the body. If the cancer has spread, the stage describes how far it has spread. Each stage can also be assigned a corresponding letter to identify the spread of the cancer more specifically:

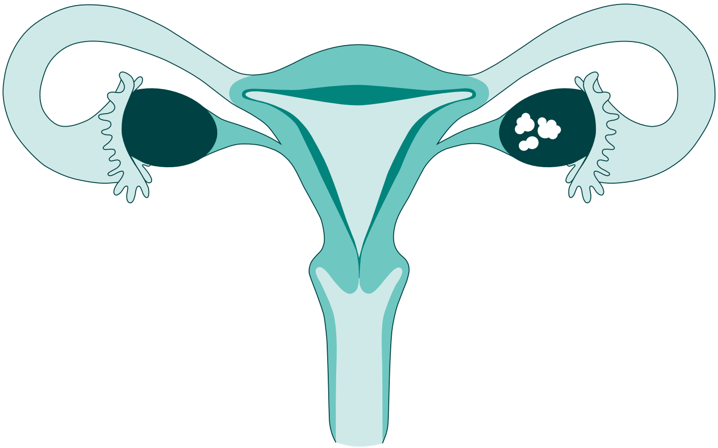


Figure 3: Stage 1 ovarian cancer

STAGE 1

The cancer is limited to one or both of the ovaries.

Stage 1A: the cancer is limited to inside one ovary. The capsule of the ovary (which is the ovary's outer layer) has not broken.

Stage 1B: the cancer is limited to inside both ovaries. The capsules of the ovaries have not broken.

Stage 1C: the cancer is limited to one or both ovaries with any of the following:

- A surgical spill has occurred, meaning that the ovary's capsule broke during surgery and the cancer spilled outside.
- Cancer cells are on the surface of one or both ovaries, or the ovary's capsule broke before surgery.
- Cancer cells are found in the ascites fluid or in the peritoneal washing (note: ascites refers to the buildup of abdominal fluid and peritoneal washings refers to a saltwater solution that is used during surgery to check for cancer cells).

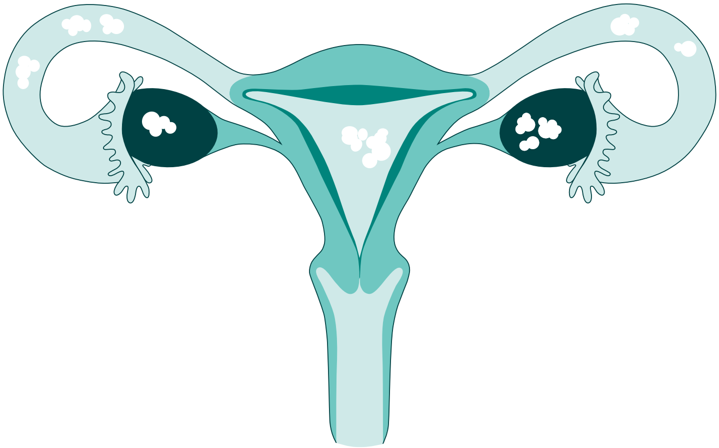


Figure 4: Stage 2 ovarian cancer

STAGE 2

The tumour has spread beyond the ovaries to nearby pelvic organs.

Stage 2A: the cancer has spread to the uterus and/or the fallopian tube(s).

Stage 2B: the cancer has spread to the bladder, colon, rectum, or other pelvic tissues.

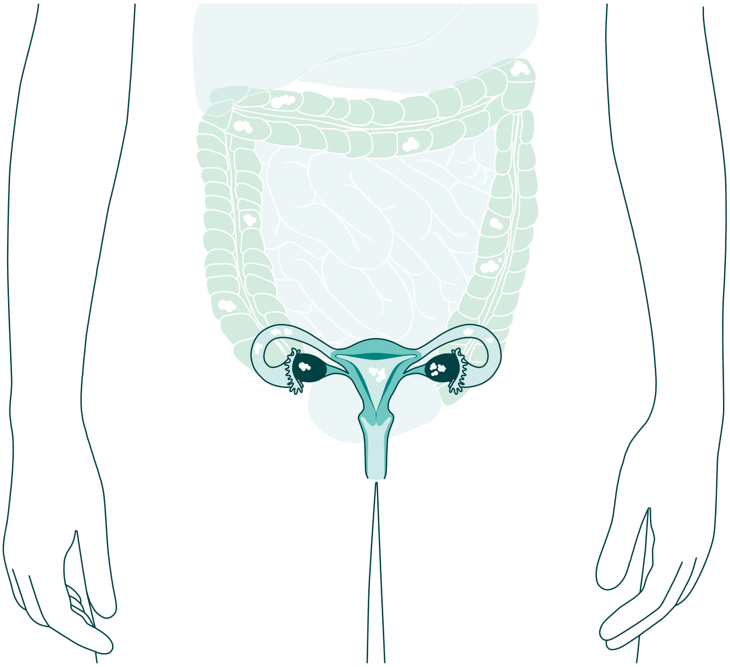


Figure 5: Stage 3 ovarian cancer

STAGE 3

The cancer has spread to the lining of the abdomen or to the lymph nodes.

Stage 3A: the cancer has spread beyond the pelvis, but growths are too small to see without a microscope and/or retroperitoneal lymph nodes (the lymph nodes in the back of the abdomen) are involved.

Stage 3B: the cancer can be seen on the lining of the abdomen, but growths are smaller than 2cm in diameter with or without lymph node involvement.

Stage 3C: cancer growths are larger than 2cm in diameter with or without lymph node involvement. Ovarian cancer is most commonly found at stage 3C.

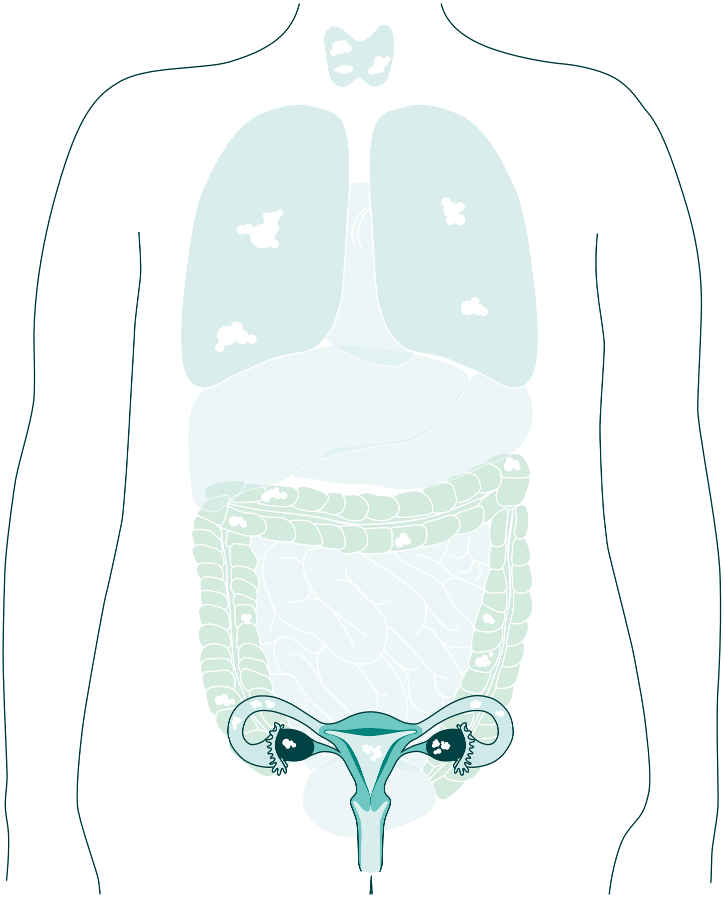


Figure 6: Stage 4 ovarian cancer

STAGE 4

The cancer has spread to the liver, lungs, or other organs.

Stage 4A: there is excess fluid around the lungs (also called pleural effusion) that contains cancer cells.

Stage 4B: there is liver, spleen, inguinal lymph nodes (in your groin) or other organ involvement.

Most ovarian cancers are found in stage 3C. It is important to ask your doctor to explain your stage to you, as other staging systems are also used.

HOW DOES OVARIAN CANCER SPREAD?

Cancer cells can spread from the ovaries to other tissues and organs. They may form new tumours (called, "seeding") on the peritoneum (the membrane lining the inside of the abdominal cavity and the surface of all organs in the abdomen) or the diaphragm (the muscle that separates the abdomen from the chest). Cancer cells can also spread to distant areas in the body through the lymphatic system and start new tumours.

Ovarian cancer is unique from other cancers because it does not need the blood or the lymphatic system to spread. Cancerous cells can “break off” from the tumour and spread through peritoneal fluid, which is the fluid in the abdominal cavity.

IS MY LIFE EXPECTANCY AFFECTED BY OVARIAN CANCER?

This is a very common question and there is no easy answer. There are many different types of ovarian cancer, and each person has very unique circumstances. Therefore, the answer to this question depends on many things, including the type of ovarian cancer you have, the grade, the stage, your age, your general health, your response to treatment, as well as many other factors.

Sometimes the statistics about ovarian cancer can cause some anxiety, but these statistics should be interpreted with caution.

We would advise that you do not Google ovarian cancer statistics, because these are simply averages and are not reflective of you or your unique case. *Remember, you are an individual, not a statistic.*

> “It is hard living with the knowledge of being a carrier (of a BRCA mutation)—but ignorance is not bliss.”
>
> –MARILYN

CHAPTER 03

WHY DID I GET OVARIAN CANCER?

There is no good or easy answer to this question. In fact, the majority of ovarian cancer cases are considered random. There is nothing that you did, or did not do, that caused your ovarian cancer. There is no singular, known cause of this disease.

WHAT RISK FACTORS ARE ASSOCIATED WITH OVARIAN CANCER?

Anyone born with ovaries and fallopian tubes (including women, some intersex people, trans men, and some nonbinary, gender fluid, and gender queer people) is at some risk of ovarian cancer. Like many diseases, ovarian cancer is the result of many different factors interacting together. Some additional factors that may increase a person's risk of developing ovarian cancer include:

Age

Risk for ovarian cancer increases as a person ages. As we age, cells become damaged, making it more likely for cancer to develop. This disease is more common between the ages of 50 to 79, although some rarer types of ovarian cancer are more common in younger females.

Genetic mutations or a family history of certain cancers

If you have a family history of ovarian, breast, prostate, pancreatic, uterine, or colorectal cancer on your biological mother's or father's side of the family, there is a possibility of a genetic mutation being passed from generation to generation.

Ethnicity

Some genetic mutations, including BRCA 1 and BRCA 2 mutations, are more common among certain ethnic groups, including people of Ashkenazi Jewish, French-Canadian, and/or Icelandic/Dutch descent. This does not mean that all people in these groups have a genetic mutation. The only way to know for sure is to get a genetic test.

Endometriosis
Risk for endometrioid and clear cell ovarian cancer may be higher if there is a history of endometriosis, which is a benign condition associated with growth of endometrial (lining of the uterus) tissue inside the ovary. However, reasons for the correlation have not been confirmed.

Number of lifetime ovulations
Ovulation refers to the period of time during the menstrual cycle when the egg is released from the ovary.

There is a theory, called the *incessant ovulation hypothesis*, that suggests that ovarian cancer may be related to the number of times a person has ovulated throughout their lifetime. The theory proposes that ovulation is an inflammatory event that may increase ovarian cancer risk, and therefore the more times a person ovulates, the greater their risk of ovarian cancer. The following are related to number of lifetime ovulations:

- Being pregnant and breastfeeding: ovulation stops during pregnancy and while breastfeeding, therefore pregnancy and breastfeeding may decrease one's risk of ovarian cancer.

- Using oral contraceptives (the birth control pill): birth control pills stop ovulation and therefore their use may decrease one's risk of ovarian cancer. Research shows that when used for 5 years or more, the birth control pill may reduce a person's risk of ovarian cancer by up to 50%.

- Age of first menstrual period: a person who had their first period at a younger age will ovulate more times throughout their life, which may increase their risk of ovarian cancer.

- Age of menopause: a person who experiences menopause at a later age will have ovulated more times throughout their life, which may increase their risk of ovarian cancer.

WHAT ROLE DO MY GENES PLAY IN MY OVARIAN CANCER?

Genetic testing is a crucial component of ovarian cancer care, determining treatment options and prevention opportunities for you, and prevention opportunities for your biological relatives. Therefore, it is important to ask your doctor for a referral for genetic testing.

About 25% of ovarian cancers are known to be hereditary, or “run in the family”. Everyone has two copies of each gene, one inherited from our biological father and one from our biological mother. If a parent has a genetic mutation, their child has a 50% chance of inheriting that mutation. It is very important to understand that genetic mutations related to ovarian cancer can be inherited from both your biological father and your biological mother and can be passed on to both male, female, and intersex children.

Genes tell the body’s cells what to do and make sure that the body functions properly. If these genes are altered, they will stop working properly. These alterations are called genetic mutations and can turn normal cells into cancer cells. You may hear some people refer to genetic mutations as “genetic variants” or “harmful variants”. The only way to know for sure if you have a genetic mutation is to get a genetic test.

There are two categories of genetic mutations:

1. **Germline (inherited):** A genetic mutation that is inherited from a biological parent is called a germline mutation and can be found in all the body’s cells. Germline mutations can be passed down from both the biological mother and biological father, so it is important to review the medical history on both sides of your family. Germline mutations can put you at risk for more than one type of cancer. For example, a BRCA mutation increases your risk of ovarian and breast cancer.

2. **Somatic:** A genetic mutation that develops during one's lifetime is called a somatic mutation and is found only in the cells of the tumour. Therefore, somatic mutations are not inherited. These types of mutations may be the result of a mistake that happens when a cell is dividing, or from certain environmental exposures (for example, smoking or UV rays).

Having an inherited genetic mutation does not mean that you have cancer. However, it may mean that you are at an increased risk for certain cancers.

The most common genetic mutations associated with ovarian cancer are in the BRCA1 or BRCA2 genes.

The two main hereditary syndromes associated with ovarian cancer are Hereditary Breast and Ovarian Cancer Syndrome (HBOC) and Lynch Syndrome.

Hereditary Breast and Ovarian Cancer Syndrome

HBOC increases a female's risk of both breast and ovarian cancer. HBOC is connected to germline (inherited) BRCA 1 and BRCA 2 mutations and accounts for most cases of ovarian cancers that run in families. Everyone is born with BRCA 1 and 2 genes. These genes are tumour suppressors, meaning that they prevent the body from developing tumours. If these genes cannot perform their normal function, our bodies are less able to protect us from developing cancer. A BRCA 1 mutation increases a female's risk of ovarian cancer to 39-50% by age 70. For a BRCA 2 mutation, the risk is 11-18% by age 70. For context, a person at average risk of ovarian cancer (meaning they have not inherited a related genetic mutation) is at a 1.4% lifetime risk of developing the disease. HBOC is most commonly associated with high grade serous ovarian cancer.

Lynch Syndrome

Lynch Syndrome, also known as hereditary nonpolyposis colorectal cancer (HNPCC), is an inherited condition that puts people at increased risk for certain types of cancer at a younger age, including but not limited to ovarian, colorectal, and uterine cancers. Mutations in the following genes are associated with Lynch Syndrome: MLH1, MSH2, MSH6, PMS2, EPCAM. Populations at risk for having Lynch Syndrome have:

- Three or more relatives with a Lynch Syndrome-related cancer, and one relative must be a first-degree relative (such as a parent, sibling, or child) of the other two.

- At least two generations with cancer (such as a parent and child).

- One or more cases of cancer diagnosed younger than age 50.

  Lynch Syndrome accounts for a very small percentage of ovarian cancers and is often associated with endometrioid and clear cell ovarian cancer. If you have one of these types of ovarian cancer, it is important to talk to your doctor about your risk for other cancers, including colorectal and uterine cancer.

Scientists are learning more about genetic mutations all the time. Currently, about 25% of all ovarian cancers are related to a genetic mutation (and the majority of these are due to BRCA mutations), but this number may rise as more genetic mutations are discovered.

You may have a genetic mutation that increases your risk of ovarian cancer, even if no one in your biological family has had ovarian cancer or other related cancers. This may be because you have a small family with few female biological relatives, or the mutation may be passed down through your biological father, biological grandfather, and so on. Some of your relatives may also have a genetic mutation, even if they have not developed cancer.

Be sure to talk to your doctor about getting a genetic test.

SHOULD I GET A GENETIC TEST?

The short answer to this question is "yes, you should get a genetic test if you have been diagnosed with ovarian cancer". A genetic test can provide you with very valuable information to help you make decisions about your care, and to help you and your biological relatives learn more about your risk for certain cancers and take action to reduce your risk, if appropriate.

Germline genetic testing is done using a blood or saliva sample. This test is looking for a mutation that you inherited from a biological parent. The genes that are tested for will vary across provinces and territories.

Genetic Mutation	Estimated Lifetime Risk
BRCA1	39-44% by age 70
BRCA2	11-18% by age 70
BRIP1	~6% by age 80
MLH1	20% by age 70
MSH2	24% by age 70
RAD51C	11% by age 80
RAD51D	13% by age 80

Figure 7: Estimated lifetime risk of ovarian cancer by genetic mutation and age

There are many possible results of a genetic test, and it is important to understand and be prepared for the possibilities.

Some possible genetic test results include:

1. Positive result
2. Inconclusive result
3. Benign variant
4. Negative result

Positive result
This may also be called a pathogenic mutation, meaning that a change in the DNA sequence of a gene has been detected that impacts the function of the protein and has been linked to an increased risk of a specific disease (e.g. ovarian cancer). In other words, a positive results means that you have inherited a genetic mutation that increases your risk of developing a certain disease.

Inconclusive result
This may also be called a variant of unknown significance (VUS), meaning that a change in the DNA sequence of a gene has been detected that impacts the function of the protein, but this change has not yet been definitively linked to a specific disease. In other words, a genetic mutation has been found, but scientists do not yet know if this genetic mutation causes any problems. It is important to note that the classification of genetic mutations change over time as scientists learn more. Therefore, many VUS are reclassified as benign, meaning they do not cause harm. However, some VUS may be reclassified as pathogenic, meaning they do cause harm. It is important to follow up with the clinic that performed your genetic test every few years to find out if your VUS has been reclassified as benign or pathogenic. At this time, the clinic will ***not*** follow-up with you if your VUS is reclassified.

Benign variant
This means that a change in DNA sequence was detected, but that this change has no impact on the function of the protein. In other words, a genetic mutation was found, but this genetic mutation is not known to cause any problems.

Negative
This means that no changes in DNA sequence were detected. In other words, no genetic mutations were found.

Most people with ovarian cancer will test negative for a related genetic mutation. This is because most ovarian cancers are not related to an inherited genetic mutation that we know about at this time. Remember, this may change as more people get genetic testing and scientists learn more. For this reason, *you may want to reach out to the clinic that performed your genetic test every few years to request to have your sample retested.*

If your doctor tells you that you are not eligible for genetic testing, there are options available to you. For example, there are private companies that do genetic testing. You would have to pay for these tests. There is also a major research project being conducted out of Women's College Research Institute in Toronto, Ontario called The Screen Project. At the time of printing this book (2023), The Screen Project is enrolling any Canadian over age 18 for BRCA 1 and BRCA 2 genetic testing. Participants in the Screen Project can also request testing of up to 43 additional genes at no extra costs. Some of these additional genes are related to ovarian cancer.

HOW CAN OVARIAN CANCER BE PREVENTED?

You may be thinking about your children and other biological relatives and wondering about their ovarian cancer risk. This is a very understandable and common concern.

There are ways to lower your risk of ovarian cancer:

- **Surgical:** a person's ovarian cancer risk can be reduced by having surgery to remove their ovaries and/or fallopian tubes before they develop ovarian cancer. There are two types of surgeries to reduce ovarian cancer risk:

1. **Risk-reducing surgery:** these surgeries are done for people who are at an increased risk of ovarian cancer due to an inherited genetic mutation. These surgeries are done with the explicit purpose of reducing ovarian cancer risk and involve the removal of both ovaries and fallopian tubes. This surgery is called a risk-reducing salpingo-oophorectomy (RRSO). This surgery will result in surgical menopause. If you are looking for support to deal with surgical menopause, the Menopause Foundation of Canada has many resources and can help you find a doctor that specializes in menopause.

2. **Opportunistic surgery:** these surgeries are done for people at average risk of ovarian cancer (anyone born with ovaries). This involves "jumping on the opportunity" of an unrelated surgery. For example, if a person is having pelvic surgery that is unrelated to ovarian cancer (for example, having their "tubes tied", or having a hysterectomy), they can ask to have their fallopian tubes removed in order to reduce their ovarian cancer risk (remember, the most common type of ovarian cancer starts in the fallopian tubes). This surgery is called an opportunistic salpingectomy.

- **Non-surgical:** a person's ovarian cancer risk can also be reduced by disrupting their ovulation (please see **page 34** for information on the incessant ovulation hypothesis). Ovulation can be disrupted in different ways, including with the use of birth control pills and with pregnancy/breastfeeding.

Additional genetic resources

- FORCE (Facing Our Risk of Cancer Empowered)
- The Canadian Association of Genetic Counsellors
- The Screen Project at Women's College Research Institute

> **“The night before my first chemo treatment, I barely slept. I had no idea what to expect and was terrified about how I was going to feel. Before my second treatment I was nervous but no longer scared.**
> **By my fourth treatment I felt like a pro.”**

–CARRIE

CHAPTER 04

HOW IS OVARIAN CANCER TREATED?

After receiving your diagnosis, you may feel overwhelmed by the amount of information about your treatment and potential side effects. It is okay to feel scared and confused. This chapter will guide you through treatment-related information and will include some important questions to ask your medical team.

HOW IS OVARIAN CANCER TREATED?

There is no one-size-fits-all treatment for ovarian cancer. The treatment is going to depend on numerous factors, including (in no particular order):

- Grade of ovarian cancer
- Stage of ovarian cancer
- Type of ovarian cancer
- First time diagnosis vs recurrence
- Your general health
- Your other medical conditions
- Any genetic mutations associated with ovarian cancer
- Your personal values and preferences
- Your age

The goal of primary treatment (the first time a case of ovarian cancer is treated) is to cure the cancer. If the cancer recurs (if it comes back), then it can no longer be cured. In those cases, the goal of treatment would be to manage the cancer as a chronic disease.

Your healthcare team will likely offer you one or more treatment options. Very broadly, the standard approach to ovarian cancer treatment will include surgery to remove as much of the cancer as possible, and chemotherapy.

As previously stated, treatment plans will vary based on the type of ovarian cancer, stage, grade, and many other important factors. In the majority of cases, the surgery takes place first, followed by chemotherapy—this is called adjuvant chemotherapy. The purpose of the chemotherapy that is done after the surgery is to kill any cancer cells that may have been missed during the surgery. In some cases, chemotherapy is given before the surgery—this is called neoadjuvant chemotherapy. The purpose of neoadjuvant chemotherapy is to reduce the size of the tumour and/or the number of cancer cells so that the surgery can be more effective.

Please see **Chapter 06: What can I expect during my follow-up care?** for more information about how you will be monitored to see if the cancer comes back.

SURGERY

Surgery is very important in helping your medical team better understand your situation. Firstly, surgery will help to identify whether the mass is cancerous (malignant) or not cancerous (benign). After the tumour is removed, a pathologist will look at it underneath a microscope to confirm if it is in fact ovarian cancer, and if so, which type and grade. Surgery is also important for staging the cancer, which involves determining how far the cancer has spread. You can read more about ovarian cancer types, grades, and staging in **Chapter 02: What is ovarian cancer?** All of this information will help you and your medical team determine the best treatment for you.

It is very important that the surgery is performed by a gynecologic oncologist. A gynecologic oncologist is a medical doctor with five years of postgraduate training in obstetrics and gynecology plus an additional two years of cancer training. When surgery is performed by a gynecologic oncologist there is a higher chance that the ovarian tumours will be completely removed, which can result in a longer time to possible recurrence and increased survival.

If you have not seen a gynecologic oncologist, ask to be referred to one as soon as possible. If you have difficulty finding a gynecologic oncologist, contact the Society of Gynecologic Oncology of Canada:

- Call or text: 1-888-496-3662
- Email: enquiry@gynecology.ca
- Website: gyneoncology.ca

WHAT WILL HAPPEN DURING SURGERY?

The surgery will depend on which organs and tissues are affected by cancer. Depending on how far the cancer has spread, the surgical team will do one or more of the following:

- **Unilateral oophorectomy:** the removal of one ovary.
- **Bilateral oophorectomy:** the removal of both ovaries.
- **Unilateral salpingectomy:** the removal of one fallopian tube.
- **Bilateral salpingectomy:** the removal of both fallopian tubes.
- **Hysterectomy:** the removal of the uterus.
- **Omentectomy:** the removal of the omentum, which is a layer of fatty tissue that covers the organs in your abdomen, including your stomach and intestines (ovarian cancer frequently spreads to the omentum).
- **Lymphadenectomy:** the removal of lymph nodes (lymph nodes are small structures found throughout the body that are part of the immune system).

- **Total abdominal hysterectomy and bilateral salpingo-oophorectomy (TAHBSO):** the removal of the uterus, cervix, both fallopian tubes, and both ovaries. TAHBSO is performed when there is suspicion that the ovarian cancer is advanced.

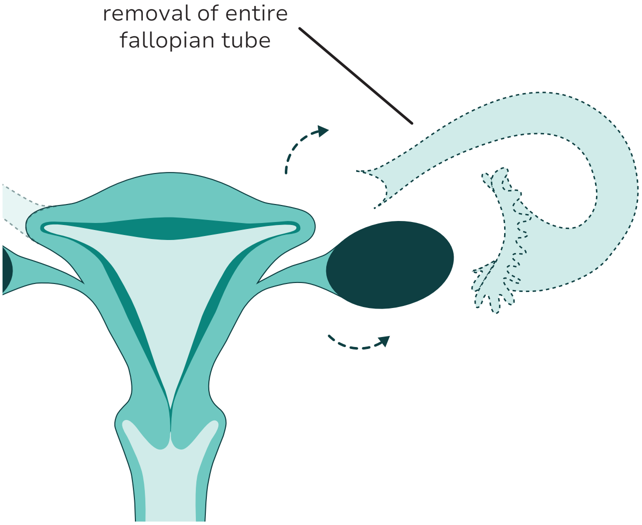


Figure 8: Diagram of salpingectomy

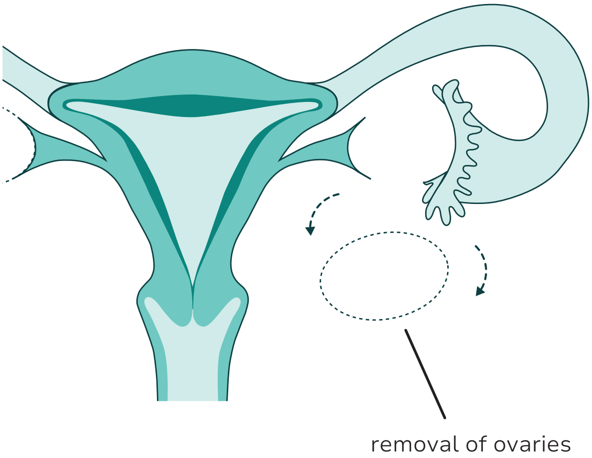


Figure 9: Diagram of oophorectomy

Another term that your medical team may use is debulking surgery (also called cytoreduction). This refers to the process of surgically removing as much of the cancer as possible.

In some cases, the surgical team may put a flexible tube, called a “port” into the abdominal wall so that chemotherapy can be administered directly into the abdominal cavity. This is called intraperitoneal (IP) chemotherapy. You can read more about IP chemotherapy on **pages 55**.

WHAT CAN I EXPECT LEADING UP TO MY SURGERY?

Before surgery, you will have a physical examination, which will include a complete pelvic exam. During this exam, the doctor will insert one finger into the vagina, and one finger into the rectum. You will also have blood tests done to evaluate your general health (for more information on blood tests, please go to **pages 61–65**). This will include a complete blood count (CBC) and a CA125 blood test. The CA125 blood test looks for a protein in the blood that is sometimes elevated in people with ovarian cancer. It is also possible that your doctor will have you get a chest x-ray, a pelvic ultrasound, and a CT scan. All of these tests can help your medical team better understand your unique case before going into surgery so that they are well prepared and able to provide the best possible care.

It is also possible that someone on your medical team will send part of your tumour sample to a tissue bank. A tissue bank is a central place where human tissues are stored and available for scientists to use in their research, for decades to come. By studying these tissues, scientists can better understand ovarian cancer and how it can change over time, and learn more about ways to prevent, diagnose, and treat the disease.

When preparing for your surgery, you will not be allowed to eat or drink after midnight the night before. You may also be told to use a “bowel preparation”, which will empty your colon. This process will give you diarrhea. Your medical team will give you instructions about what you will need to do. Be sure to ask questions if you do not understand their instructions.

The information provided about surgery so far is meant to be general. It will be important to ask your medical team questions to help you better understand your specific situation leading up to surgery.

Some of these questions could include:

"What will surgery involve?"

"How will I be told the results of my surgery? When can I expect this information? Who will deliver this information?"

"What are the risks of this surgery?"

"What will be done to minimize these risks? What will you do? What can I do?"

"What kind of scar can I expect? How can I care for my scar?"

"Will I have a colostomy or ileostomy bag after the surgery? Or a catheter? If so, how long will I have these for? How will I care for them? What can I expect?"

"How will I feel after surgery?"

"How long will I be in the hospital for?"

"What will my recovery be like at the hospital? What about after I go home?"

"Should I arrange for homecare? For example, a community nurse or a personal support worker? If so, how can this be arranged?"

"How will we manage my pain? Will you be prescribing medications?"

"If someone is waiting for me to come out of surgery, where can they wait? How will they be notified when I am out of surgery? How soon after the surgery can they be with me?"

WHAT CAN I EXPECT AFTER MY SURGERY?

After the surgery, it is important to ask your medical team questions to better understand your specific situation. Some questions that you can consider asking include:

"Do I have ovarian cancer? If so, where was it found and what type of ovarian cancer is it?"

"What did you remove during surgery? How will this affect me?"

"What is the grade and stage of the cancer?" (note: it may take some time for the pathology results to come back)

"What is next in terms of treatment? What can I expect?"

"What changes in my body can I expect in the upcoming weeks and months? What is safe for me to do and what should I avoid?" (for example, going to work, physical activity, sexual activity, driving, etc.)

"What are some possible complications of the surgery that I should be aware of? How can I monitor for these complications? What should I do if I notice a complication?"

"What side effects can I expect with the pain medications you have prescribed, and how can I best manage these side effects?" (Common pain medications may cause constipation.)

"Are there any foods that I should try eating after surgery? Are there any foods that I should avoid?"

Recovery from surgery may take 6-8 weeks and will depend on many factors, including your general health going into the surgery, the extent and complexity of the surgery, and how much rest you are able to get. Most people will go home within one week following their surgery, but if there are complications such as an infection, you may be in the hospital longer.

There are some inherent risks with all surgeries, including surgery for ovarian cancer. Some of these side effects may include:

- Vaginal bleeding or discharge
- Urinary frequency and/or urgency
- Problems with your incision
- Lymphedema (Swelling that results from the removal of lymph nodes. The regular flow of lymph fluid is disrupted and therefore the fluid builds up in the soft tissues of a limb, such as the leg.)
- Gastrointestinal problems
- Fatigue
- Pain
- Swelling
- Rash or itching
- Decreased libido/interest in sex
- Increased feelings of stress, anxiety and/or depression

Be sure to speak with your healthcare team if you are experiencing any of these side effects.

Try	Avoid
Try to get lots of rest.	Avoid heavy lifting.
Try to take time off work, if possible.	Avoid sexual intercourse. Talk to your doctor/nurse about when it is safe to resume having intercourse.
Try to move around, if possible. For example, walk short distances when you feel able.	Avoid driving as pain from the surgery may limit your ability to move and react.
Try speaking with a counsellor about what you are going through.	Avoid germs as much as possible, as your risk for infection is increased following surgery.
Try to do things that bring you comfort, like watching a favourite movie, reading your favourite book, listening to calming music, or calling an old friend.	Avoid pushing yourself too hard. It is important to let yourself physically and emotionally recover from surgery.
Try connecting with *Ovarian Cancer Canada* for support and to meet other people experiencing ovarian cancer (info@ovariancanada.org).	

Figure 10: Suggestions for self-care post-surgery

HOW DO I TAKE CARE OF MYSELF AFTER SURGERY?

As much as you can, try to prioritize self-care following surgery. It is important to be gentle with yourself and consider activities that might help you feel better, and some that you may want to avoid, including the items in Figure 10.

Talk to your healthcare team about how to manage any side effects that you are experiencing. They may have specific recommendations that will be helpful for you, or they may be able to prescribe certain medications, recommend physiotherapy, refer you to counselling for emotional support, and so on.

For many, the phase of treatment before and after surgery happens very quickly, and many find it confusing and overwhelming. This is very normal. Sometimes, people wake up from their surgery to find out they have ovarian cancer, and they are still dealing with the effects of the surgery. This can be a time of information overload. It is a good idea to have someone with you during this time – at appointments, in the hospital after surgery, and at home during recovery. This support person can help you communicate with your medical team and help you process and understand all the information that you are being given. They can also help you with practical things, such as helping you move around, helping you with your medications, running errands, preparing meals, and so on. This person can be a family member or a friend. There are also supports available in communities across the country that can help with these types of things. These supports will have different names depending on where you live, so you can start by asking your medical team, or searching online for "community care support services" in your area.

Additional chapters in this guide providing tips and information on this topic include:

Chapter 01: Introduction
Chapter 07: Who are the members of my healthcare team?
Chapter 08: How do I tell people that I have cancer?
Chapter 09: What supports are available to me?
Chapter 10: What does cancer survivorship mean?
Chapter 13: Asking the tough questions
Chapter 14: Conclusion

CHEMOTHERAPY

Chemotherapy literally means “to treat disease with chemicals”. There are many different ways to use chemotherapy to treat ovarian cancer. This will depend on the type of ovarian cancer, the grade, how far it has spread, and your general health. In some cases, chemotherapy may not be needed because the cancer was caught at an early stage and the surgeon is confident that they removed all of the cancer during surgery.

Chemotherapy, or “chemo”, is the use of one drug or, more commonly, a combination of drugs that target and kill fast growing cells throughout the body. This includes both cancer cells and normal cells. Chemo drugs can be given in different ways:

- **Intravenously (or by “IV”):** the chemo drugs are injected into a vein so that they can circulate through the blood stream. Many of the chemotherapy drugs that are used to treat ovarian cancer are given into a vein using a catheter while you are in the chemotherapy treatment room. In some cases, a special temporary or longer-term device may be required, called a Hickman Port-a-Cath for IV chemotherapy. This device is placed under the skin on the upper chest, where it connects to a major vein. Its advantage is that it can be used for many treatments over several months.

- **Intraperitoneally (or by "IP"):** the chemo drugs are given directly into the abdomen through a plastic tube that would have been put in during surgery. This method concentrates the chemotherapy drug on the cancer cells on the abdominal lining, allowing the drug to get into the bloodstream from the abdomen. IP chemo is most often used for stage 3 and 4 ovarian cancers.

- **Orally (by mouth):** the chemo drugs are given in the form of a tablet that you take by mouth.

Chemotherapy affects the whole body, rather than just one part of it. Therefore, you may hear it referred to as a "systemic therapy", meaning that it affects cells throughout your body. A "course" of chemotherapy treatment typically lasts several months and involves a series of "cycles". A cycle of chemotherapy refers to the time between rounds of treatment. Therefore, during a cycle, which is usually about 3 weeks long, you will have some days of chemotherapy, and then a break. Then you will be given another round of chemotherapy. Don't be alarmed if your chemotherapy cycle is postponed due to "low blood counts". Your healthcare team will monitor your blood throughout chemotherapy to ensure you are well enough to continue. For more information on how you will be monitored during chemotherapy, please go to **pages 61–65**.

The duration of your chemotherapy will depend on many factors, including your type of ovarian cancer and how you are responding to the treatment.

WHAT ARE THE CHEMO DRUGS USED TO TREAT OVARIAN CANCER?

Chemotherapy drugs stop or slow the growth and spread of cancer cells and can shrink the size of a tumour. They do so by interfering with their growth and division. Chemotherapy to treat ovarian cancer typically includes a combination of two different chemo drugs. The first chemo drug is usually a platinum product, either “cisplatin” or “carboplatin” (platinum is a metal and is an important ingredient in many anti-cancer drugs. It binds to DNA to prevent the cancer cells from dividing and causes them to die).

The second chemo drug is usually a taxane, either paclitaxel (brand name: Taxol) or docetaxel (brand name: Taxotere). A taxane is a type of drug used to treat cancer by preventing the division of cells.

Other, less commonly used chemotherapy drugs used to treat ovarian cancer include gemcitabine (brand name: Gemzar) and liposomal doxorubicin (brand name: Caelyx).

HOW CAN I PREPARE FOR CHEMO?

Before starting chemotherapy, you may want to fill your kitchen with some foods that are easy to digest, for example, eggs, soup, applesauce, and cottage cheese. It’s likely that you will not feel up for grocery shopping during your chemotherapy treatment. You might also consider “batch cooking” before your chemotherapy starts. This would involve making meals that can be frozen in large quantities, for example, soups and chilis. This will provide you with quick and easy meals when your energy is low. If people in your life ask how they can help, don’t be afraid to ask them for freezable meals! For more information on nutrition, please read **Chapter 09: What supports are available to me?** on **pages 135–138**.

When your chemotherapy treatment schedule is set up, you will be told the dates, times, and location. Your schedule is usually determined by the chemotherapy drug(s) you will receive. Some are given once every three weeks, while others are given more/less frequently. Your schedule may also depend on the days of the week that the ovarian cancer treatment clinic is open.

Before starting chemotherapy, it is a good idea to ask your medical team about what to expect. This may help you feel less nervous and more comfortable and prepared. Many cancer centres offer education sessions about chemotherapy that will provide helpful information and answer many of your questions. Be sure to ask your medical team about these sessions.

You likely have many questions about your chemotherapy treatment that are unique to you. Be sure to write them down as soon as you think of them. Here are some common questions that may come up:

"How flexible is my chemo schedule? Will I be able to attend holidays or special events?"

"Who will give me the treatment? Who will be with me? What are their roles?"

"May I bring family/a friend to my chemotherapy treatment?"

"Will I have to wait at the treatment centre before or after my treatment?"

"Will someone need to drive me home from treatment?"

"How will we know if the chemotherapy is working?"

"How will we know if we need to pause/take a break from chemotherapy?"

"How often will I see my oncologist during chemotherapy?"

"Will I be able to work or travel during my chemotherapy?"

"How will I feel while receiving the chemotherapy drugs? What about in the next few hours? Days? Weeks?"

"What are the most common side effects and how can I manage them?"

"What do I do if the side effects become unbearable? Who do I talk to? What options would be available?"

You may find it helpful to keep a record of your treatment schedule and what you are experiencing. Information you may consider recording includes:

- Which treatment cycle it was (first cycle, second cycle, etc.).
- The date and time of the treatment.
- The type of treatment you received (for example, the names of the chemotherapy drugs).
- What you experienced during treatment, and in the following hours, days, and weeks.
- Medications (include the dose) you take to manage your side effects, and how often you take them.

Recording this information may help you feel more comfortable going into each cycle of chemotherapy, as you will learn more about how you are responding to treatment and what to expect. For many, it is the unknown that causes anxiety.

A common tip is to drink a large amount of clear fluids after chemotherapy in order to stay hydrated and to flush out some of the toxic effects of chemotherapy. Drink more than you usually do the day before and the day after your chemo treatment. If you find drinking enough water challenging, speak with your healthcare team for other options to stay hydrated.

Side Effects	Tips for Management
Nausea	Take your prescribed anti-nausea medication, have small meals throughout the day, get lots of fluids, and sit up for an hour after eating.
Reflux	Take liquid anti-acids (30 minutes after meals and at bedtime), eat small/frequent meals, avoid tight clothing, sleep with the head of your bed raised 4-8 inches, sleep on your right side.
Constipation	Drinks lots of fluids (if you are having trouble getting enough water, try popsicles, broths, etc.), eat foods containing fibre, get some light exercise after meals, try to eat at the same time each day.
Brain fog	Use apps and calendars to track important information, like upcoming appointments, etc. Bring someone with you to your appointments who can take notes. Other strategies to address brain fog include meditation, cognitive exercise (for example, puzzles), and physical activity.
Aches & pains	Use hot/cold packs, stay active, get a massage, and/or take medications like acetaminophen (Tylenol) and ibuprofen (Advil).
Peripheral neuropathy (weakness, numbness, pain in the hands/feet)	Hold onto a cold water bottle during chemotherapy, talk to your doctor about medications, and/or find ways to avoid injury (consider a cane, check water temperature with your elbow, wear mittens in the winter, make sure there are no pebbles in your shoes, wear cotton socks, check feet for irritation, sores).

Side Effects	Tips for Management
Fatigue	Balance rest with activity (short rests are better than long rests), try to keep a normal sleep routine, drinks lots of fluids, and eat many small meals each day.
Low blood counts	Try to eat a well-balanced diet (including your comfort foods!), and try to avoid injury and germs.
Hair loss	Use a soft hairbrush and mild shampoos (baby shampoo), cut hair short before hair loss, use a satin pillowcase, consider if a wig/head covering is right for you. For more hair loss support, visit LGFB.ca ("Look Good Feel Better") Cold caps may also be an option for you. These are hats/helmets that you can wear during your chemo treatments that narrow the blood vessels in your scalp, therefore protecting your hair follicles from the chemo drugs. Talk to your oncology team to learn more about cold caps and to find out if they are an option for you.
Sexual changes	Watch *Ovarian Cancer Canada*'s "Speaker Series" titled "The 411 on sexual changes after cancer". You can find this video on our website in our library of education and support videos. Some cancer centres have sexual health and rehabilitation clinics that provide support and resources in the areas of sexuality, hormones, intimacy, and body image. Ask a member of your healthcare team to refer you to this clinic.

Figure 11: How to manage side effects from chemotherapy

WHAT ARE THE COMMON SIDE EFFECTS OF CHEMO?

Although chemo drugs are effective at killing cancer cells, they can also damage normal cells that grow rapidly, such as hair follicles, stomach lining, and blood cells. This can result in side effects. People vary in the degree to which they experience side effects of chemotherapy, therefore, it is hard to predict which side effects you will have until you start chemotherapy.

Please review Figure 11 for information on some common side effects of chemotherapy and how to manage them.

Learn more on managing the side effects of chemotherapy and why they occur by visiting *Ovarian Cancer Canada*'s website and reviewing our library of resources, including webinars such as "Managing the Side Effects of Treatment" and "Improving Bowel Habits Through Diet".

The side effects of chemotherapy may be reversed once chemotherapy ends, although it may take some time and varies for everyone.

Special resources:
Information about intraperitoneal chemotherapy is available on the websites of the Society of Gynecologic Oncology of Canada at g-o-c.org and the BC Cancer Agency at bccancer.bc.ca.

Ovarian Cancer: NCCN Guidelines for Patients is a resource with understandable information about treatment.

The National Comprehensive Cancer Network is a US organization. Visit nccn.com.

HOW WILL I BE MONITORED DURING CHEMO?

Chemotherapy affects the cells in your body that divide quickly, which includes blood cells. Therefore, during chemotherapy you will have regular blood tests to check your blood cell levels, and to monitor how these levels may change over the course of your treatment. These blood tests include a complete blood count (CBC) which looks at the number and characteristics of your blood cells, specifically your red blood cells, white blood cells, and platelets. Your medical team may advise you not to eat or take certain medications before your CBC test in order to ensure that the results are accurate.

When chemotherapy is working, there will be a drop in your blood cell counts. If the drop in blood cell counts stays within the normal range, then it is safe to continue with chemotherapy. However, if your blood cell counts drop below a safe level, your medical team may want to change your chemotherapy dosage or pause your treatment until your levels rise back to a safe level. *It is okay if your medical team changes your dosage. This does not mean that you are not getting enough chemotherapy drugs. It simply means that you will now be given the right amount for you.*

Depending on the type of chemotherapy, it typically takes about seven to ten days for the CBC to drop to its lowest point, and it can take several weeks for them to recover. Your medical team may have you do chemotherapy every three to four weeks, therefore your CBC may not be "back to normal", but it should have risen back to a safe enough level to undergo your next chemotherapy.

During chemotherapy, you may have low neutrophils, which is a type of white blood cell that protects your body from infection. This is called neutropenia. You may also have low platelets, which help to prevent and stop bleeding. This is called thrombocytopenia. You will not be able to feel neutropenia or thrombocytopenia, so it is important to assume that you are at higher risk of infection or bleeding during chemotherapy. You may also have low red blood cells as a result of chemotherapy. This is called anemia and can cause fatigue. Therefore, you should be prepared to feel more fatigued with each cycle of chemotherapy.

The following blood cells are monitored during chemotherapy:

White Blood Cells (WBC): WBCs are cells that protect your body from infection by fighting off viruses and bacteria. Examples of WBCs include neutrophils, lymphocytes, monocytes, eosinophils, and basophils.

Red Blood Cells (RBC): RBCs are cells that carry oxygen throughout your body and remove carbon dioxide from your body.

Platelets: Platelets are blood cells that help your blood clot.

WHAT IS BEING TESTED?

White Blood Cells (WBC): During a CBC, there are two measurements of white blood cells:

1. **White blood cell count:** the number of white blood cells in your blood
2. **White blood cell differential:** the number of each type of white blood cell in your blood (See above)

Red Blood Cells (RBC): During a CBC, there are four measurements of red blood cells:

1. **Red blood cell count:** the number of red blood cells in your blood
2. **Hematocrit:** the percentage of your blood made up of red blood cells
3. **Hemoglobin:** the amount of protein carrying oxygen in your red blood cells
4. **Mean corpuscular volume (MCV):** the size of your red blood cells

Platelets: During a CBC, the total number of platelets in your blood are counted.

WHAT ARE THE SYMPTOMS OF LOW COUNT?

White Blood Cells (WBC): Fever, chills, sweating

Red Blood Cells (RBC): Fatigue, chest pain, dizziness, shortness of breath

Platelets: Bleeding, easy bruising, heavy menstrual bleeding

Your medical team will also do blood chemistry tests that will examine your electrolytes, glucose, and kidney and liver function. These tests allow your medical team to ensure that your chemotherapy is not causing you to become dehydrated, is not hurting your kidneys or liver, and is not aggravating diabetes (the steroids that you may be given to help with energy and nausea can increase blood sugar levels).

Your medical team will likely advise you to eat foods high in protein and to try to remain physically active during chemotherapy, if possible. This is to prevent muscle loss, as many people report that the fatigue they experience from muscle loss is much more bothersome than anemia-related fatigue (which is caused by a drop in red blood cells). They will likely advise that you also eat foods high in magnesium. This is because common chemotherapy drugs can cause your magnesium levels to drop. Please review **Chapter 09** for nutrition-related information on **pages 135–138**.

Unless your blood cell counts drop significantly, you will likely not have symptoms. This is why your medical team monitors your bloodwork closely during treatment.

Remember, when chemotherapy is working, you will have low blood cell counts. There are ways to take care of yourself during this time, including:

- Eating a nutritious, well-balanced diet (that includes your comfort foods!) Please review **Chapter 09** for nutrition-related information on **pages 135–138**.
- Avoid injury because low platelets affect the body's ability to control bleeding, and because there is a greater risk of infection due to low white blood cells.
- Avoid germs by washing your hands frequently, avoiding crowded areas, and avoiding people that you know are sick.
- Wear a mask when in public/crowded places.

During treatment your medical team may also monitor your CA125 levels. In some cases of ovarian cancer (for example, for people who had elevated CA125 levels when diagnosed), this will help to determine if your body is responding to the treatment. It is important to remember that the CA125 blood test is not a screening tool or diagnostic tool. Not everyone with ovarian cancer will have an elevated CA125, which is why it is not used to track the effectiveness of treatment in all patients. For more information on the CA125 blood test, please review **Chapter 06: What can I expect during my follow-up care?** on **pages 88–91**.

Other blood tests and imaging tests may be ordered during your treatment to monitor your health and to see how well your body is responding to the treatment.

WILL I NEED RADIATION?

Radiation therapy may be used to treat some cancers, although it is not often used in ovarian cancer treatment.

Radiation uses high energy x-rays to damage or destroy cancer cells and damage the DNA of the cancer cells so that they can no longer divide and grow. Radiation therapy may be used if there is no or minimal residual cancer left after surgery, or if the ovarian cancer recurs.

There are some side effects of radiation to be aware of:

- Fatigue.
- Gas.
- Mild redness or skin sensitivities.
- Loss of appetite.
- Hair loss in pelvic region.
- Nausea and vomiting.
- Diarrhea or constipation.
- Bladder problems (frequent urination, discomfort, bleeding).
- Vaginal irritation.
- Treatment-induced menopause (The Menopause Foundation of Canada can help you find a doctor specializing in menopause).
- Low blood counts.
- Vaginal atrophy/tightness (vaginal dilators can be prescribed).
- Sexual changes.

These problems will fade once radiation therapy ends.

There are several webinars on *Ovarian Cancer Canada*'s website with experts that will help you to understand and manage side effects of treatment, including:

- *Ovarian Cancer Canada* Speaker Series: The 411 on sexual changes after cancer
- *Ovarian Cancer Canada*'s Fall Symposium: Managing the side effects of treatment

Your cancer centre also has numerous supports and resources available that will be valuable to you throughout your treatment. In many cases, these resources are culturally specific. For example, if you are a member of an Indigenous community, you might consider asking your medical team to connect you to the Indigenous Patient Navigator at your cancer centre so that your traditional knowledge and practices can be integrated into your care. If English is not your first language, you might consider asking your medical team to connect you with the cancer centre's translation services so that you can discuss your care in the language that is most comfortable for you. Regardless of your identity, talk to your medical team about what is important to you, culturally, spiritually, and emotionally. They will be able to connect you with the cancer centre resources.

WHAT MEDICATIONS WILL I BE GIVEN?

You will likely be prescribed medications during your treatment to help manage pain and side effects. After surgery and chemotherapy are complete, your doctor may prescribe you a medication that may prevent or delay a recurrence. It is important to remember that not everyone will be given these medications. As with everything we have covered so far, this will depend on the unique characteristics of your case, including the type and stage of your ovarian cancer.

The medications that may be used to prevent or delay a recurrence belong to a group of drugs called "PARP inhibitors". PARP is an acronym which stands for "poly-ADP ribose polymerase". PARP is an enzyme that repairs damaged DNA. PARP inhibitors prevent (or "inhibit) cancer cells from repairing their damaged DNA, therefore increasing cancer cell death.

PARP inhibitors are taken orally (by mouth). When prescribing a PARP inhibitor, your oncologist will take many aspects of your unique case into consideration, including the type and stage of your ovarian cancer, your response to chemotherapy, and whether or not you have certain genetic mutations.

Currently, there are two PARP inhibitors available in Canada:

- olaparib (brand name: Lynparza)
- niraparib (brand name: Zejula)

Olaparib is for patients with a BRCA mutation. You do not have to have a BRCA mutation to be prescribed niraparib.

Bevacizumab (sometimes called “bev”) is another medication that may be prescribed. Bevacizumab belongs to a group of drugs called angiogenesis inhibitors. Angiogenesis refers to the development of new blood vessels. Therefore, bevacizumab prevents (or “inhibits”) cancer cells from being able to make new blood vessels, which slows or stops the cancer’s growth and spread. Bevacizumab is given intravenously, meaning that it is given directly into the vein. The bevacizumab available in Canada is called “Bambevi”.

Unlike chemotherapy drugs, PARP inhibitors and Bevacizumab are targeted therapies. This means that they do not target all the cells in the body, but instead look for specific cells.

Your oncologist may recommend that you adjust the dose of the medication(s) that you are taking, perhaps as a result of the side effects that you are experiencing. Try not to let this worry you. Everyone’s body is unique and will respond differently to medications. You and your healthcare team are working together to find the right dose for you.

There is a lot of information about medications for ovarian cancer, and it can be confusing. Be sure to ask if your cancer centre has an oncology pharmacist that you can connect with. An oncology pharmacist is a highly trained member of your health care team with advanced expertise in cancer-related medications. To learn more about oncology pharmacists, visit the library of resources on *Ovarian Cancer Canada*'s website and watch the webinar titled "Getting to know your oncology pharmacist".

Your oncologist may also recommend certain molecular tests that will help them determine the best treatment plan for you, for example, HRD testing. This is a rapidly evolving area of ovarian cancer care. Please talk to your doctor to learn more.

ARE THERE DIFFERENT TREATMENTS FOR RARE TYPES OF OVARIAN CANCER?

Your treatment plan is going to depend on many different factors, including which type of ovarian cancer you have. This guide has provided a broad and general overview of treatments commonly used in ovarian cancer. It is important to talk to your medical team about your type of ovarian cancer, and all other factors that are being considered in determining your treatment plan.

It is also important to note that people will respond differently to treatment depending on their ovarian cancer type, and a combination of other factors. For example, surgery is the primary treatment for low grade serous ovarian cancer, and despite being relatively chemo-resistant, chemotherapy following surgery is still the standard of care for this rare ovarian cancer. In many cases of low grade serous ovarian cancer, a hormonal maintenance therapy may be used after chemotherapy to improve outcomes. Hormone therapy may be effective for some types of ovarian cancer by lowering the levels of estrogen in the body. An example of a hormone therapy is a class of drugs called aromatase inhibitors, which work by lowering estrogen levels. This may be effective in slowing the progress of some types of ovarian cancer as estrogen can affect the growth of some ovarian cancer cells. An example of an aromatase inhibitor is a medication called letrozole.

Non-epithelial ovarian cancers (germ cell and sex cord-stromal cell tumours) are much rarer, and therefore, there is less data that can be used to guide the clinical care of these cancers. Fortunately, these ovarian cancers tend to be found at earlier stages and therefore are associated with a better prognosis. Surgery remains the main treatment for many types of non-epithelial ovarian cancers, with other therapies (for example, chemotherapy) used after surgery in some cases (for example, when the cancer is more widespread). For patients who are post-menopausal or do not plan to have (anymore) children, the medical team will likely recommend a bilateral salpingo-oophorectomy and total abdominal hysterectomy, which means that both fallopian tubes, both ovaries, the uterus and cervix will be removed. Younger patients wanting to spare their fertility may be advised to instead undergo a unilateral salpingo-oophorectomy, which means that only the cancerous fallopian tube and ovary are removed. In other words, if one of the ovaries and fallopian tubes is not affected by the cancer, then it will not be removed so that the person still has the option to get pregnant in the future. If it is relevant to you, be sure to speak with your medical team about the possibility of sparing your fertility. If you are not satisfied with their response, remember that you can ask to be referred to another oncologist.

Lastly, some patients with granulosa cell tumors are prescribed leuprorelin (brand name: Lupron). This medication is categorized as an LHRH agonist (luteinizing-hormone-releasing hormone agonist), which means that it stops the ovaries from producing estrogen.

WHAT OTHER TREATMENT OPTIONS ARE AVAILABLE TO ME?

It is important to remember that you are a very important member of your healthcare team, and that it is okay to discuss your values and preferences with your doctor.

Complementary therapies

Complementary therapies are not offered as cures for cancer; however, they may be used to help you feel better. They are called complementary therapies because they are meant to “complement”, or “work with” your cancer treatment. An example of a complementary therapy is the use of ginseng to assist with treatment-related fatigue.

Some complementary therapies have been found to help, while others have not been tested. Therefore, it is very important to talk with your medical team about other therapies that you may be using (for example, taking herbal medications), as they may interact negatively with other aspects of your treatment.

To learn more about complementary therapies and ovarian cancer care, visit the library of resources on *Ovarian Cancer Canada*’s website and watch the webinar titled, “Lunch and Learn: Complementary Therapies”.

Traditional sources of knowledge

The treatments for ovarian cancer that have been reviewed in this guide are the current and best available options in western biomedicine. The majority of doctors, nurses, and other clinicians are aware and respectful of other traditional sources of medical knowledge, for example, Traditional Chinese Medicine, Indigenous Ways of Knowing, etc. If you are looking to learn more about your culture’s relationship to health and healthcare, ask your medical team to connect you with culturally-specific resources at your cancer centre. If you have knowledge that you would like your medical team to be aware of and that you would like to discuss integrating into your care, you can share that information with them. In most cases, the medical team will be committed to working with you to design a treatment approach that is going to work best for you. If you are unsatisfied with your medical team’s response to your request to integrate your own culturally-specific knowledge into your care, you can ask to be referred to a different oncologist.

Making yourself comfortable during treatment

Treatment for ovarian cancer can be unpredictable. You will find yourself in many unfamiliar environments that may make you uncomfortable. Take some time to think about what you need to make yourself more comfortable during appointments, in waiting rooms, during chemotherapy, or other treatments, scans, hospital stays, and emergency room visits.

You may consider putting together a personal bag of comfort items to bring with you to appointments and procedures. Some items you may want to have with you include:

- Cell phone or tablet (preloaded with favorite music, games, meditation apps, pictures that make you smile, or distracting movies and videos).
- Charging cords or batteries (bring a long charging cord so that you can keep using your device while it charges).
- Phone numbers of people who support you.
- A notebook with all your questions and concerns recorded in advance to help you advocate for yourself while at treatment.
- Earphones for music, conversations or games.
- Favourite stuffed animal.
- Sweater or shawl.
- Weighted blanket or neck pillow.
- Picture of a loved one or a special place.
- Favourite snack (if allowed) or water bottle.
- Money if you would like to buy a treat at the hospital's coffee shop or gift shop.
- Eye mask or ear plugs.
- Games, books, magazines or puzzles.
- Pen and paper or colouring books and pencils.
- Knitting or crocheting.

CHAPTER 05

SHOULD I CONSIDER A CLINICAL TRIAL?

Clinical trials are designed to test new treatments and interventions at many different stages of the disease, as early as diagnosis. This is surprising to many people, because of the common myth that clinical trials are only used as a last resort; if all other treatment options have “failed”. This chapter will provide more information about clinical trials and will help you talk to your doctor about whether a clinical trial may be right for you.

WHAT IS A CLINICAL TRIAL?

A clinical trial is a type of research study that tests health interventions (for example, a new medication) on people. Clinical trials can connect you with new and emerging treatments for ovarian cancer and are very carefully designed to ensure the utmost safety and as little risk as possible to participants. The learnings from clinical trials are extremely valuable for medical advancement by answering important questions, such as: Does this new medication improve outcomes? Are there side effects and how manageable are they? Does it help people feel better? This helps healthcare providers to decide what will work best for different people in order to promote their health and well-being.

If you are interested in clinical trials, ask your medical team what trials you may be eligible for. Many cancer centres have staff members that match patients to clinical trials that they may be eligible for. These people are important members of your healthcare team. They may have different titles in different cancer centres, but they are likely called something like *clinical trials navigators*.

ARE CLINICAL TRIALS SAFE?

Clinical trials are carefully designed to minimize risk as much as possible for participants. Pre-clinical work is conducted for many years in advance of a clinical trial (for example, on cancer cells, tissue samples, mice, etc.) to ensure that the new treatment is safe to test on humans.

All clinical trials conducted in Canada must adhere to the Food and Drugs Regulations, Division 5. Specifically, all clinical trials conducted in Canada must:

- Protect the health and well-being of the participants.
- Be overseen by trained professionals.
- Be closely monitored and side effects must be reported.
- Be reviewed and approved by a Research Ethics Board.

HOW ARE CLINICAL TRIALS DESIGNED?

Clinical trials are designed by a team of qualified specialists, including researchers, doctors, scientists, statisticians, and/or industry sponsors. A clinical trial aims to answer one or more important questions about the impact of a specific health intervention.

DO CLINICAL TRIALS ONLY STUDY MEDICATIONS?

No. In addition to medications, clinical trials also examine many different types of health-interventions, including surgery, radiation, diagnostic processes, lifestyle, and more.

WHERE ARE CLINICAL TRIALS DONE?

There are many different settings for clinical trials, including hospitals, private companies, doctors' offices, and community clinics.

WHAT DOES "PHASE" MEAN IN THE CONTEXT OF CLINICAL TRIALS?

Clinical trials are categorised into different phases.

Phase 1
The health-intervention (for example: a medication) is being tested on people for the first time. The purpose of Phase 1 trials is to establish that the medication is safe, to understand dosage, and to learn about any potential side effects. There are usually 20-80 participants in Phase 1 clinical trials.

Phase 2
Researchers want to learn if the health-intervention works as intended. This is also when the clinical trial team will learn more about side effects and determine if the dosage needs to be changed. There are usually about 100-300 participants in Phase 2 clinical trials.

Phase 3
Also called "randomized clinical trials", these trials test how long the effects of the intervention last. The clinical trial team will also learn more about side effects during Phase 3 trials. There are usually thousands of participants in Phase 3 randomized clinical trials.

Phase 4
Also called "post-marketing surveillance" because this is the phase when the intervention (for example, the medication) is monitored after it is available on the market. During this phase, the trial team studies long-term side effects on a very large group of people.

WHAT DOES "RANDOMIZATION" MEAN?

Randomization is a process used to compare two or more health-interventions. In randomized trials, participants are randomly assigned (by chance) to receive one of the health-interventions (for example, the new treatment being tested, or the current standard of care).

WHAT ARE PLACEBOS AND ARE THEY USED IN CANCER TRIALS?

Placebos are inactive therapies that resemble active therapies. A common description of a placebo is a “sugar pill”. Placebos are very rarely used in cancer clinical trials because the new treatment is being compared to the current standard of treatment. Therefore, every person in a clinical trial for cancer does receive a real treatment (either the currently accepted treatment, or the new treatment being tested). In the very rare case that a placebo might be used, participants would be made aware of that possibility during the informed consent process.

WHAT IS INFORMED CONSENT AND HOW DO I GIVE IT?

Participation in a clinical trial is completely voluntary. The informed consent process ensures that you are provided with all the information you need to decide if you want to take part in the clinical trial. During this process, you should be given the opportunity to ask questions and discuss the trial with the people in your life in order to determine if it is right for you.

An “Informed Consent Form” is a document that provides you with all the important information about the clinical trial. The research team will give you enough time to understand the consent form and ask any questions that you might have. Your medical team will help you to understand the potential benefits and possible risks, so that you can decide if you would like to participate in the trial. If you decide to participate in the clinical trial, you will be asked to sign the consent form and you should be provided with your own copy.

The informed consent process continues throughout the clinical trial. You can choose to withdraw from the trial at any time.

WHAT IS A CLINICAL TRIAL PROTOCOL?

Clinical trial protocols contain extensive information about the clinical trial. For example, the protocol will explain why the trial is being conducted, how it will be done, how the data will be collected and analysed, how the results of the trial will be shared, and who is involved.

HOW DO I FIND A CLINICAL TRIAL?

There are many different ways to find a clinical trial, for example:

- Talk to your health care team.
- Look on your cancer centre's website. Consider calling or emailing your cancer centre for more information.
- Many major cancer centres post information about their clinical trials on their websites. You can talk to your medical team about referring you to a different cancer centre so that you can participate in their clinical trial.
- Find a clinical trials navigator at your cancer centre. These are professionals who can help you find a clinical trial, explain the eligibility criteria, and help you decide if joining the clinical trial is right for you.
- If there are no clinical trials open at your cancer centre, ask if there is one somewhere else in Canada that you can be referred to.
- Use a clinical trial finder, for example:
    - Health Canada Clinical Trial Search: health-products.canada.ca/ctdb-bdec/index-eng.jsp

- Canadian Cancer Trials: canadiancancertrials.ca
- Clinical Trials Ontarios' national trial finder: trial-finder.ctontario.ca
- Looking for clinical trials worldwide? The trial finder from the U.S. National Library of Medicine can help: clinicaltrials.gov
- Looking for clinical trials in Quebec? This trial finder can help: oncoquebec.com

If you would like support in using the "clinical trials finder", contact *Ovarian Cancer Canada*.

IS A CLINICAL TRIAL RIGHT FOR ME?

Here are a few things to consider when deciding if a clinical trial is a good fit for you:

- Determine if you meet the eligibility criteria (this will be done in consultation with the medical team).
- You should not have to pay to participate in a clinical trial (although there may be some additional expenses related to travel and accommodations, etc.).
- Determine if the clinical trial team is qualified. The clinical trial team should have related experience and an affiliation with an academic institution and adhere to regulations and the ethics review process.
- The clinical trial application should have been reviewed by a regulatory agency (for example, Health Canada).
- The clinical trial should be reviewed/approved by a research ethics board and by the institution/hospital where it is taking place.

WHERE CAN I FIND MORE INFORMATION ABOUT A CLINICAL TRIAL I AM INTERESTED IN?

Most clinical trials will have a primary contact person who can answer your questions.

IF I DECIDE TO PARTICIPATE IN A CLINICAL TRIAL, WILL MY FUTURE MEDICAL CARE BE AFFECTED?

- In some clinical trials, you may require additional follow-ups.
- Participation in a clinical trial may limit you from participating in other clinical trials.
- It is important to ask the clinical trial team if your eligibility could change throughout the clinical trial, and how the clinical trial may affect your future medical care.

WILL I RECEIVE ADEQUATE CARE DURING A CLINICAL TRIAL?

Clinical trial participants are very closely monitored and significant measures are taken to reduce risk and promote safety.

Although there are risks associated with clinical trials, many precautions are taken to minimize them as much as possible. Participants are closely monitored by the clinical trial team.

In the majority of cancer clinical trials, a new intervention is being compared to the current standard of care. Therefore, every person in a clinical trial for cancer does receive a real treatment (either the currently accepted treatment, or the new treatment being tested).

WHAT SHOULD I ASK THE CLINICAL TRIAL TEAM?

Questions to learn more about the clinical trial

"Am I eligible for this clinical trial? What might change my eligibility throughout the clinical trial?"

"What is the study intervention (for example, medication)? How will it be administered? For how long? How is this treatment different from my current treatment?"

"How many appointments will I have to attend? How long are the appointments? What will happen at these appointments? Where are the appointments? Should someone come with me to the appointments?"

"What are possible risks? What are possible benefits? "

"How long will this clinical trial last?"

"Will there be follow-up after the clinical trial is over? Short-term? Long-term?"

Questions about potential side effects

"How are 'unacceptable side effects' defined?"

"What should I do if I start to experience unacceptable side effects during the clinical trial?"

"If I do experience side effects, how will I be treated for them?"

"Who is responsible for dealing with unacceptable side effects (my family doctor, my oncology team, and/or the clinical trial team)?"

"If I need medications to manage side effects, will they be supplied for me? Will there be a cost to me?"

"What happens if I have to temporarily delay or stop treatment until unacceptable side effects are dealt with? Does this lengthen the trial period?"

Questions about your medical care

"Will I continue to see my usual medical team during the clinical trial?"

"If I am not assigned to the intervention group (for example, if I do not receive the trial drug), will I receive the current standard of care?"

"Who else gets information on my health during the trial period? Will my family doctor and oncology team be kept up to date with any changes to my health?"

"If my condition starts to improve during the clinical trial, can I stay on the treatment when it is over?"

Questions about the clinical trial team

"Who is the study physician?"

"Who is funding this trial?"

"What are the experiences/credentials of the study team?"

"Who can I contact during the clinical trial if I have concerns?"

Other questions

"Do I need to pay to participate in this clinical trial?"

"Do I need to travel for this clinical trial? When? Where? For how long? How often?"

"Will I be reimbursed for travel-related costs? If so, what is the reimbursement process?"

"If I want to withdraw from the study before it is over, how do I do that?"

"Will I learn about the results of the clinical trial? How will the results be shared?"

"Is it possible to participate in this clinical trial virtually?"

WHAT CAN I EXPECT WHEN PARTICIPATING IN A CLINICAL TRIAL?

If you have decided to participate in a clinical trial, you likely have many questions about what the experience is going to be like. Take time to ask the study team any questions that you may have. Some suggestions for what to ask are included here.

WHAT HAPPENS IF I DECIDE TO LEAVE THE CLINICAL TRIAL BEFORE IT IS OVER?

If you withdraw from the clinical trial, your regular medical team will continue to care for you, and you will receive your routine care. However, if you leave the study due to side effects, you may need treatment for those side effects.

WHAT HAPPENS AFTER THE CLINICAL TRIAL IS OVER?

When a clinical trial ends, you will continue to receive your routine medical care from your regular medical team.

You may receive treatment for side effects from the clinical trial.

In some cases, you may continue to be monitored by the study team for follow-up tests and additional findings.

HOW DO I SHARE INFORMATION ABOUT MY CLINICAL TRIAL PARTICIPATION WITH MY MEDICAL TEAM?

You should receive a copy of the informed consent form when you enrol in a clinical trial. This form will describe the clinical trial in detail. You can share this information with your medical team, family/friends/loved ones, etc.

HOW LONG WILL IT TAKE TO KNOW IF THE CLINICAL TRIAL HAS HELPED?

Most clinical trials include a schedule of tests (for example, CT scans, blood tests, etc.) that will measure the results and/or efficacy of the intervention being tested.

Be sure to ask the study team for more information, including how they will measure the success of the trial.

IS THERE A WAY TO KNOW WHICH TREATMENT I RECEIVED?

Typically, you will not know which group you were assigned to until the study is complete, or your participation in the study is complete. However, your group assignment may be identified if medically necessary.

WHAT SHOULD I DO IF I THINK I'M EXPERIENCING LONG-TERM SIDE EFFECTS FROM THE CLINICAL TRIAL?

Speak with your medical team if you are experiencing long-term side effects.

IF MY CONDITION STARTS TO IMPROVE DURING THE CLINICAL TRIAL, CAN I STAY ON THE TREATMENT WHEN IT IS OVER?

This will depend on the clinical trial and the intervention being studied. There are some reasons why you may not be able to receive the intervention after you are finished the clinical trial, including:

- It may not be approved for use in Canada.
- Your medical team may not think it is the best option.
- You may determine that it is too expensive if not covered by any other source.

Ask the study team about your options.

WHAT WERE THE RESULTS OF MY CLINICAL TRIAL?

You can ask the study team to inform you of the results of the clinical trial after the trial is complete.

THE CLINICAL TRIAL DID NOT GIVE ME ANY BENEFITS. NOW WHAT?

Speak with your medical team if you did not experience any benefits from your clinical trial. There may be other options or other clinical trials available to you.

CHAPTER 06

WHAT CAN I EXPECT DURING MY FOLLOW UP CARE?

In the months and years after your treatment is finished, you will be followed closely by your healthcare team. Many people with ovarian cancer have shared that one of their main emotional challenges during this time is dealing with the fear that the cancer will come back. This chapter will provide an overview of what you can expect during this follow-up care period, and how you will be monitored for recurrence.

WHAT CAN I EXPECT DURING MY FOLLOW UP CARE?

For the majority of patients first diagnosed with ovarian cancer, the primary goal of treatment is to cure the cancer. It is very common, however, for ovarian cancers to return, especially the most common type (high grade serous ovarian cancer). Therefore, your oncology team will follow you closely for the 5 years following your treatment to monitor for a return of the cancer, and to support you in your overall health and well-being following your ovarian cancer experience. Please note, however, that monitoring may be slightly different depending on your type of ovarian cancer.

Although you may be hoping to hear your oncologist tell you that your cancer is in “remission”, this term is not typically used in the gynecologic oncology world. The term remission means that there is no evidence of cancer – however, this implies that there is an expectation that the cancer will return and that your cancer is only inactive. Therefore, most gynecologic oncologists do not use this term, because the goal of treatment is for the cancer to never return. Instead, gynecologic oncologists use the phrase *“no evidence of disease” (NED)*. This means that there is no evidence of the cancer on imaging tests, clinical examination, or blood work. NED is often used after surgery to tell the person that there is no visible cancer left in their body.

Your oncologist may also use the phrase “cancer-free” to tell you that there is no evidence of active cancer on imaging tests, clinical examination, or blood work.

The word “recurrence” refers to evidence of cancer following a period of time where there was no evidence of disease.

If you have been diagnosed with a recurrence, please refer to **Chapters 11 and 12** of this book. These chapters include detailed information about ovarian cancer recurrences and can answer many of the questions that you likely have. *It is important to remember that although an ovarian cancer recurrence is not curable, it is treatable.* It may be helpful to think of a recurrent ovarian cancer as a chronic disease that needs to be managed.

HOW WILL I BE MONITORED FOR A RECURRENCE?

Follow-up care plans will be based on many factors, including your type of ovarian cancer, the specifics of your case, and the outcomes of your initial treatment. Although there may be some variation across provinces/territories and between cancer centres, the gold standard for monitoring for a recurrence of ovarian cancer is clinical. This means that your oncology team will ask you many questions to assess any symptoms and may do a physical examination. The physical examination will likely involve a pelvic exam and an examination of your abdomen. This monitoring can be done by a physician or a nurse practitioner, and typically takes place every three months following your initial treatment. These appointments will likely become less frequent over time.

If your physical examination and/or symptom assessment reveal any findings that are of concern, your oncology team will investigate further. This may involve an imaging test, like a CT scan, and/or bloodwork, including CA125. It is important to remember that a routine CT scan is only done in very specific situations, and it is not the standard of care.

Finding an ovarian cancer recurrence early does not make a difference to overall survival. Researchers have found that there is no survival benefit to starting treatment for recurrence before the development of symptoms, which is why the standard of care for recurrence monitoring involves symptom assessment. In fact, diagnosing and treating a recurrence early does not lead to an increase in progression free survival, which refers to the amount of time that you are cancer-free following the completion of treatment.

During the COVID-19 pandemic, many follow-up appointments were moved online. Studies out of the United States have shown that ovarian cancer recurrences are not being missed with this move to virtual monitoring. It is understandable that many people with ovarian cancer are distressed that they are being seen virtually, but there is good data to show that virtual monitoring is sufficient. It is important to remember, however, that virtual monitoring is only sufficient if you are feeling well. If you develop any new or different symptoms, be sure to let your doctor know so that they can examine you in person and order any appropriate tests, which may include bloodwork and imaging.

You may be asking yourself why your follow-up care does not include routine CA125 blood tests. This is a very reasonable question that many people ask. The use of the CA125 blood test will vary across the country, and it will also vary based upon the type of cancer that you have, and the specific details of your case. In general, however, the CA125 blood test is not an effective tool in monitoring for an ovarian cancer recurrence. In fact, Canadian and European guidelines recommend against using routine CA125 blood tests to monitor for recurrence.

The CA125 blood test is used to identify the levels of a specific protein named CA125 in the bloodstream. This protein may become elevated with some types of cancer and therefore can be used as a tumour marker in very specific clinical situations. It is important to note that a rising CA125 may be the result of many other things, including your period, an infection or inflammation in your abdomen, liver or heart failure, and even COVID-19. It is also very important to note that not all ovarian cancers are associated with elevated CA125 levels.

Research studies have examined the potential for the CA125 blood test to effectively identify ovarian cancer recurrences, and unfortunately the results have found that it is not a helpful tool. These studies found that a rise in CA125 does not accurately predict a recurrence unless the CA125 rises to double the upper limit of normal. To clarify, the normal upper limit of CA125 in the bloodstream is 30-40. In order to predict an ovarian cancer recurrence with accuracy, that number would have to double (so, to 60-80). Therefore, small rises in CA125 do not predict a recurrence, and may actually create undue anxiety.

There was a very important landmark randomized clinical trial published in 2010 called the “MRC OV05/ EORTC 55955 collaborative trial”. This trial examined the effectiveness of the CA125 blood test in predicting recurrence, and the results changed clinical practice. The research team randomly divided people into two groups and monitored the CA125 levels of people in both groups. Participants in the first group were given chemotherapy as soon as their CA125 levels started to rise. Participants in the second group were not given chemotherapy (even if their C125 levels started to rise) until they actually developed symptoms. Importantly, the researchers found no difference in survival between those who had treatment right away as compared to those who waited until they had symptoms. In fact, those who had treatment right away were actually found to have a worse quality of life as a result of their early treatment. Therefore, most oncologists agree that the CA125 blood test is not helpful in monitoring for recurrence because it does not change survival and can actually make your quality of life worse.

Now that we know that the CA125 blood test is not useful in monitoring for recurrence, it is worth noting some situations where it may be helpful. When someone first presents to their doctor with symptoms of ovarian cancer, for example a pelvic mass, the CA125 blood test might help their doctor understand where that mass is coming from. The CA125 blood test may also be useful in monitoring how well treatment is working for people who had a rise in levels with their initial ovarian cancer diagnosis.

Your oncologist might have you do occasional CA125 blood tests if you are taking a maintenance medication, such as a PARP inhibitor. This is because there is some risk involved with all treatments, therefore your oncology team will want to monitor you more closely while on treatment.

It is important to talk with your oncology team about how you will be monitored for recurrence, and if a recurrence happens, when to start treatment. Remember, there is no survival benefit to starting treatment for recurrent ovarian cancer before symptoms develop.

IF I HAVE MILD SYMPTOMS BETWEEN FOLLOW-UP APPOINTMENTS, SHOULD I CALL MY DOCTOR?

You may find it difficult and stressful to constantly monitor yourself for possible symptoms of a recurrence of your ovarian cancer. If you do feel something, you may not be sure if you need to call your doctor. As a general rule of thumb, you can call your doctor if you are worried. They are there to support you. Your oncology team will want to know if you have any symptom that is new to you, persists over time, and gradually gets worse (over a period of 2-3 weeks).

There are no specific symptoms that you should be monitoring for, as ovarian cancer can come back anywhere. However, some common symptoms of recurrence can be quite generic and include somewhat vague abdominal symptoms including pain, bloating, lack of appetite, and/or constipation/diarrhea. Some individuals will have other symptoms, so it is important to notice anything that is not normal for you. We all have strange and unexplained bodily sensations from time to time, and you know your body best. Try not to worry if you experience something for just a day or two. If symptoms persist and/or worsen over a period of 2-3 weeks, call your oncology team.

HOW DO I KNOW WHAT ARE SYMPTOMS OF A RECURRENCE, AND WHAT ARE SIDE EFFECTS FROM MEDICATION?

Whenever you start a new medication, it is important to give your body time to adjust. In general, this adjustment period is about 6 weeks. Therefore, if you are experiencing any new symptoms during the first 6 weeks on a new medication, it is likely due to that medication. After you've given yourself that time to figure out how you feel on your medication, then you can start to monitor for new and persistent symptoms.

DOES FOLLOW-UP CARE DIFFER ACROSS CANADA?

Broadly speaking, there may be some variation in follow-up care across Canada. This is because healthcare is provincially mandated, and therefore follow-up care may look a little bit different depending on where you live. Regardless of where you live, however, you should be receiving the gold standard of follow-up care, which is a symptom assessment and physical examination every 3 months following completion of your initial treatment. These appointments will likely be spread out over time.

Remember, there is no survival benefit to getting a routine CA125 blood test or imaging in the follow-up care setting. However, these tools may prove helpful if your oncologist finds something concerning during your physical exam and symptom assessment. Some larger cancer centres may do routine CA125 blood tests for the purposes of clinical trial enrolment. Therefore, some cancer centres will do routine CA125 blood tests, and some will not. If you have any questions about why you are, or are not, getting a routine CA125 blood test, be sure to speak with your oncology team.

> “I try to treat my team as I would want to be treated as a patient—to connect with them as people, not just as healthcare professionals. I want them to remember that ovarian cancer is just a part of my life—it's not all of me.”
>
> –ANITA

CHAPTER 07

WHO'S ON MY HEALTHCARE TEAM?

As you move through your experience with ovarian cancer, you will have ongoing interactions with your healthcare team. This team is made up of several different types of healthcare professionals. This chapter will provide details about these different people, and information to help you gain the knowledge and support that you need from them.

WHO ARE THE MANY MEMBERS OF MY HEALTHCARE TEAM?

There are many different types of healthcare professionals, and their titles may differ depending on the province/territory that you live in. All healthcare providers should introduce themselves to you by name and describe their role in your care. If they do not, be sure to ask who they are and what their role is. The information below will help you to better understand who some of these people are and what their role will be in your care.

Firstly, ***it is very important that you have a gynecologic oncologist.*** These doctors are highly specialized in cancers of the female reproductive system, including the ovaries and fallopian tubes. If you have not seen a gynecologic oncologist, ask to be referred to one as soon as possible. If you have difficulty finding a gynecologic oncologist, contact the Society of Gynecologic Oncology of Canada:

- Call or text: 1-888-496-3662
- Email: enquiry@gynecology.ca
- Website: gyneoncology.ca

If you live in a larger city, you may see different oncologists ("cancer doctors") with different specialities. A gynecologic oncologist should perform your surgery and will likely be involved in other aspects of your treatment. There are other oncologists with specialties that may also be involved:

- **Medical oncologists:** specialize in non-surgical treatments of cancer (for example, chemotherapy and clinical trials).

- **Radiation oncologists:** specialize in radiation therapy.

Nurses will also be extremely important members of your healthcare team. “Nursing” is actually an umbrella term that refers to the activities of numerous healthcare providers with varying levels of education and training. Throughout your ovarian cancer experience, you will interact with a number of nurses, each with their own unique expertise, speciality, and scope of practice. All nurses must complete a nursing education program approved by regulatory bodies, pass an entry-to-practice exam, and register with the appropriate regulatory body (for example, nurses in Ontario must register with the College of Nurses of Ontario).

Some examples of the nurses you may interact with include:

- **Nurse Practitioners (NPs):** these nurses must have a Master’s degree and have the largest scope of practice of all nurses. They are able to diagnose and manage illness, interpret diagnostic tests, prescribe treatments, and perform some procedures. It is possible that at some of your appointments during your ovarian cancer experience you will be seen by a NP instead of a physician. You can be assured that in many situations NPs are the most appropriate healthcare provider for you to see and are able to provide you with the highest quality of care.

- **Registered Nurses (RNs):** these nurses must have a four year Bachelor of Science in Nursing degree. In Quebec, RNs may start practicing with either a degree or a 2 year diploma. RNs deliver direct healthcare services to patients, help to coordinate their care, and support patients in the longer-term management of their health. Many of the nurses in your gynecologic oncology clinic will be RNs.

- **Oncology Nurses:** oncology nurses may be NPs or RNs. In addition to providing direct physical care, they will provide emotionally supportive care and will help you to navigate the healthcare system. Oncology nurses are an important resource for questions that you will have throughout your treatment journey.

- **Registered Practical Nurses (RPNs):** these nurses must have a 2 year diploma in nursing. RPNs make up about 29% of the nursing workforce in Canada. The practical nursing designation was established after World War II when it became clear that "nursing aides" required formal education. RPNs are directly involved in patient care. Depending on the hospital that you are at, you may interact with RPNs, and much of the care provided in the community is by RPNs.

If you are interested in reading more about the various nursing roles and responsibilities in Canada, you can visit the Canadian Nursing Association website at cna-aiic.ca

The number and type of healthcare providers that you interact with will depend on the province/territory that you live in, and your cancer centre. In addition to your doctors and nurses, the list below provides an overview of some of these professionals. Be sure to ask your doctor or nurse about these important members of your healthcare team, what they are called at your cancer centre, and how you can connect with them.

- **Oncology pharmacists** specialize in medications used in the treatment of cancer. They are an important source of information about your medications, including potential side effects, how to manage side effects, and drug interactions.

- **Genetic Counsellors** specialize in genetics and can help you and your family better understand any genetic conditions and support you in making informed decisions about your ovarian cancer care. They can also provide important information and guidance about preventing ovarian cancer (and other cancers) for your biological family members. Genetic Counsellors are also trained to provide support related to the emotional and familial aspects of learning about genetic conditions. *(About 25% of ovarian cancers are related to an inherited genetic mutation. Please see* ***pages 35–40*** *for more information.)*

- **Clinical trials navigators** are professionals who can help you find a clinical trial, explain the eligibility criteria, and help you decide if joining the clinical trial is right for you.

- **Social workers** can help you with practical issues, such as support services, financial concerns, and the emotional impact of your ovarian cancer diagnosis.

- **Physiotherapists** are highly trained healthcare providers who can help to evaluate and manage problems with movement and function as the result of an injury or disease. They can support you as your recover from your treatment, for example, with pelvic floor physiotherapy.

- **Occupational therapists** are very specialized members of your healthcare team that can help you restore your health after treatment so that you can live as high a quality of life as possible. They can support you in getting back to your everyday activities, including basic self-care, work, hobbies, and social activities.

- **Indigenous patient navigators** are available to provide specialized support and advocacy for First Nations, Inuit, Métis, and urban Indigenous people. Specifically, they help to coordinator care, ensure the integration of cultural and spiritual considerations into care, and work with your healthcare team to ensure that your ovarian cancer experience is culturally safe.

- **An interpreter** is very important if English or French is not your first language and if you need/prefer to have health-related information communicated in your first language.

- **Registered Dieticians (RDs)** are health professionals that are registered by an appropriate regulatory body. RDs are experts in food and nutrition science. Some dieticians specialize in oncology, meaning that they are experts in helping you make the nutritional choices that are best for you. You will find RDs especially helpful if parts of your gastrointestinal system are removed during surgery.

- You will interact with healthcare professionals, like **Lab and Imaging Technicians**, that will be drawing blood and running imaging tests. The people that draw your blood are called phlebotomists. It is important to remember that these professionals are not able to discuss or interpret the results of the tests with you.

- **Physician Assistants (PAs)** are not independent healthcare providers, but rather work under the direction of a supervising physician. They may be involved in several different aspects of care, including but not limited to taking a patient's history and performing physical exams.

- **Personal Support Workers (PSWs)** are vital members of the healthcare team and provide direct care to support patients in their activities of daily living. PSW care is most often provided in the community. Depending on where you live in Canada, PSWs may also be called home care workers, personal care attendants, or personal aids.

In addition to the healthcare workers listed above, administrative professionals will be extremely important in the organization and management of your care. In some cancer centres these people may be referred to as "Patient Flow Coordinators". These people are extremely important in ensuring the smooth operation of cancer care services, clinic environments, and much more.

Most cancer centres will have a department of Psychosocial Oncology. This department will link you with social workers, psychologists, dieticians, chaplains, and other professionals to support you and your unique needs and circumstances. Ask your doctors and/or nurses to refer you.

Your family doctor is also a very important member of your healthcare team. They are particularly important in the coordination of care across other specialties and other healthcare professionals. Therefore, they act as a central hub for all health information that comes from your oncology team and any other specialties that are providing you care.

Your family doctor can be an important advocate for you and can help you navigate the healthcare system. Therefore, it is important to keep your family doctor updated.

Please don't forget – *you are a vital member of your healthcare team.* Your preferences, values, and needs should be integrated into all decisions relating to your care. As many people with ovarian cancer say, "I am the captain of my ship".

HOW CAN I COMMUNICATE EFFECTIVELY WITH MY HEALTHCARE TEAM?

Communication works best when a trusting partnership develops between you, your loved ones, and your healthcare team. Ask questions and share your thoughts so that your healthcare team can give you all the information and support that you need. Everyone is different when it comes to how much information they want to know about their cancer. Take time to reflect on the information that you want, and perhaps the information that you would rather not know. And remember, you can always change your mind and ask for more information later on. You may find that you want to know more or less details as your experience unfolds. Share these thoughts with your doctor.

You can also ask for a copy of your medical records and reports, as it is your right under Canadian law to have this information. You may need to ask members of your healthcare team to help you interpret this information, as it is often written in technical medical language. Keep in mind that you may have to pay a fee to obtain your medical records. Many people who have experienced ovarian cancer recommend that you do ask for your medical records, especially because you will need them if and when you apply for financial support.

It is extremely common to feel overwhelmed by all the information that your healthcare team shares with you.

You may feel emotional, scared, confused, and like they are speaking another language. You are not alone. Take a moment to reflect on the ways that you learn and process information best, and then work with your healthcare team to set up a communication plan that is going to work best for you and your loved ones. The “10 Ps” below may help you figure out what is best for you. These Ten Ps can be valuable for all people, however, they are particularly helpful for neurodivergent people, people with autism, and people for whom English or French is not their first language.

Ovarian Cancer Canada would like to acknowledge Lindsey Holmes and Paula Holmes-Rodman as the creators of the 10 Ps. Lindsey is living with autism and ovarian cancer, and Paula is her sister and caregiver.

When reviewing the 10 Ps below, it is important to start by asking yourself, "What do I want my healthcare team to know about me that they would not learn from reading my medical chart?"

1. **Patient:** You, as the patient, are at the centre of all decisions about your care. It is important for your healthcare team to know who you are.

   How do I self identify? How do I want to be referred to (name, nickname, title, gender pronouns)? How do I define a good quality of life? What are my coping skills? What are my strengths? Where do I need support?

2. **Place**: The physical place that you receive information may affect your comfort level, and how much information you are able to process.

   How do I respond in new environments? Do I need a quiet place, or a darker place, for my appointments? What would make me more comfortable at appointments?

3. **Personnel:** The healthcare professionals that you interact with are important sources of information and support.

   Who is on my healthcare team and what are their roles? Would it help if I saw the same person consistently? Do they know the most important information about who I am (gender identity, cultural background, communication preferences, learning style, neurodivergence)? Would I benefit from a patient navigator? Would I benefit from a translator and/or an interpreter so that information is presented in my first language?

4. **Pace**: How slowly or quickly information is presented may affect how well you are able to understand.

   Do I need to ask my doctor and nurses to speak more slowly? Do I need a lot of repetition? Do I prefer plain/simple language or more medical/technical language? How much detail do I want? Does translation into my first language through a person or a device require extra time?

5. **Platform:** The way information is presented may have an effect on how well you are able to interpret that information.

   Do I learn best by reading? Listening? Seeing pictures and images? Watching videos? Do I need any assistive technologies to support effective communication? Would it help to record my appointments? How am I able to contact my healthcare team? Virtual appointments? Phone? Email? Do the members of my healthcare team know about these needs and preferences?

6. **Physicality:** Some people, particularly those who identify as neurodivergent, have sensory issues that should be considered.

What physical supports do I need? Do I have any sensory issues? (eg. light or sound sensitivity) Would noise reducing headphones help me relax in waiting rooms and treatment rooms? How can I best communicate these needs to my healthcare team? How have I experienced and expressed discomfort, pain, or distress in the past? Do I have difficulty articulating sensations? If I have experienced trauma or assault in the past, how can I ensure that I feel safe and supported during my cancer treatment?

7. **Preparation, planning, and predictability:** Many people find safety and comfort in routine, and these can be challenged in the course of cancer treatment.

   How can my healthcare team help me prepare for the unknowns of cancer treatment? Can any treatments or procedures be adapted to manage my pain, anxiety, or discomfort? What can I expect from my treatments? How can I develop a predictable routine? What other areas of my life may be disrupted by my cancer treatment and how can I make pre-arrangements? Can I pre-arrange meals, speak to my employer, arrange for childcare, pet care? What can we do to keep things as predictable as possible throughout my ovarian cancer experience?

8. **Processing:** Everyone processes new information differently. We all have different needs in order to fully understand what we are being told.

   What helps me understand new information? Do I need a quiet place to think? Do I need to write down my questions as they come to me? Do I need to audio record my appointments? Do I need longer appointment times? Who might I ask if this is possible? Do I need to bring a *support person to help me ask questions and make decisions? Who can I contact if I have questions after an appointment? How can I reach them?*

9. **People:** The people around you, like your friends and family, can help process all the new information that you are being given.

   Who helps me on a day-to-day basis? Who do I trust? Who do I want at my appointments and at my treatments? Can people attend virtually? Who do I need for at-home support following surgery and other treatments? Do I need the support of a homecare nurse and/or personal support worker? What do I need from my healthcare team to facilitate these needs?

10. **Patience:** You may need more time to process what you are learning. It is okay to ask your healthcare team to have patience with you, and it is important to remain patient with yourself.

    How can I tell my healthcare team that I don't understand something or that I need them to slow down? Who can I turn to for clarification when I don't understand something? How can I be patient with myself while I go through my ovarian cancer experience?

Here are some additional questions that you may want to ask your healthcare team:

About your cancer:

"What type of ovarian cancer do I have? Please explain."

"What is the stage of my cancer? Please explain."

"What is the grade of my cancer? Please explain."

"Should I get a genetic test?"

About your treatment:

"What are my treatment options?"

"Why have you recommended this particular treatment for me?"

"What resources can you provide to help me better understand my options?"

"How often will I get treatment? For how long?"

"What side effects can I expect from my treatment? How do I manage them? What can we do if the side effects are unbearable?"

"What happens if I want to stop treatment?"

"How will treatment affect my work? When can I go back to work?"

"How will treatment affect my physical activity levels?"

"Will treatment affect my fertility? Can my fertility be preserved?"

"How will treatment affect my sex life?"

"Should I consider being on a clinical trial? Where can I learn more about clinical trials? How do I find out about clinical trials that I may be eligible for?"

"Is all my treatment covered by my provincial/territorial health insurance? If not, what are my funding options?"

For more support:

"Where can I get more information about ovarian cancer and its treatment?"

"What do I do if I have questions after an appointment? Who can I call?"

"What should I be eating? Can you please refer me to a registered dietician?"

"Where can I meet other people affected by ovarian cancer?"

"What complementary therapies do you suggest that might be helpful for me?"

"I have a disability. What can be done to accommodate my disability throughout my ovarian cancer experience?"

"I identify as neurodivergent or on the autism spectrum. Are there specific resources for me?"

"I am Indigenous and would like traditional cultural knowledge incorporated into all aspects of my care. Can you please refer me to an Indigenous Patient Navigator?"

"I am a trans man/nonbinary person/do not identify as a woman. Are there supports and resources at my cancer centre for members of LGBTQIA+ communities?"

"I would prefer to communicate in my first language. Can we please have an interpreter present at all my appointments and treatments?"

"I would like to discuss some of my unique needs with a registered social worker. Can you please refer me to one?"

CAN I ASK FOR A SECOND OPINION?

Getting a second (or third) opinion is very common in healthcare, particularly cancer care. You do not need to worry about upsetting your doctor if you ask for a second opinion. They are very used to this request and understand that many people are looking for as much information as possible.

It is your right to ask for a second opinion, if you want one.

If the second opinion confirms the first doctor's diagnosis and recommends the same treatment plan, it may give you peace of mind. If the new opinion is different, you may need more information to help you decide what to do.

You can ask your oncologist to refer you for a second opinion. Or if you prefer, you can ask your family doctor to refer you to a different oncologist. Remember, this is very common practice.

You may be surprised to learn that differing opinions are somewhat common. Medicine is a science – but it is also an art. Healthcare providers have different perspectives, approaches, and styles of care. One approach is not necessarily better than the other – they are simply different.

If you do have concerns about the care you are receiving and would like to make a formal complaint, most cancers centres have a department dedicated to this process. You can call your cancer centre directly to find out what this department is called – it is usually something along the lines of "Patient Experience and Feedback", "Patient Care and Quality Office", or "Patient Relations".

For more advice to help you understand the clinical information being shared with you so you can feel confident and supported along your journey, watch *Ovarian Cancer Canada*'s video, "Mind the Gap" in our online resource library at ovariancanada.org

And remember, you can connect with an *Ovarian Cancer Canada* staff member to ask questions and discuss your ovarian cancer experience:

- Email: info@ovariancanada.org
- Phone: 1-877-413-7970

“In my case it was better to be open about having ovarian cancer and I have not regretted that. People have been very kind and thoughtful. It was truly up to me to decide what I wanted to say and what I wanted other people to know.”

–ANITA

CHAPTER 08

HOW DO I TELL PEOPLE THAT I HAVE OVARIAN CANCER?

A cancer diagnosis, as with any health information, is very personal and intimate. Although your ovarian cancer will affect your family and friends, and those in your social circle, you may find it hard to talk to others about your experiences. This chapter will provide guidance as you think through how to talk to people about your ovarian cancer in a way that feels right to you.

HOW DO I TELL PEOPLE ABOUT MY DIAGNOSIS?

Your cancer affects all those in your close circle. Sharing the news about your diagnosis with your friends and family may be difficult at first. You will have to decide how much to tell them and when. Perhaps you don't want to burden them and make them worry. Maybe you are afraid they will avoid you because of your illness. Maintaining connection and open communication at this time is more important than ever. As you cope with ovarian cancer, the support of your friends and family will be invaluable and you may need to rely on them more.

It is up to you how and when to tell people about your diagnosis. There will be some people you will choose to tell right away, but you may choose to wait a while before you tell others. When you tell certain family members or friends, you might want to have someone with you for support who already knows about your diagnosis. For others, you may choose to write a letter or send an email. The written form will enable you to draft the news in a way that you feel is most helpful to the recipient. Again, it is up to you to decide what will be best for you and your loved ones.

What is beyond your control is how people react to your news. Some people will provide much comfort and reassurance, becoming closer to you because of the challenges you are facing. They will offer their support and be there when you need them. Others may surprise you and see you less often because they have trouble coping with your cancer, or they may worry that they will be a bother at a time when you are not feeling well. It may take time for certain people to come to terms with the changes in your life. Although a person's reaction may be disappointing, it is important to remember that it is not really a reflection of how much they care for you. Instead, it may be an expression of their own fears, worries, and insecurities.

Most often, sharing your news with your loved ones will bring you comfort and may put some of your fears to rest. Some people feel very alone and are afraid that they might become a burden. But speaking honestly and openly with your family and friends may ensure that they will be available when you need them and that they will be in touch with you regularly.

If you are single, you may feel especially vulnerable without a partner that you can count on. For the time being, you may need to ask others close to you to help you.

Once you have let people know about your ovarian cancer, keep in touch and don't hesitate to ask for help. Most people want to help but often don't know what will be useful to you. Take advantage of any offers and let people know specifically how they can help you. If you create a community of friends and family members you can count on, you will not have to go through this alone.

Here are some tips for talking to people about your cancer:

- Be direct.

- Consider how best to tell the people closest to you. You can do it in person or tell them over the phone or by email – each has advantages and disadvantages.

- Tell your family and friends what you are feeling and what you need. Accept that sometimes you may not know what you are feeling or what you need. Let them know that too.

- Be with people who are good for you. Different people are helpful in different situations.

- Understand that there are some people you can share feelings with and others who just want to do things with you or for you.
- Be prepared for a variety of reactions. Sometimes you will be surprised at the reaction you get.
- Ask people to do specific things to help. For example, they may be able to drive you to and from treatments, pick up groceries, care for your pets, or help with childcare.
- Find out from others who have cancer how they went about telling others.
- Seek professional support and assistance, if needed.

You may find that there is a lot of communication happening between you and people who are concerned about what is happening to you. This can be encouraging and supportive but could also become a little overwhelming.

The CaringBridge website enables you and your loved ones to easily create and maintain a free personalized web page to stay informed and updated about your treatment. Visit caringbridge.org

HOW DO I TALK TO MY CHILDREN ABOUT OVARIAN CANCER?

Your cancer might be especially hard on your children, particularly younger children. There are several things you can do to reduce their fears.

Although you may want to protect your children from knowing about your cancer, it may be best to tell them about it. When you speak honestly and openly about the cancer, it allows your children to express their feelings and to support you and others in your family. Letting your kids know what is going on maintains trust.

It is likely best to tell your children as soon as possible after you receive your diagnosis. If they overhear you talking about things that you are trying to keep from them, they will likely think your illness is much more serious than it is. If you feel too upset to talk with your kids, your partner, a grandparent, or a close family friend may be able to help.

How much you tell your children and how you tell them will depend on their age. Some things you may consider telling your children include:

- Tell them the name of the cancer.
- Describe some of the side effects of treatment – you might lose your hair, and you will likely feel very tired.
- Tell them that these side effects are normal when a person receives cancer treatment.
- They did not cause your cancer.
- They cannot catch cancer by touching you or being close to you.
- Nothing they can do can change the fact that you have cancer.
- Life at home may be different, but you, your family, and your friends will take care of their needs.
- They can do things to help you and other family members.
- There are other children whose parents have cancer.

You might want to consider taking an older child to see where you have your treatments or to be with you during treatment. Adult children may want to take on a more active role to support you at home or accompany you to doctors' appointments or treatment.

If your children ask about death, what you say depends on their age and level of maturity. It is important to be honest while you calm their fears and give a sense of hope. A response such as “some people die of cancer, but my doctors and nurses and everyone else on the team are working as hard as they can to help me get better” can help.

Here are some more tips for talking with your children:

- Trust your intuition as a parent.
- Let your children know if their routines will be affected, and how.
- Maintain routines and habits as much as possible. Continue to talk and interact with your children as you have always done.
- Give your children updates on your condition.
- Share your feelings and ask your children what they are feeling.
- You and your children may need to go over things that you have already talked about. After a time you may need to talk to them about your cancer in more depth. New questions, new situations, and new feelings may arise as time goes by.
- Consider family or individual counselling if you have trouble talking with your children about your cancer. Discuss this with a social worker at your treatment centre.

SHOULD I TELL MY CHILDREN’S TEACHER?

Your children's teachers need to know that something significant is going on at home. Teachers can watch for changes in your children’s behaviour, provide special help, and listen if your children want to talk.

SHOULD I TALK ABOUT MY DIAGNOSIS AT WORK?

Work is a very positive aspect of many people's lives. If you work, ovarian cancer will affect your work life. You will have to figure out how your ability to do your job may change and what to tell your employer/employees and co-workers about your illness. They may be supportive when they find out you have cancer. Some of them, or someone close to them, may have been affected by a serious illness as well.

But there may be a downside. Some co-workers may distance themselves from you if you tell them you have cancer. Your employer may wonder if you are still able to do your job. You will need to think about what you want and need to say, and how to say it, to your employer/employees and co-workers. Decide what feels most comfortable for you. If you are direct and honest, you can let them know what you feel and what assistance you may need to perform your job.

Here are some things to consider when talking about your illness at work:

- You may wish to talk only with people you are comfortable with and trust.
- Talking outside a work setting might be more comfortable.
- If the co-worker has family or friends who have been affected by cancer, they may be more understanding of your situation.
- You can be an educator about cancer in your workplace.

HOW DO I TELL MY EMPLOYER?

Some people want to tell their employer about their diagnosis right away, while others wait until they must tell them. This might be when side effects from treatment, such as hair loss, become obvious.

If you have to take a medical leave:

- Find out how the company has handled this in the past. You may want to ask a co-worker that you trust to explore this for you.

- What are the company policies about medical leave? What benefits does your employer offer?

- Find out about your legal rights. Human rights legislation prohibits discrimination on the basis of several criteria, including disability. Cancer is considered a disability under human rights laws.

- Have a plan that you can suggest to your employer about how you might work during treatment. You may be able to work from home, work part-time, or work with co-workers in creative ways.

Speak with your doctor. They may have advice about work issues. They may also need to write letters saying you are able to work, how much you may be able to do, or that you are unable to work. The social worker on your healthcare team and others living with cancer may be able to provide advice and guidance. You can also talk to community agencies or your provincial Ministry of Labour for advice about employment issues.

If you believe that your employer and/or co-workers are discriminating against you, write detailed notes about your experiences. Have your responsibilities been cut back? Are you being treated differently? Have your insurance benefits changed in any way? If you need to consult a lawyer, your notes will provide a record. The website of your provincial Human Rights Commission will have information on protecting your rights at work when you have an illness.

For further information about financial resources, programs, and coverage, please refer to in **Chapter 09**.

> **“I learned two lessons that I think are the hardest for a modern woman to learn: (1) stop being a super woman for everyone else and put myself first, and (2) ask for help.”**
>
> –CARRIE

CHAPTER 09

WHAT SUPPORTS ARE AVAILABLE TO ME?

Emotional and practical support is important during and after cancer treatment. People, groups, organizations, information, and services are available to provide that support.

WHAT SUPPORTS ARE AVAILABLE TO ME?

There are so many different ways to reach out for assistance. This chapter outlines some of the support that you may find helpful.

Many cancer support organizations across Canada, including *Ovarian Cancer Canada*, offer a variety of support programs, some of which can be found in local communities. These programs can include support groups, art therapy, yoga, exercise classes, peer-to-peer counselling, nutrition classes, education resources, financial information, and relaxation techniques. You can ask about these community organizations at your local cancer centre, or contact *Ovarian Cancer Canada* for more information:

- Phone: 1-877-413-7970
- Email: info@ovariancanada.org
- Website: ovariancanada.org

SHOULD I JOIN A SUPPORT GROUP?

A support group is a group of people with common experiences or concerns who can provide each other with encouragement, comfort, and information. Groups can meet in person or online. A support group can give you the chance to talk with others who are going through experiences like yours. Through support groups, you may get practical information you can use, or you may find that you feel less alone.

Being in a support group may help you to cope, communicate, and live better with ovarian cancer. You may also find that sharing what you have experienced helps other members of the support group. These are safe places to talk about things that you might not be able to share with other people in your life. Some people find that they can speak more freely with others going through a similar experience. You can join a support group at any time during or after your ovarian cancer treatment.

While participating in a support group, you will hear other people's stories, and you may feel many emotions. You may wonder if being in a support group is right for you. This is very normal, and that's okay. If you like, you can attend just a few sessions to build comfort and trust, and to decide if a support group is right for you.

If you live in a city, there may be many support groups available to you. If you live in a smaller town or more rural area, it may not be possible. In some communities there may be a support group available that include people with a variety of cancer diagnoses.

Many of the supports offered by *Ovarian Cancer Canada*, including support groups, are available virtually, so that you can join from anywhere. To learn more, please reach out at:

- Phone: 1-877-413-7970
- Email: info@ovariancanada.org
- Website: ovariancanada.org

There are many types of support groups. They may operate in different ways or have a special focus:

- A professional will lead some support groups. This could be a social worker, psychologist, or nurse.

- Peer leaders will lead some support groups. These are people who have had cancer themselves.

- Some support groups are specific to ovarian cancer. Others may be for all gynecological cancers (which are cancers of the female reproductive system).
- Some support groups are for all different types of cancers, may include men and women, and people of many different ages.
- Some support groups are for people who share a specific culture or speak a certain language.
- Some support groups are large and have a specific program with guest speakers at every meeting, while others have unstructured agendas.
- Some support groups are free, but for others you may have to pay a fee.
- Some support groups meet in hospitals and cancer centres, while others meet in the community.
- Some support groups are virtual, while others are in-person. Virtual support groups are a good option for people who live in more rural or remote communities, or for people who are in treatment and not feeling well.
- Some support groups are for caregivers and children.

In addition to cancer support groups, other groups in your community can support you. These might include interest groups or classes at women's centres, at your place of worship, at a community centre, and so on.

HOW DO I FIND A SUPPORT GROUP?

Please visit ovariancanada.org to learn more about our support group offerings.

WHAT IF A SUPPORT GROUP IS NOT RIGHT FOR ME?

Some people do not like support groups, and that is okay. It also might not be the right time for you to join one, and that is okay, too. Your needs and preferences are the most important and may change over time. Some people prefer to talk to other people affected by cancer over the phone, by email, or by text message. Some prefer to see a professional (such as a therapist, social worker, clergy member) for one-on-one support. Online discussion forums may be useful for people who don't like to be part of face-to-face groups or who are unable to get to in-person meetings. As a member of an online community, you can choose to be as active as you like or stay in the background and just read the discussions. Regardless, we are here for you.

Lastly, some people are just not in a place to reach out for support. Remember, there is support available if and when you think you may need it.

SHOULD I CONSIDER COUNSELLING?

Sometimes it is necessary to reach out for professional help for you and/or your family. This is very healthy, quite common, and nothing to be embarrassed about. You are dealing with so many new experiences and it is normal to feel overwhelmed, confused, angry, sad, etc.

If you feel you and/or your family may benefit from some professional support, here are some places to start:

- You can ask your medical team to refer you for counselling.
- If you have health benefits through your employer, those benefits may include a free Employee Assistance Program.
- Check with your local municipal or provincial family services office.

- Ask your family doctor for a referral to a respected and qualified counsellor or therapist.

- If you have a friend or family member that you know has benefited from professional counselling, you can ask them to connect you.

WHAT PRACTICAL SUPPORTS WILL I NEED?

You might find that you need help at home with practical support and self-care. There are nursing services, personal support workers, and home health aides to assist you with your recovery or to help you maintain your independence. Please note that the title of these professionals will depend on which province or territory you live in. You can check with a social worker at your cancer centre about home care services and assistance with meals. They will be able to provide information about home and community support, and provide some coordination of services.

A few things to consider:

- If you have an extended health or other benefit plan, check what services and equipment are covered and find out whether you need authorization before purchasing them.

- A doctor or other healthcare professional will need to provide a requisition for Community Care Services and some extended health plans. You can ask them for a referral, or for a letter.

- The Canadian Cancer Society may be able to provide transportation by volunteer drivers, locally and out of town.

HOW WILL MY RELATIONSHIPS CHANGE?

In our relationships with friends and family, we all play certain roles. You will likely find that these roles will change during your ovarian cancer experience. Whether you are part of a couple, a single parent, or live alone, you and your loved ones will experience a period of adjustment as everyone adapts to their changing roles. You may find that your partner, children, parents, siblings, and friends need more attention during this time. The following are some things you may want to consider so that this transitional period goes as smoothly as possible:

- Set up a household plan in which duties and tasks can be shared. Some things may simply have to be taken off the to do list, at least for the time being, and that is okay. If possible, try to make sure no one is overburdened. Talk with one another kindly, be patient, and reach out to others for support when possible.

- Your children may want to help out and feel like they are contributing. You can allow them to do so. As the person going through cancer treatment, you need to save your energy. It's okay to ask others, including your children, for help. You will often find that when you ask, they are willing to help. You may need help with concrete things such as transportation, taking the kids to school, childcare, shopping, and housekeeping. If you have the financial resources to do so, consider hiring someone, if only for a few hours every week.

- If your children are older and do not live with you, tell them what is going on. They will likely want to make themselves more available to you and keep in touch more often.

- It is extra important to ask others for help If you live alone or your family is not nearby. Consider who in your network you could ask. Remember, there are community care supports available, and these supports will have different names depending on where you live. You can start by asking your medical team, or searching online for "community care support services" in your area.

- If you have pets, then you know that they are sources of affection and comfort. You may need to ask others to help you care for your pets, perhaps by walking your dog for you. You can ask a neighbour who also has a dog to take your dog with them when they go for their daily walks. Or, if you are financially able to do so, you can research local dog walkers and dog daycares in your community.

WHAT FINANCIAL SUPPORTS ARE AVAILABLE TO ME?

Ovarian Cancer Canada staff members are not financial professionals and the information in this guide should not be the only source of information you consult on how to best manage your finances. The information provided below does not represent all the information that you may need.

Many people have financial worries when they are diagnosed with cancer: What will happen to my income? How long will I be off work? What financial benefits might I receive? How will I pay for any treatment expenses not covered by provincial/territorial insurance? Will I be able to travel?

The funding and financial resources available for each person are unique, based on income, contributions to various programs, assets, and options. You may use a combination of resources.

You can take a number of steps to manage your finances while you are receiving and recovering from cancer treatment:

- **Make a plan:** What money and coverage can you access? How much can you expect and when? Learn all you can about the income programs that might be available to you (see below for some information on this). You will need to know if they are asset-tested (that is, support is based on how much money you have). It is also important to know about the various definitions of illness or disability that are used in order to qualify.

- **Find people and agencies to support and guide you:** Do you have any friends who know a lot about finances that you trust and who can help you? Do you know people with cancer (or other serious illnesses) who have gone through this and can give you advice? Your hospital social worker, federal and provincial/territorial government programs, community agencies, and community legal clinics can all help. You may also wish to consult a financial advisor or a credit-counselling agency.

- **Use the internet:** Most federal and provincial/territorial government programs have a website. When searching for programs specific to your province/territory try searching "financial benefits and assistance in X province/territory". For information about benefits at the federal level, please visit canada.ca/en/services/benefits.html

- **Get your doctor's help:** You will need to ask your doctor to provide medical records and to fill out forms. They will have to complete them with all the details and within deadlines. Ask your doctor if you will be billed for this service. Is your doctor willing to help you with this? Does your doctor believe that you meet the criteria for various programs? Understand that it may take some time for your doctor to complete the necessary paperwork. Ask well in advance of your deadlines.

- **Keep copies of medical reports:** Make sure these reports are as detailed as possible. You may need them if you apply for financial assistance and other benefits.

- **Keep a treatment journal:** Write down any treatments, tests, and procedures that you have. Also make notes about how they affect you physically and emotionally.

- **Be patient and vigilant:** Working with government programs, health insurance companies, and community agencies can take a lot of time. Patience will help you deal with the delays, bureaucracy, and stresses that are bound to come up. To stay on top of things, consider:
  - Marking important application deadlines in your calendar and set follow-up dates to contact the agency or program administrators to check on the status of your application. It is very normal to follow-up frequently and to ask questions.
  - Keeping track of any application numbers that you are given when you submit anything to the government.
  - When speaking to an agency or program administrator, ask for their name (or ID number). This may prove to be very helpful if any issues come up, and you need to provide more information about the process.

SOURCES OF FINANCIAL SUPPORT

Income resources can be separated into four categories:

- Contribution programs, including Employment Insurance Benefits (EI) and Canadian Pension Plan Disability Benefits. Both of these are federal government programs.
- Asset-tested programs, which are usually municipal or provincial/territorial programs, sometimes called social assistance, welfare, or disability benefits. Each municipality and province/territory operates under its own rules and legislation.
- Income programs from your employer, which may include short-term and long-term disability payments.
- Personal assets that are unique to each person. These can include liquid assets (easily turned into cash) such as

savings, investments, and retirement savings plans, plus other assets such as life insurance policies and property.

- Other valuable resources for coping with the cost of your illness include medical and drug coverage.

  Coverage may be available through:

  - Extended health plans with your employer.
  - Personal health plans you purchased yourself.
  - Municipal or provincial/territorial drug benefits programs.
  - Federal drug coverage programs for refugees and refugee claimants.

CONTRIBUTION PROGRAMS

Employment Insurance Benefits

If you have to stop working, you may qualify for EI. To access these benefits, you need to have contributed to the EI program through your employer and to have worked for a required number of hours. EI provides a special sickness benefits program.

To apply, complete the online application form at servicecanada.gc.ca and submit a medical certificate and all Records of Employment (ROE) received from your employer.

EI sickness benefits are usually paid for a maximum of 15 weeks and pay a maximum of about $500/week. There is a two-week waiting period before benefits start, and it usually takes at least four weeks to receive your first payment. If you are still working part-time, employment earnings will be deducted dollar-for-dollar from your EI sickness benefits.

Canada Pension Plan – Disability Benefits

This is a federal government program for people between 18 and 65 years of age. There are very strict eligibility criteria for this benefit and a review of the application can take a long time. Visit servicecanada.gc.ca for more information.

ASSET-TESTED PROGRAMS

Provinces/territories and municipalities offer financial assistance to their residents. Each province/territory and city or town is different, so you will need to find out what your province/territory or municipality offers. You can check the websites for your province or territory and your municipality to find information about income replacement and other programs for those dealing with an illness. Provincial/territorial/municipal websites will have a search bar where you can type key words such as “financial assistance or income/financial programs”. These programs are generally available to applicants who have a low asset and income level. The following may be included:

- Emergency financial assistance, such as welfare and social assistance.
- Provincial/territorial disability programs, which usually pay more and offer better health benefits, (such as drug, dental, or vision coverage, and some services for returning to work).
- Coverage for special needs (such as wheelchairs, walkers, and canes) and home-healthcare needs.

INCOME PROGRAMS FROM EMPLOYERS

Many companies offer their employees wage protection programs such as short-term and long-term disability benefits. Learn all you can about what benefits your company offers by reading your benefits book or by talking to someone in the human resources office or to the claims adjudicator at the insurance company.

To apply for these benefits, you will have to complete an extensive application process, and your doctor will need to provide medical documentation. You need your doctor's support because their medical evidence is extremely important to this process.

Be discreet about giving out your information to individuals other than the insurance company. Your employer does not need to know details of your medical condition. Consider how your employer knowing that information might affect your taking a leave from your job or returning to that job after being away for a time. To make sure medical information is confidential, it should go to the insurance company, not to your employer.

Remember, you are still an employee of the company while you are on short or long-term disability.

Short-term disability

Short-term disability payments cover a certain number of weeks away from work and cover part or all of your wages. The amount of time covered and the size of the payments depend on the benefits plan your employer offers. Make sure you ask the following questions:

- What conditions apply and what do the benefits cover?
- How do disability benefits work with EI benefits?
- Do payments start right away or is there a waiting period?
- How much does it pay?
- What documents are needed to apply?

Long-term disability

Long-term disability benefits usually begin six months to a year after you have stopped working because of ill health. The starting time depends on the contract that was negotiated between your employer and the insurance company.

Make sure you ask the following questions:

- What conditions apply and what benefits do they cover?
- How does long-term disability work with short-term disability and EI?
- Will my long-term disability benefits be taxable income? (If you paid a long-term disability premium when you are working, your long-term disability benefits may be tax free).
- What is the definition of disability that will be used?
- Does your doctor have enough information to support your application?
- Will your long-term disability payments be reduced if you receive other income, including the Canada Pension Plan?

PERSONAL ASSETS

Before using any of the options described below, investigate them carefully. Read all the documents related to the asset and ask a financial advisor or insurance company about anything you don't understand. Some of the strategies may affect your eligibility for some government programs or may be taxable income.

Life Insurance

Life insurance policies may be turned into funds you can use now.

- **Cash surrender policy:** By surrendering your policy, you are in effect cancelling the policy and taking back a small percentage of the full value of the policy. Usually, the amount you receive equals what you have contributed to date through premiums. You will need to check your policy to see if this option is available.

- **Disability premium waiver:** If you are not able to make an insurance premium payment, some life insurance companies offer a waiver of premiums for a certain period of time. Your policy documents should give you details about this option if it is available to you.

- **Living benefits:** These benefits are an advance on part of the value of a life insurance policy, usually up to 50%. If your policy allows for this option, you will need to supply medical documents from your doctor that indicate that you have a shortened life expectancy, usually less than one or two years due to your illness. Your doctor will need to fill in various forms. Living benefits income is taxable income. Each year that you survive, tax is taken off the remaining amount. Upon your death, the amount that remains goes to your beneficiaries.

OTHER ASSETS

Investigate other assets that you may have. If you have made large purchases such as a home or an automobile, you may have purchased insurance on the loan. Some people also have insurance to cover credit card balances and bank account overdrafts. This insurance may have a long-term disability waiver clause. If you are unable to work because of poor health and cannot afford to meet the payments for your mortgage or car, this insurance may cover payments and allow you to keep your home or care. You will need to apply for this benefit and supply medical documentation.

You may be able to cash in or sell investments, savings, retirement savings plans (RSPs), and similar assets. Find out about the regulations, possible penalties for cashing in the assets, and the effect on your taxes. Speak with your bank manager, investment specialist, or financial planner about the pros and cons of using these assets. If you have debts, credit counselling may also be helpful.

MEDICAL AND DRUG COVERAGE

Your provincial/territorial health insurance plan

Most of your healthcare costs will be covered by your provincial/territorial health insurance plan. If you move to another province or territory during your treatment, find out how to apply for the provincial/territorial plan there. Ask if there is a waiting period before you are covered. In most cases you have to be a resident for a minimum of three months to obtain provincial health insurance. Your previous province/territory may continue to cover you until your new coverage starts.

If you are not covered for a period of time under the provincial/territorial plan, you may need to think about buying private health insurance. If you purchase private insurance, carefully review the policy because companies often do not cover some or any costs related to a pre-existing condition (but will cover costs for other things). Ask questions before you purchase the policy – it is better to be informed from the start.

If you travel outside of Canada, you will need to know the following:

- What medical services will your provincial/territorial health insurance cover while you are away?
- Will you need to pay up front for medical treatment you receive in other countries?
- Will you need to buy private insurance? Your travel insurance company will want to know details about your health and about any illness that may exclude you from their coverage. There may be limits on how long, and for how much, it will cover you. Again, know the policy in detail before you buy it. In some cases, you may not be able to purchase travel insurance because you have cancer.

Provincial/territorial drug plans

You do not have to pay for medications that are given to you while you are in the hospital. However, in most provinces/territories, once you go home from the hospital, you are responsible for the cost of any prescribed medication. Standard chemotherapy drugs are usually covered by your provincial/territorial health insurance plan, but other drugs may not be. These drugs may be covered under group insurance through your (or your spouse's) employer. If not, find out if there is a provincial/territorial drug plan that can help pay for your medications. Not all provinces/territories cover all medications, so find out if the drugs you are taking are covered.

You can also ask a social worker at your hospital or cancer centre if there are foundations or drug companies that may be able to help with drug costs.

Pharmaceutical company patient support programs

Some pharmaceutical companies provide support and reimbursement for the cost of some of their products. Specifically, Astra Zeneca and GSK, which are the manufacturers of Lynparza (olaparib) and Zejula (niraparib), respectfully, offer financial reimbursement for eligible patients:

If you are on Lynparza (olaparib) or Zejula (niraparib), you can reach out to their manufacturers directly to learn more:

Lynparza (olaparib) Support Program:
- Phone: 1-877-280-6208
- Email: enrollment@azoncologypsp.ca
- Website: lynparza.com/resources-support/my-lynparza-support-program.html

Zejula (niraparib) Patient Support:
- Phone: 905-819-3000
- Email: cacsu@gsk.com
- Website: zejulahcp.com/access-support/patient-support

HOW SHOULD I BE EATING?

If you have specific questions about what you should be eating, perhaps based on the specifics of your ovarian cancer experience and how you are responding to treatment, be sure to ask your medical team to refer you to a registered dietician (RD) at your cancer centre. RDs are registered health professionals and experts in food and nutrition science. Some RDs specialize in oncology, meaning that they are experts in helping you make the nutritional choices that are best for you. You will find RDs especially helpful if parts of your gastrointestinal system are removed during surgery.

It is important to find ways to nourish yourself during your ovarian cancer treatment (and beyond) with the foods that you need and will also enjoy. Many people who have been through cancer treatment recommend batch cooking, which involves cooking larger amounts of food in advance that can be stored or frozen easily. This is an excellent way to plan your meals and optimize the time and effort that you spend in the kitchen.

When planning these meals, culinary experts recommend focusing on the following priorities:

- Finding foods that freeze well.
- Learning how to properly freeze foods for storage.
- Learning about food safety.
- Finding recipes that you will enjoy!

Tips for freezing food:

- Allow the food to cool down to room temperature before you put it in the freezer.
- Avoid trapping air when freezing food (this could lead to freezer burn or food spoilage). Wrap/store your food very tightly, using parchment paper or plastic wrap.

- Label all your frozen foods (type of food and date of freezing).
- To prevent loose foods (such as pieces of fruits or vegetables) from freezing in a clump, first place them on a baking tray, spread them out, and place them in the freezer. Once they are frozen, you can store them in a freezer bag, and they will not clump together.
- Use ice cube trays to freeze sauces, purees, dressings, and other similar items. Then, place the frozen cubes in a freezer bag. You can do the same with fresh herbs – just chop them up finely and add water, place them in an ice cube tray, and add water. You can then add one of the frozen herb cubes directly into a soup or stew.
- Do not freeze raw food once you've thawed it.

Some food items do not freeze well, including:

- Eggs
- Creamy dairy products (yogurt and creams)
- Vegetables with high water content (cucumbers, lettuce)

A few ways to thaw frozen foods include:

- Put the food in the fridge.
- Use the defrost setting on your microwave. This is especially good for leftovers. If you are defrosting raw frozen foods, this process may start to cook the food, so be sure to use it right away.
- If a frozen food is well sealed, you can cover it in water to defrost it. Be sure to change the water every 30 minutes until it is completely defrosted.

Food safety for weakened immune systems	
Storing cooked leftovers	• It's not safe to leave some foods at room temperature for too long. Be sure that leftover foods cools down quickly. Store them in the fridge/freezer right away. • When you have a large amount of leftover food, divide it into small, shallow containers. This will help it to cool down quickly. • Cover containers with a lid or tightly sealed plastic wrap, and label with the item name and date. • Refrigerate or freeze cold leftover food within two hours of cooking it. • If you do not plan to eat leftovers within 2-3 days, put them in the freezer.
Storing canned leftovers	• Leftover canned foods (canned tuna or salmon) should be put into a glass container, covered with lid or tightly sealed plastic wrap, and labeled. Store in the fridge and use within 2-3 days.
When to throw out leftovers	• Leftover food that has been in the fridge for 3+ days should be thrown out. • Food that has been at room temperature for 2+ hours should be thrown out.
Safely reheating food	• When reheating food, the internal temperature of the food must reach 74˚C (165˚F). • Use a digital food thermometer to check internal temperature. Clean the thermometer with soap/water after. • Stir soups/stews/sauces when reheating to ensure the heat is evenly spread.

Figure 12: Food safety for weakened immune systems

For more general food safety tips, visit Health Canada's webpage on Safe Food Storage.

You may have noticed changes to your bowel habits as a result of treatment. If so, please watch *Ovarian Cancer Canada*'s webinar, “Improving Bowel Habits Through Diet”, available online in our resources at ovariancanada.org

SPECIAL RESOURCES

- Visit the Caregiver Action Network’s website at caregiveraction.org
- If you are a veteran, a member of a First Nation, have a disability or are a member of another group that may receive federal or provincial/territorial assistance, check what benefits may be available to you.
- Contact your local health authority or Community Care Services to have a financial assessment to determine your needs and the costs involved. Usually, assistance is scaled according to your family’s income and assets.
- The cost of nursing and personal care may be subsidized, but housekeeping tasks, such as cooking and cleaning may not be.
- You may claim medical equipment, services, and other expenses that you had to pay for as deductions on your income tax return. You may also be eligible for the federal disability tax credit. Find more information on the Canadian Revenue Agency website at canada.ca/en/revenue-agency.html
- Find credit counselling in your area if you are in debt or want to consolidate debts.
- If you have legal concerns, your local legal aid office or community legal clinic may be of help.

> “You may find yourself in treatment tunnel vision. Just making it through to the end. And then you get to look back and process everything.”
>
> –VICTORIA

CHAPTER 10

WHAT DOES CANCER “SURVIVORSHIP” ACTUALLY MEAN?

The term “survivor” can be a divisive one. Some people find it empowering, while other people reject the label. Regardless of how you feel about the term “survivor”, you will likely hear many people in your life and on your healthcare team talk about “cancer survivorship”. This chapter will help you better understand what is meant by “survivorship”, and how to take care of yourself during the “survivorship period”.

WHAT DOES CANCER “SURVIVORSHIP” ACTUALLY MEAN?

Cancer survivorship is a relatively new term that was coined in response to the fact that more people than ever before are surviving cancer and adjusting to a “new normal”. Survivorship care is concerned with the well-being of a person from the time of their cancer diagnosis until death (the cause of death may be cancer, or a completely unrelated cause, such as “old age”). Survivorship care focuses on the many areas of one’s life that cancer affects – a person’s physical, mental, emotional, social, and financial wellbeing. Survivorship experiences include follow-up care related to the person’s cancer, as well as their regular medical checkups, the late and/or lasting effects of their cancer treatment, cancer recurrences, and quality of life.

Take some time to think about your survivorship needs, and the new normal of your life post ovarian cancer treatment. What is different now? What support do you need?

WHAT WILL MY LIFE BE LIKE AFTER TREATMENT?

Many people are surprised by the overwhelming emotions that they feel after they are finished treatment and are trying to adjust to their new normal. For many, they push their emotions aside just to get through the treatment phase, and then are faced with incredibly difficult and confronting emotions when treatment is complete.

Don’t be surprised if this is your experience. Going through an ovarian cancer diagnosis and treatment is shocking, and this shock may prevent you from processing what has happened to you. It is very normal for these emotions to come rushing to you once the dust settles after treatment.

Each chapter of this guide includes information about the supports and resources available to you to help you navigate this time of your life. Refer to additional chapters as you see fit and reach out to *Ovarian Cancer Canada* for assistance and to connect you with others in the community.

After completing treatment, you will have ongoing follow-up appointments with your oncology team. For more information about what to expect at these appointments, please read **Chapter 06: What can I expect during my follow-up care?**

Here is a list of approaches that may help you manage your emotions during this time:

- Accept that there may be times when you feel angry, annoyed, or sad.
- Take one day at a time. Be grateful for every good day.
- Do things you enjoy or that help you feel close to loved ones.
- Try to practice mindfulness by paying attention to your present surroundings – sights, sounds, tastes, smells.
- Take time to reflect on what you are going through. Writing in a journal can be a helpful way to do this.
- Don’t rush into a routine – give yourself time.
- If you decide to go back to work, make sure the schedule is realistic for you. Ask your employer for the supports that you need for a successful transition back to work.
- Share your thoughts with others – these could be your family and friends, or a support group.

- If spirituality is a part of your life, you may wish to speak with the leader of your spiritual or religious group.

- Get the support you need from your family doctor or the social worker or counsellor on your healthcare team.

If at any time you are feeling depressed and hopeless, get professional help right away from a social worker, psychologist, or psychiatrist at your treatment centre or in your community.

WHEN SHOULD I GO BACK TO WORK?

If you were working before your diagnosis and treatment, the question of when to go back usually comes up when you finish treatment. It can take a long time to recover physically from all that has happened. How long depends on your treatment – surgery, chemotherapy, and/or radiation. It may also take some time for side effects to fade.

You may also need some time to recover from the emotional impact on you and your family and to regain a sense of control over your life. Give yourself time to recover and resist the temptation to take on too much too soon. It is important to discuss returning to work with your healthcare team and to consider your personal situation and what is best for you. You are the one who can best determine what you are ready for and when. You might want to ask whether there is a return to work class or seminar in your area.

HOW DO I GET BACK TO "NORMAL"?

As time goes on, a "new normal" evolves. To help yourself cope with a serious disease, you may have shifted your perception of the future. Many people express this as a change to living in the moment or focusing on today. Dealing with ovarian cancer is a very complex experience and you may have lost something you took for granted in the past:

your health, your hair, your routines, your certainty about the future, and/or your ability to have biological children. Sadness or grief can come from any loss and it can take time to heal. At the same time, you may be surprised with how you have handled all the things that have happened. You may feel grateful for all the support you have received and actually feel stronger and wiser from all you have learned throughout your ovarian cancer experience.

Cancer is something that has happened to you – it is not who you are.

> **“[I’ve had] three recurrences… and after ten years I’m still here and going strong.”**
>
> –HELEN

CHAPTER 11

WHAT IS AN OVARIAN CANCER RECURRENCE?

What is an ovarian cancer recurrence? Why did it happen to you? You may be feeling shocked, confused, and scared. You may be asking yourself some very difficult questions, including if or when to start treatment, and you may be worried about your survival. Understanding ovarian cancer recurrences can help you better grasp what is happening. We're here to help you understand and this chapter will provide more information to support you.

WHAT IS AN OVARIAN CANCER RECURRENCE?

After your initial treatment of ovarian cancer (also called "frontline treatment"), there can be different outcomes:

- **No evidence of disease (NED):** there is no evidence of cancer on imaging tests, clinical examination, or blood work.

- **Stable disease:** the cancer is still present, and scans and tests reveal no change in your condition over time.

- **Disease progression:** evidence of growth of known cancer (either on or off treatment). If there is no cancer-free time, then cancer growth would be considered a progression, not a recurrence.

- **Recurrence:** evidence of cancer following a period of time where there was no evidence of disease.

WHERE DOES OVARIAN CANCER RECUR?

The ovarian cancer may come back in the same location as the original cancer, or in another part of the body. Cancer cells that remain after the first treatment can start to grow again in the same places, or travel to other tissues and organs. The speed at which they grow and spread can vary. If the cancer recurs in a different part of the body such as the liver, it is still called ovarian cancer as the cancer started in the ovary (i.e. it is not called liver cancer).

Common parts of the body where ovarian cancer can spread:

- The peritoneum (the membrane lining the inside of the abdominal cavity and the surface of all organs in the abdomen)
- Lining of the bowel
- Lining of the bladder
- Liver
- Lungs

WHY DID MY OVARIAN CANCER COME BACK?

Not everyone will experience a recurrence, but for many, there is no evidence of the disease for a period of time, and then the cancer comes back. Your initial treatment may have slowed or stopped the growth of the cancer, but a recurrence means that the treatment did not remove all of the cancer cells from your body. The following factors influence the likelihood that an ovarian cancer will recur:

- **Grade:** the grade of an ovarian cancer refers to how abnormal the cancer cells look compared to normal cells. This indicates how quickly the cancer will grow. Please see **pages 23–24** for more information on grades of cancer.
- **Stage:** about 75% of people diagnosed with ovarian cancer in Canada are diagnosed at stage 3 or 4. This means that the cancer has spread beyond the ovaries to other parts of the body. Please see **pages 25–29** for more information on cancer staging.
- **Type:** there are many different types of ovarian cancers, and some are more likely to recur than others. Please see **pages 18–23** for more information on the different types of ovarian cancer.

It is very normal to ask yourself if there is anything you could have done to keep your ovarian cancer from recurring, such as eating differently, exercising more, taking vitamins, or managing stress better. Although research finds that there are many positive effects of these activities for your overall health, they do not prevent ovarian cancer recurrences. Recurrence is not a result of something that you did or did not do—it is the nature of the disease. It is not your fault.

WHY DOES OVARIAN CANCER RECUR AT A HIGH RATE?

This is a complicated question to answer, but in general, the high ovarian cancer recurrence rate is associated with when and how the cancer spreads. The most common type of ovarian cancer, which is high grade serous ovarian cancer, spreads early in the disease and spreads throughout the peritoneum (membrane lining the inside of the abdominal cavity and the surface of all organs in the abdomen). It is not a large mass that grows into a larger mass that can be easily seen and “cut out” by a surgeon. Instead, the cancer cells scatter throughout the abdomen, leaving behind tiny deposits of cancer cells. Although surgeons do their best to remove all these cancer cells during surgery, these cells are very small—not visible to the naked eye—and surgeons cannot remove cancer cells that they cannot see. This is why chemotherapy is used after surgery, to kill remaining cancer cells that could not be seen during the surgery. Chemotherapy, unfortunately, will not always kill all the remaining cancer cells.

WHAT IS MY PROGNOSIS?

Being diagnosed with a recurrence of ovarian cancer can be very scary. You may find yourself thinking about dying, and you may wonder if that is now more of a reality. Although it is understandable to be feeling this way, it is important to understand that many people will go through cycles of no evidence of disease (NED), followed by a recurrence, then back to NED. You may have multiple recurrences and times of NED over a period of many years.

Although recurrent ovarian cancer is not curable, it is treatable. Many people can live for years with a good quality of life. The goals of treatment at this point will have shifted from curing the cancer (this was the goal of frontline treatment) to controlling the cancer and stabilizing it, as well as managing any symptoms. You may find it helpful to think of recurrent ovarian cancer as a chronic disease that you will have to manage, like diabetes or heart disease. For many, they consider their recurrent ovarian cancer as a long-term condition, and they continue living their lives with ongoing treatment and a satisfactory quality of life.

> “I quickly realized that going on a guilt trip was not going to help anything and that I needed to set my mind on fighting the cancer again.”
>
> –MARILYN

CHAPTER 12

HOW IS AN OVARIAN CANCER RECURRENCE TREATED?

Chapter 04 provides an overview of how ovarian cancer is treated. If you've been diagnosed with a recurrence of your ovarian cancer, you likely have many of the same questions and emotions that you did when you were first diagnosed, such as *"How will my cancer be treated?" "What options are available to me?" "When should I start treatment again?"* This chapter will guide you through some important information about treating ovarian cancer recurrences and answer many of the questions that you are likely asking yourself.

HOW IS AN OVARIAN CANCER RECURRENCE TREATED?

The answer to this question will depend on many factors, including how long it has been since your original treatment. In general, however, chemotherapy is the recommended treatment for recurrence. This chapter will discuss many questions you may have including the goals of treatment for recurrent ovarian cancer, when you should start treatment, what to ask your oncologist, if you should consider complementary therapies, and more.

WHAT ARE THE GOALS OF TREATMENT FOR RECURRENT OVARIAN CANCER?

As discussed in **Chapter 11**, the goals of treatment will shift with a recurrence. The goal of treating ovarian cancer when it is first diagnosed is for the cancer to never come back. If the cancer does return, however, then the new goal is to help you live as long as possible and as well as possible with your cancer. Ovarian cancer is now a chronic disease that needs to be managed.

WHEN SHOULD I START TREATMENT FOR RECURRENT OVARIAN CANCER?

Many people diagnosed with a recurrence are not sure when to start treatment again. The right answer will vary for every patient. You and your doctor (and your caregivers) will work together to determine the best time for you to start treatment. And if you do not want to start treatment again, that is your decision.

If you struggled with chemotherapy during your first treatment and your symptoms are mild, you may decide that you do not want to start treatment. If the symptoms of recurrence become more significant and bothersome, then you may want to talk to your doctor about starting treatment sooner.

Many people think that they need to start treatment for a recurrence as soon as possible, but research has found that there is no survival benefit associated with starting treatment for a recurrence before symptoms develop. This is why recurrence monitoring relies on an assessment of any symptoms. Please see **Chapter 06** for more information on recurrence monitoring. Oncologists will typically recommend starting treatment when symptoms develop for two reasons:

1. It will help you feel better.
2. Your symptoms may get worse, and you may become too sick to start treatment.

Some symptoms that may trigger the start of treatment include:

- **Abdominal symptoms:** pain, bloating, lack of appetite, constipation/diarrhea.

- **Respiratory symptoms:** shortness of breath, dry cough.

In addition to the physical symptoms of an ovarian cancer recurrence, many oncologists will also consider your emotional and mental health symptoms. For example, if you have significant anxiety knowing that you have cancer and nothing is being done about it because you do not have symptoms, you and your doctor may decide together that it is time to treat the recurrence.

WHY DOES DELAYING THE TREATMENT OF A RECURRENCE NOT AFFECT SURVIVAL OUTCOMES?

To answer this question, it is important to understand that the goals of treatment are different when treating an ovarian cancer recurrence. Please read **Chapter 11** for more information on goals of treatment. Because treating a recurrence will not cure the cancer, the goal is now to treat the disease, prolong life, and improve quality of life. Because the treatment is not curative, it is okay to live with the cancer (as long as the cancer is not causing significant symptoms). This does not mean that you should never treat the cancer, but waiting a little while before starting treatment will not shorten your life. So, if you are planning to start treatment for an ovarian cancer recurrence, but there is an important life event coming up, such as a vacation or family event, you can talk to your doctor about pushing back your treatment. Your cancer will still respond to treatment in the same way, even if you wait a few weeks or months to start treatment.

Please note, however, that you may find that the longer you wait, the more unwell you become, which will make treatment more difficult. It is important to work with your oncology team and loved ones to find the right balance for you.

IF TREATMENT DOES NOT LEAD TO "NED", WHAT DO I DO?

In some cases, treatment for recurrent ovarian cancer does not lead to NED (no evidence of disease). This may leave you with many questions about what to do next: *“Should I take a break from treatment?” “Should I resume treatment?” “Should I stop treatment all together?” “Should I consider a clinical trial?”*

If you tolerate chemotherapy well, it is likely that your oncologist will recommend that you continue treatment until you reach a “maximum response”. This means that the treatment is no longer decreasing your CA125 levels (if that is a relevant test for you), and/or the cancer is not shrinking on imaging tests (such as CT scans). For example, if your cancer looks the same on a CT scan after cycle 8 of chemo as it did after cycle 5 of chemo, that would be considered a maximum response because things are no longer changing. This does not mean that you are no longer responding to chemotherapy. It is reasonable to assume that your cancer is still responsive to the chemotherapy because it is not growing. This may be a good time to talk to your oncologist and your loved ones about taking a break from treatment. A break from chemotherapy is typically around three months. If you are still feeling well after the break and you do not have any symptoms, then you may want to discuss waiting another three months. However, if you are experiencing symptoms or the cancer is growing, then you may want to consider resuming treatment again.

WHAT SHOULD I ASK MY ONCOLOGIST ABOUT TREATING RECURRENT OVARIAN CANCER?

Chapter 04 includes many questions that you may want to ask your medical team about treatment. You may consider adding these questions to your list when discussing treatment for recurrence:

- What will happen if/when I start treatment?
- What will happen if I don’t start treatment? Or, if I start treatment at a later date?
- If I find chemotherapy very difficult, can I stop? Can I take a break? What might happen if I take a break?
- If I decide to stop treatment, can I change my mind later?
- Are there clinical trials that I may be eligible for? Can you please connect me with the clinical trials navigator at the cancer centre?

IS THERE A MAXIMUM NUMBER OF TIMES I CAN HAVE CHEMOTHERAPY?

A person can have chemotherapy many times. In general, however, the answer to this question will depend on how well you were before being diagnosed with cancer, how well you are doing now, and how long it has been since your last treatment. Chemotherapy does get harder the more times you have it, and therefore your oncologist may recommend that you switch chemotherapy drugs and/or dosages. You are also more likely to have an allergic reaction to chemotherapy the more times you have it. Therefore, although there are factors that may limit the number of times you have chemotherapy, you will likely be able to have more chemotherapy if the following are true:

- You are well enough for chemotherapy.

- There is a chemotherapy drug that you are responding to.

- You still want to have chemotherapy.

For more information on chemotherapy, see **pages 54–65**.

WHAT MEDICATIONS WILL I BE GIVEN?

Depending on the specifics of your case, you may be prescribed a PARP inhibitor as part of your treatment for recurrent ovarian cancer. For more information on PARP inhibitors, please see **pages 67–68**.

There are two PARP inhibitors approved for use in Canada, at the time of this writing:

- Olaparib (brand name: Lynparza)
- Niraparib (brand name: Zejula)

These medications are given orally and can be used as maintenance therapy for some people with recurrent ovarian cancer, if they are responding to platinum-based chemotherapy.

WILL I NEED TO HAVE ANOTHER SURGERY?

Research examining the use of surgery for recurrent ovarian cancer is very mixed. Some studies have found survival improvements with surgery in the recurrent setting. Other studies, however, have not found a difference in survival when comparing surgery and chemotherapy to just chemotherapy alone.

It is important to talk to your oncologist about whether or not you are a candidate for another surgery. Your medical team will not want to do the surgery unless they feel you will benefit. In general, there are very strict criteria determining who is eligible for a secondary surgery, and this criteria is based on the likelihood that they will benefit from the surgery. A strong candidate for a second surgery would have few spots of disease and no (or minimal) ascites (fluid buildup in the abdomen). Unfortunately, most people who experience an ovarian cancer recurrence will have multiple disease spots and ascites. Therefore, the nature of many recurrent ovarian cancers is such that surgery is unlikely to be beneficial, and the oncologist is likely to recommend chemotherapy.

WILL I NEED RADIATION?

As is true for all treatment approaches, this will depend on the type of ovarian cancer that you have. There are some rare types of ovarian cancer that may be treated with radiation. However, for the most common type – high grade serous ovarian cancer – radiation is not used because it is a localized treatment. This means that it targets a specific part of the body. As high grade serous ovarian cancer is characterized by scattered cancer cells throughout the peritoneum (the membrane lining the inside of the abdominal cavity and the surface of all organs in the abdomen), radiation would not be effective. In some cases, however, radiation may be used if there is a specific spot that is causing pain. Therefore, radiation may be used in specific cases and situations, but it is not a standard approach to treating recurrent ovarian cancer.

For more information on radiation, see **pages 65–66**.

SHOULD I CONSIDER A CLINICAL TRIAL?

A clinical trial is a type of research study that tests health interventions (for example, a new medication) on people. Clinical trials can help connect you with new and emerging treatments for ovarian cancer and are very carefully designed to ensure the utmost safety and as little risk as possible to participants. The learnings from clinical trials are extremely valuable for medical advancement by answering important questions, such as: Does this new medication improve outcomes? Are there side effects and how manageable are they? Does it help people feel better? This helps healthcare providers to decide what will work best for different people in order to promote their health and well-being.

A common myth about clinical trials is that they are only used as a “last resort”. This is not true. Clinical trials are designed to test new treatments at many different stages of the disease – not only when all other options have already been tried. If you are interested in learning more about your eligibility for clinical trials, talk to your doctor, and ask to be referred to your cancer centre’s clinical trials navigator. If there are no clinical trials open at your cancer centre, ask if there is one somewhere else in Canada that you can be referred to.

For more information on clinical trials, read **Chapter 05: Should I consider a clinical trial?**

CAN I USE COMPLEMENTARY THERAPIES WHEN TREATING RECURRENT OVARIAN CANCER?

Complementary therapies are not offered as cures for cancer, however, they may be used to help you feel better. They are called complementary therapies because they are meant to "complement", or "work with" your cancer treatment. Your oncology team will likely not be experts in complementary therapies, but most will be willing to work with you to develop a plan that will work well for you.

Although some complementary therapies have been found to help, there are others that have not been tested. It is very important to talk with your medical team about other therapies that you may be using (for example, taking herbal medications), as they may interact negatively with other aspects of your treatment. For example, Vitamin C and mistletoe can interact with chemotherapy and make it less effective. Therefore, you should avoid these particular treatments when taking chemotherapy.

Other complementary therapies may help you manage your symptoms, for example, physiotherapy and acupuncture. If you are interested in these approaches, you can talk to your oncologist about a referral. Having a referral can help you get insurance coverage.

To learn more about complementary therapies and ovarian cancer care, visit the library of resources on *Ovarian Cancer Canada*'s website and watch the webinar titled, "Lunch and Learn: Complementary Therapies".

TRADITIONAL SOURCES OF KNOWLEDGE

The treatments for ovarian cancer that have been reviewed in this guide are the current and best available options in western biomedicine (at the time of printing). The majority of doctors, nurses, and other clinicians are aware and respectful of other traditional sources of medical knowledge, for example, Traditional Chinese Medicine, Indigenous Ways of Knowing, etc. If you are looking to learn more about your culture's relationship to health and healthcare, ask your medical team to connect you with culturally-specific resources at your cancer centre. If you have knowledge that you would like your medical team to be aware of and that you would like to discuss integrating into your care, you can share that information with them. In most cases, the medical team will be committed to working with you to design a treatment approach that is going to work best for you. If you are unsatisfied with your medical team's response to your request to integrate your own culturally-specific knowledge into your care, it is your right to ask to be referred to a different oncologist.

CHAPTER 13

ASKING THE TOUGH QUESTIONS

When diagnosed with a serious illness, it is natural to ask yourself some hard questions, including whether or not you may die from your disease. This chapter is for anyone who is ready to think about some of these big “life and death” questions. There are no right or wrong answers to these big questions. Choosing to read this chapter does not mean that death is inevitable. You will learn about the myths and facts of palliative care, advanced care planning, and more. The team at *Ovarian Cancer Canada* is also here to support and guide you through these tough questions.

WHEN SHOULD I READ THIS CHAPTER?

There may be times during your experience where death is not something you want to think about. Other times, you may find yourself thinking more about these big questions. It may not be the right time to read this chapter, and that is okay, however, you may decide that reading this chapter gives you the peace of mind that you are looking for. In fact, many experts recommend that we all consider these questions and talk about them with our healthcare providers and loved ones, whether or not we are sick.

Wherever you are on your journey with ovarian cancer, this chapter can help.

WHAT IS PALLIATIVE CARE?

Many people mistakenly believe that palliative care is only provided in the final hours or days of a person's life. Palliative care refers to a much broader approach to care that aims to promote quality of life for people with serious illnesses. You may be offered palliative care at the same time as your other treatment for this disease (for example, chemotherapy) to manage symptoms, relieve pain, and focus on your holistic well-being. The doctors and nurses that provide palliative care will be able to spend more time with you and develop an individualized care plan. They will focus on your whole body, emotional wellbeing, spirituality, and the well-being of your loved ones.

Palliative care and hospice care are not the same thing. Hospice care refers to the care provided in the last hours, days, weeks, or months of a person's life. Palliative care may be provided for a number of years. Receiving palliative care does not necessarily mean that death is imminent.

Myths and Facts About Palliative Care	
Myth	**Fact**
Palliative care will lead to a quicker death.	Palliative care allows people to feel comfortable and experience the best quality of life possible.
Palliative care is only for dying people.	Palliative care offers many benefits, starting as early as diagnosis.
Palliative care is only provided in hospitals.	Palliative care can be provided in many different settings, including hospitals, hospices, long-term care facilities, and in people's homes.
Pain is an inevitable part of dying.	Pain may or may not be experienced when dying. Palliative care can help to alleviate pain.
Taking morphine will lead to a quicker death.	Morphine will not bring about death more quickly. When used appropriately, it helps people feel more comfortable.
Palliative care is only offered when there is no more hope left and the medical team has given up.	Palliative care intends to provide those with advanced illness the tools needed to experience the best quality of life possible. The focus is not on curing the disease, but on living as well as you can.

Figure 13: Myths and facts of palliative care

WHEN SHOULD I START THINKING ABOUT "DO NOT RESUSCITATE" ORDERS (DNRs)?

Many experts believe that everyone, regardless of where they are in their cancer experience (or even if they do not have cancer), should discuss their goals of care with their medical teams and with their loved ones. These goals and preferences should be well documented.

Your oncologist may ask you about your goals of care when you are diagnosed with a recurrence. The reason they may ask now is because you now have a chronic disease that is highly unlikely to go away. The expectation is that you will live with this disease, and your medical team and others around you are going to help you to live as long as possible and as well as possible with ovarian cancer.

When treating a disease without a cure, it is quite common for doctors to initiate a conversation about your goals of care, which may include a discussion about "do not resuscitate" orders (DNRs). This tells medical professionals whether you want to them to perform CPR if you stop breathing or your heart stops beating.

If your doctor does not ask about your goals of care, it is okay for you to bring it up. A conversation about goals of care and DNRs will not hasten your death. And you do not need to have been diagnosed with a recurrence to have this conversation. You may decide to have this conversation at the very beginning of your ovarian cancer experience, when you are first diagnosed. Many people report that once they talked through their end-of-life preferences, they experienced great peace of mind, could move forward in their journey, and focus on living their best life.

HOW DO I KNOW IF I QUALIFY FOR MEDICAL ASSISTANCE IN DYING (MAID)?

Although medical assistance in dying is overseen by the federal government, things may vary slightly depending on where you live. The Government of Canada website provides detailed information on MAID that will answer many of the questions that you may have.

MAID is a process whereby a healthcare provider helps an individual to end their own life, at the request of that individual. In Canada, MAID can only be performed by a physician or a nurse practitioner. MAID can be performed in two ways:

1. **Clinician-administered MAID:** the physician or nurse practitioner administers the substances that brings about the death of the individual.

2. **Self-administered MAID:** the physician or nurse practitioner provides the substance to the individual for them to take themselves to bring about their own death.

There are very strict criteria used to determine who is eligible for MAID. In order to qualify, a person must meet each of the following criteria:

- Be eligible for health services funded by the federal government.

- Be over the age of 18 and mentally competent.

- Have a grievous and irremediable medical condition.

- Make a voluntary request.

- Give informed consent.

You may be asking what is meant by a grievous and irremediable medical condition. For a medical condition to be considered grievous and irremediable, a person must meet each of the following criteria:

1. They have a serious illness, disease, or disability (this does not include mental illness at the time of printing).

2. The illness is in an advanced state of decline that cannot be reversed.

3. The person is experiencing unbearable physical or mental suffering or a state of decline that cannot be relieved under conditions that you consider acceptable.

A medical condition does not need to be fatal or terminal in order to meet eligibility criteria for MAID.

WHAT IS ADVANCED CARE PLANNING AND WHAT DOES IT INVOLVE?

Advanced care planning (ACP) is the process by which a person leaves clear instructions about how they would like to be cared for if they are in a position where they cannot speak or advocate for themselves. This process involves preparing a document called a “Power of Attorney for Personal Care” (POA). This document will identify your substitute decision maker, who is a person that you appoint to make decisions about your medical care if you become incapable of doing so. This person would also be responsible for consenting to medical interventions and/or deciding to discontinue treatment.

As you start to think through what you would like documented in your POA, you may want to reflect on the following:

- Are there any situations that you do not, under any circumstances, want to experience? For example, perhaps being on a ventilator is something that you want to avoid.

- Who is the person in your life that you trust to make decisions on your behalf?

- Is there information that you do not want to know about your medical condition or prognosis?

- Are there people (or even one person) in your life that you would like to help you make these decisions?

HOW DO I TALK TO PEOPLE ABOUT ADVANCED CARE PLANNING AND MY END-OF-LIFE WISHES?

When and how you have these conversations with the people around you is entirely your decision. There are no right or wrong answers when it comes to this topic. If and when you are ready, you may want to start thinking about who you want to start these conversations with. This may include your family, friends, medical team, lawyer, financial professional, and/or spiritual leader.

You may find it particularly difficult to bring these conversations up with loved ones. It may be helpful to broach the topic with one of the following prompts:

"This is not an imminent issue, but it would bring me a lot of peace of mind to talk through how I would like to be cared for if I'm ever unable to speak for myself. Is this something we can talk about?"

"After seeing what ______________________________ went through, it got me thinking about some big life and death questions. Do you ever think about these things? I'd like to talk about this more with you, if and when you're up for it."

WHAT SUPPORTS ARE AVAILABLE TO ME AS I WORK THROUGH THESE BIG QUESTIONS?

Supports may differ depending on where you live, but in general, most cancer centres have resources and teams dedicated to supporting you as you consider these difficult questions and start to document your preferences for advanced care. If you have not already, ask your oncologist to refer you to your cancer centre's social workers and/or psychosocial oncology department for expert guidance as you and your loved ones navigate these conversations and consider your options.

You can also visit *Ovarian Cancer Canada*'s resources library for more information and support, including the webinars titled, “Unpacking palliative: myths and realities” and “Living with resilience in the face of uncertainty”. There is no right or wrong answers when it comes to these big questions. They are very personal decisions.

CHAPTER 14

CONCLUSION

CONCLUSION

This guide was created by *Ovarian Cancer Canada* to help you and your loved ones as you move through the ovarian cancer experience. We hope this guide has answered many of your questions, and that you feel empowered to reach out to us directly for support, information, and connection.

Ovarian Cancer Canada can connect you with clinicians, scientists, and other experts, as well as other people affected by ovarian cancer.

JOIN THE COMMUNITY

There is a vibrant community of champions who are determined to make ovarian cancer a priority and ensure this cause gets the attention it deserves. These champions are also here to support you in your experience. To keep the conversation going, become an advocate, and to meet others in the ovarian cancer community, please join us online:

- Facebook: OvarianCancerCanada
- X: OvarianCanada
- Instagram: OvarianCancerCanada

To learn more and access resources, visit ovariancanada.org, or contact us directly:

- Email: info@ovariancanada.org
- Phone: 1-877-413-7970

DISCLOSURE

The information shared in this guide is purposely general in nature and will need to be considered in the context of your unique situation. Be sure to ask questions throughout your treatment and follow-up care and to think of yourself as a key member of your healthcare team. Share what matters most to you, share your goals of care, and share your comforts and discomforts. In the introduction we offered ideas to get these conversations going, which we have repeated below. Be sure to reflect on your needs, and add to this list as needed:

"I am not comfortable with some of the tests/procedures that you would like to do. Can we please discuss ways to address these discomforts?"

This prompt may be helpful for people who have experienced certain traumas, for example, a sexual assault. If you feel that your doctor is not able to provide you with safe and appropriate care, it is your right to ask to be referred to a different doctor, particularly one who specializes in trauma-informed healthcare.

"I do not identify as a woman. My gender identity is ________________________ and my pronouns are _________ . Please respect my gender identity as we move through this process together."

This prompt may be helpful for people who are trans, nonbinary, and/or gender queer. If you feel that your doctor is not able to provide you with safe and appropriate care, it is your right to ask to be referred to a different doctor, particularly one who specializes in LGBTQIA+ healthcare.

"Are there any culturally specific resources available to me? For example, an Indigenous Patient Navigator?"

This prompt may be helpful for members of communities who would like their traditional cultural knowledge respected and incorporated into their care.

"I learn best by ______________________________ . We have reviewed a lot of information today. Can you please summarize what we have discussed in a way that I will best understand?"

This prompt may be helpful for people with specific learning styles, and/or for people who are neurodivergent. If you learn best by listening, ask if you can audio record your appointment. If you learn best by reading, ask your doctor to write a short summary of your discussion. If you learn best by reflecting on information on your own time in a quiet space, tell your doctor that you will need some time to process the information before you can continue the conversation.

"I am worried about how long it may take, or how far I will have to travel, for my next appointment. Do you have access to e-referral, e-consult, or Virtual Hallway?"

If you live in a rural or remote area, there may not be a gynecologic oncologist in your region. This means you would have to travel to be seen by an ovarian cancer specialist. Many healthcare providers have access to electronic and virtual services, such as “e-consult”, “e-referral”, and “Virtual Hallway”. You can ask your doctor if they have access to these services that might facilitate an online appointment with a gynecologic oncologist.

ABOUT OVARIAN CANCER CANADA

OUR MANIFESTO

At *Ovarian Cancer Canada*, we reject the notion that ovarian cancer can't be eradicated. We are here to demand action, deliver change, and transform lives. We stand hand-in-hand with the people experiencing, affected by, or at risk of the disease.

We will not rest until women are able to live their lives freely, fully, and uninhibited by ovarian cancer.

OUR MISSION

To boldly and unapologetically take action against ovarian cancer until the number of deaths from this disease is zero.

OUR VISION

A future where ovarian cancer is preventable, curable, and ultimately eradicated.

To learn more, visit ovariancanada.org, or contact us directly:

- Email: info@ovariancanada.org
- Phone: 1-877-413-7970

APPENDIX 01

NOTE TO FAMILY AND FRIENDS

NOTE TO FAMILY AND FRIENDS

Those affected by ovarian cancer have shared two important pieces of advice for caregivers and loved ones:

1. **Practical support is very valuable.** For example, offering to help out around the house, with cooking, cleaning, caring for children, caring for pets, etc.

2. **Sometimes the hardest time for the person with ovarian cancer is after treatment, when things are going back to "normal".** During this time, they may feel like the support they had from their medical team and other caregivers is no longer available to them. They may be facing their difficult emotions for the first time, and they may be feeling very alone. For many, they need your support now more than before.

It can feel overwhelming when someone you care about has been diagnosed with cancer. Caring for someone who has a serious illness can take its toll. During this time, it's important to take care of yourself as best as you can, both physically and emotionally. If you are not well, then you will not be able to care for someone else.

Here are some suggestions to prioritize self-care:

- Watch the "Caregiving and care-getting: The importance of support" webinar in *Ovarian Cancer Canada*'s resources available at ovariancanada.org.

- Recognize your own feelings and needs. Perhaps your loved one's illness makes you feel guilty about being healthy. Perhaps you have become afraid of getting cancer and confronting mortality. When you understand and fulfil your own needs, you put yourself in a better position to be genuinely helpful.

- Gently remind yourself that it's not up to you to make everything better.
- Realize that you may feel depressed and need support for yourself.
- Try to get out of the house. Exercise. A support group may help. Consider seeing the social worker on your loved one's healthcare team – you can get their name and contact information from the nurse or doctor on the team.
- You may know other people who have had a spouse or loved one with cancer and these friends or acquaintances may be people you can share your experiences and feelings with.
- Find support services in the community that you both can use. These may include centres in the community for cancer patients and their families, as well as professional counsellors.

APPENDIX 02

GLOSSARY

The world of medicine has its own language, and it is very common to feel like you don’t speak that language. This glossary of terms will help you better understand what is meant by many of the new words that you will hear throughout your ovarian cancer experience.

A

Adjuvant chemotherapy: chemotherapy given after surgery.

Advanced care planning (ACP): the process by which a person leaves clear instructions about how they would like to be cared for if they are in a position where they cannot speak or advocate for themselves.

Angiogenesis inhibitors: a type of medication that prevents (or inhibits) the development of new blood vessels in a tumour (for example, bevacizumab).

Aromatase inhibitors: a type of medication that works by lowering estrogen levels (for example, letrozole).

Ascites: fluid buildup in the abdomen.

B

Benign: not cancerous.

Bevacizumab: a medication that is given by IV to prevent the development of new blood vessels in a tumour, which therefore slows or stops the growth and spread of cancer. Bevacizumab belongs to a class of drugs called angiogenesis inhibitors.

Bilateral oophorectomy: the surgical removal of both ovaries.

Bilateral salpingectomy: the surgical removal of both fallopian tubes.

Borderline ovarian tumours: tumours that are less likely to be cancerous. They have not been classified as ovarian cancer since 2000.

C

CA 125: a protein in the bloodstream that may become elevated due to many factors, including some cancers (for example, ovarian cancer).

Cancer: a collective term that describes a group of diseases in which abnormal cells divide out of control and can spread to other parts of the body.

Cancer-free: a person may be considered cancer-free if there is no evidence of active cancer on imaging tests, clinical examination, or blood work.

Capsule (of the ovary): the outer layer of the ovary.

Carboplatin: a common chemotherapy drug that contains platinum. It binds to DNA to prevent cancer cells from dividing, therefore causing them to die.

Catheter: a flexible tube that moves fluid into or out of your body. For example, a urinary catheter is a flexible tube that is inserted into the bladder to remove urine from the bladder. The urine then collects in a bag outside the body.

Chemotherapy: the use of one drug or, more commonly, a combination of drugs that target and kill fast growing cells throughout the body. Chemotherapy literally means “to treat disease with chemicals”.

Cisplatin: a common chemotherapy drug that contains platinum. It binds to DNA to prevent cancer cells from dividing, therefore causing them to die.

Clear cell ovarian cancer: a type of epithelial ovarian cancer.

Clinical trial: a type of research study that tests health interventions (for example, a new medication) on people.

Clinical trial navigator: a healthcare professional who helps match patients with clinical trials that they may be eligible for.

Colostomy: a procedure that may take place during surgery that involves connecting the colon to the outside of the body, allowing stool to leave the body and collect in a colostomy bag.

Complete blood count (CBC): a blood test that measures the levels of various cells in the blood.

Cycle (of chemotherapy): the time between rounds of chemotherapy, which is typically around 3 weeks.

Cytoreduction: (also called “debulking”) surgically removing as much of the cancer as possible.

D

Debulking: (also called “cytoreduction”) surgically removing as much of the cancer as possible.

Diaphragm: a dome-shaped muscle that separates the abdomen from the chest.

Disease progression: evidence of growth of known cancer (either on or off treatment). If there is no cancer-free time, then cancer growth would be considered a progression, not a recurrence.

Do not resuscitate orders (DNRs): directions that tell medical professionals whether or not a person wants them to perform CPR if they stop breathing or their heart stops beating.

Docetaxel: a chemotherapy drug that prevents the division of cells (brand name: Taxotere).

Dysgerminoma: the most common type of germ cell ovarian cancer.

E

Endometrioid ovarian cancer: a type of epithelial ovarian cancer.

Endometriosis: a somewhat common and typically benign condition in which tissue similar to the endometrial lining inside the uterus grows outside the uterus.

Epithelial ovarian cancer: a group of ovarian cancers that start in the cells that cover the lining (also called the epithelium) of the fallopian tubes and/or ovaries.

F

Fallopian tube: funnel-like tubes that connect the ovaries to the uterus, acting as a passageway for the egg to travel from the ovary to the uterus.

Frontline treatment: the initial (first) treatment of the cancer.

G

Genetic mutations: alterations to genes that stop them from working properly. These alternations can turn normal cells into cancer cells (genetic mutations are sometimes called “genetic variants” or “harmful variants”).

Genetics counsellor: a healthcare professional who specializes in genetics and helps families to understand any genetic conditions.

Germ cell ovarian cancer: a group of ovarian cancers that start in the germ cells, which are the cells inside the ovaries that form the eggs.

Germline genetic mutation: a genetic mutation that is inherited from a biological parent (sometimes called an "inherited mutation").

Grade: the grade of a cancer refers to how abnormal the cancer cells look compared to normal cells.

Granulosa cell tumours: a type of sex cord-stromal ovarian cancer that can be either "adult-type" or "juvenile-type".

Gynecologic cancers: cancers that originate in the female reproductive system.

Gynecologic oncologist: highly trained doctors specializing in cancers of the female reproductive system.

H

Hematocrit: the percentage of blood that is made up of red blood cells.

Hemoglobin: the protein that carries oxygen in your red blood cells.

Hereditary Breast and Ovarian Cancer Syndrome (HBOC): one of the main hereditary syndromes related to ovarian cancer. It is associated with inherited mutations in the BRCA 1 and 2 genes.

Hickman Port-a-Cath: a device placed under the skin on the upper chest that connects to a major vein. This device can be used to administer chemotherapy over several months.

High grade serous ovarian cancer: the most common type of ovarian cancer.

Hormone therapy: a treatment approach that may be effective for some types of ovarian cancer that works by lowering estrogen levels in the body (for example, aromatase inhibitors).

Hospice care: a holistic approach to care that is provided in the last hours, days, weeks, or months of a person's life.

Hypercalcemia: a condition characterized by elevated levels of calcium in the blood.

Hysterectomy: the surgical removal of the uterus.

I

Ileostomy: a procedure that may take place during surgery that involves connecting the ileum (which is part of the small intestine) to the outside of the body, allowing stool to leave the body and collect in an ileostomy bag.

Immature ovarian teratoma: a type of germ cell ovarian cancer.

Incessant ovulation hypothesis: a theory that suggests that ovarian cancer may be related to the number of times a person has ovulated throughout their lifetime.

Indigenous patient navigator: a healthcare professional who provides specialized support and advocacy for First Nations, Inuit, Métis, and urban Indigenous people.

Interpreter: a vital member of the healthcare team of any person for whom English/French is not their first language. Interpreters facilitate clear and effective communication between a patient and their healthcare team.

Intraperitoneal chemotherapy: the administration of chemotherapy drugs directly into the abdomen.

Intravenous chemotherapy: the administration of chemotherapy drugs directly into a vein.

L

Lab/imaging technicians: healthcare professionals that draw blood and run imaging tests.

Letrozole: a type of medication that works by lowering estrogen levels. Letrozole belongs to a class of drugs called aromatase inhibitors.

Localized therapy: a treatment that targets a specific part of the body (for example, radiation).

Low grade serous ovarian cancer: a type of epithelial ovarian cancer.

Lupron: a medication sometimes prescribed to people with granulosa cell tumours that stop the ovaries from producing estrogen.

Lymph nodes: small structures found throughout the body that are part of the immune system.

Lymphadenectomy: the removal of lymph nodes.

Lymphedema: swelling that results from the removal of lymph nodes.

Lynch Syndrome: one of the main hereditary syndromes related to ovarian cancer. It is associated with inherited mutations in the following genes: MLH1, MSH2, MSH6, PMS2, EPCAM.

Lynparza: the brand name of the PARP inhibitor, olaparib. It prevents (or inhibits) cancer cells from repairing their damaged DNA, therefore increasing cancer cell death.

M

Malignant: cancerous.

Maximum response: treatment is no longer decreasing CA125 levels (if that is a relevant test for the person), and/or the cancer is not shrinking on imaging tests (for example, CT scans).

Mean corpuscular volume (MCV): the size of red blood cells.

Medical assistance in dying (MAID): a process whereby a healthcare provider helps an individual to end their own life, at the request of that individual.

Medical Oncologist: a highly trained doctor who specializes in non-surgical treatments for cancer (for example, chemotherapy and clinical trials).

Metastasize: to spread to other parts of the body.

Mixed cell type: an ovarian cancer that originates from two or more types of cells.

N

Neoadjuvant chemotherapy: chemotherapy that is given before surgery.

Neutropenia: a condition characterized by low neutrophils levels.

Neutrophils: a type of white blood cell.

Niraparib: a medication that belongs to a group of drugs called PARP inhibitors. It works by preventing (or inhibiting) cancer cells from repairing their damaged DNA, therefore increasing cancer cell death. The brand name of niraparib is “Zejula”.

No Evidence of Disease (NED): there is no evidence of cancer on imaging tests, clinical examination, or blood work.

Nonepithelial ovarian cancers: a group of ovarian cancers that do not start in the cells that cover the lining (also called the epithelium) of the fallopian tubes and/or ovaries. For example, germ cell and stromal cell ovarian cancers.

O

Occupational therapist: a very specialized healthcare provider who helps people restore their health after treatment so that they can live as high a quality of life as possible.

Olaparib: a medication that belongs to a group of drugs called PARP inhibitors. It works by preventing (or inhibiting) cancer cells from repairing their damaged DNA, therefore increasing cancer cell death. The brand name of olaparib is “Lynparza”.

Omentectomy: the removal of the omentum.

Omentum: a layer of fatty tissue that covers the organs in your abdomen, including your stomach and intestines (ovarian cancer frequently spreads to the omentum).

Oncologist: a doctor that specializes in cancers.

Oncology pharmacist: a healthcare professional that specializes in medications used in the treatment of cancer.

Opportunistic salpingectomy: a surgery for people at average risk of ovarian cancer during which one or both fallopian tubes is/are removed. These surgeries are performed when a person is having pelvic surgery unrelated to ovarian cancer (for example, a hysterectomy).

Ovarian cancer: a collective term that refers to a group of diseases that originate at or near the ovaries.

Ovary: small, almond-shaped organs that produce eggs and the female sex hormones.

Ovulation: the period of time during the menstrual cycle when the egg is released from the ovary.

P

Paclitaxel: a chemotherapy drug that prevents the division of cells (brand name: Taxol).

Palliative care: a broad approach to care that aims to promote quality of life for people with serious illnesses.

PARP inhibitors: a group of medications that prevent (or inhibit) cancer cells from repairing their damaged DNA, therefore increasing cancer cell death (for example, niraparib and olaparib).

Peripheral neuropathy: a potential side effect of chemotherapy characterized by weakness, numbness, and/or pain in the hands and/or feet.

Peritoneal fluid: the fluid in the abdominal cavity.

Peritoneal washing: a saltwater solution that is used during surgery to check for cancer cells.

Peritoneum: the membrane lining the inside of the abdominal cavity and the surface of all organs in the abdomen.

Personal support workers (PSWs): healthcare workers that provide direct care to support patients in their activities of daily living (depending on where you live in Canada, PSWs may also be called home care workers, personal care attendants, or personal aids).

Phlebotomists: healthcare professionals that draw blood for blood tests.

Physician assistant: a staff member that works under the direction of a supervising physician.

Physiotherapist: a highly trained healthcare provider that can help to evaluate and manage problems with movement and function as the result of an injury or disease.

Placebos: inactive therapies that resemble active therapies (sometimes called a “sugar pill”).

Platelets: a type of blood cell that causes your blood to clot.

Platinum: a metal found in many anti-cancer drugs, including cisplatin and carboplatin.

Power of Attorney for Personal Care: a document that outlines clear instructions for how a person would like to be cared for if they are in a position where they cannot speak or advocate for themselves.

Primary peritoneal cancer: cancer that develops in the membrane that lines the surface of all abdominal organs and the inside of the abdominal cavity.

Primary treatment: the first time a case of ovarian cancer is treated.

Prognosis: a prediction of the outcome/development of the disease.

Progression: the growth/spread of a cancer.

Progression free survival (PFS): the amount of time that a person is cancer-free following the completion of treatment, or the amount of time that a person's cancer remains stable (meaning it does not worsen).

Psychosocial oncology: a department at most cancer centres that links patients with social workers, psychologists, dieticians, chaplains, and other professionals to support their unique needs and circumstances.

R

Radiation: the use of high energy x-rays to damage or destroy cancer cells and damage the DNA of the cancer cells so that they can no longer divide and grow.

Radiation oncologist: a highly trained doctor who specializes in radiation therapy.

Randomization: a process used to compare two or more health-interventions. In randomized trials, participants are randomly assigned (by chance) to receive one of the health-interventions.

Recurrence: evidence of cancer following a period of time where there was no evidence of disease.

Red blood cells: a blood cell that carries oxygen to your body tissues and carries carbon dioxide away from your body tissues.

Registered dietician (RD): a health professional with expertise in food and nutrition science.

Remission: no evidence of cancer. This term is not typically used in relation to ovarian cancer.

Risk-reducing salpingo-oophorectomy (RRSO): a surgery done for people who are at increased risk of ovarian cancer due to an inherited genetic mutation. This surgery is done with the explicit purpose of reducing ovarian cancer risk and involves the removal of both ovaries and both fallopian tubes.

S

Seeding: when cancer cells spread from the ovaries to other tissues and organs and form new tumours.

Sertoli-Leydig cell tumours: a type of stromal cell ovarian cancer.

Small cell carcinoma of the ovary (SSCO): a very rare type of ovarian cancer that cannot be categorized into epithelial or non-epithelial ovarian cancer because it is unclear what type of cell this cancer originates from.

Social worker: a healthcare professional who supports patients with practical issues, such as support services, financial concerns, and the emotional impact of a cancer diagnosis.

Somatic genetic mutation: a genetic mutation that develops during one’s lifetime (it is not inherited from a biological parent).

Stable disease: the cancer is still present, and scans and tests reveal no change over time.

Stage: Staging is the process of finding out how much the cancer has spread in the body. If the cancer has spread, the stage describes how far it has spread.

Stromal cell ovarian cancer: a group of ovarian cancers that start in the stromal cells, which are the cells that hold the ovaries together and produce the female sex hormones (also called “sex cord stromal ovarian cancer”).

Substitute decision maker: a person appointed to make decisions about another person's medical care if they become incapable of doing so.

Surgical spill: the ovary’s capsule (outer layer) broke during surgery and the cancer spilled outside.

Systemic therapy: a treatment that affects the whole body (for example, chemotherapy).

T

Targeted therapy: a treatment that targets only specific types of cells (for example, some medications).

Taxane: a chemotherapy drug that prevents the division of cells (for example, paclitaxel and docetaxel).

Taxol: the brand name of paclitaxel, which is a chemotherapy drug that prevents the division of cells.

Taxotere: the brand name of docetaxel, which is a chemotherapy drug that prevents the division of cells.

Thrombocytopenia: a condition characterized by low platelet levels in the blood.

U

Unilateral oophorectomy: the surgical removal of one ovary.

Unilateral salpingectomy: the surgical removal of one fallopian tube.

W

White blood cells (WBC): a type of blood cell that helps your body fight off infections.

Y

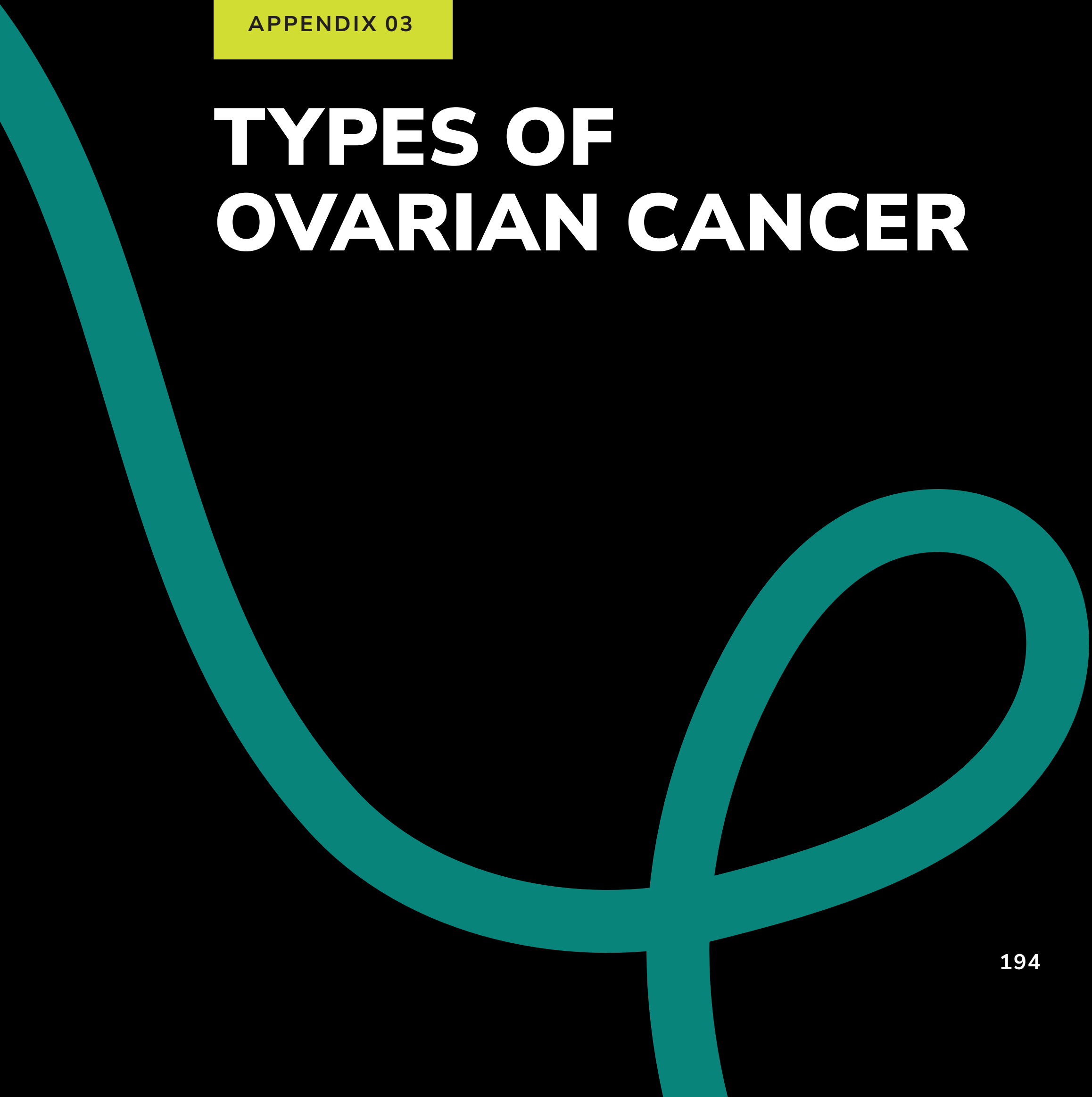
Yolk sac tumours: (sometimes called "endodermal sinus tumours") a type of germ cell ovarian cancer.

Z

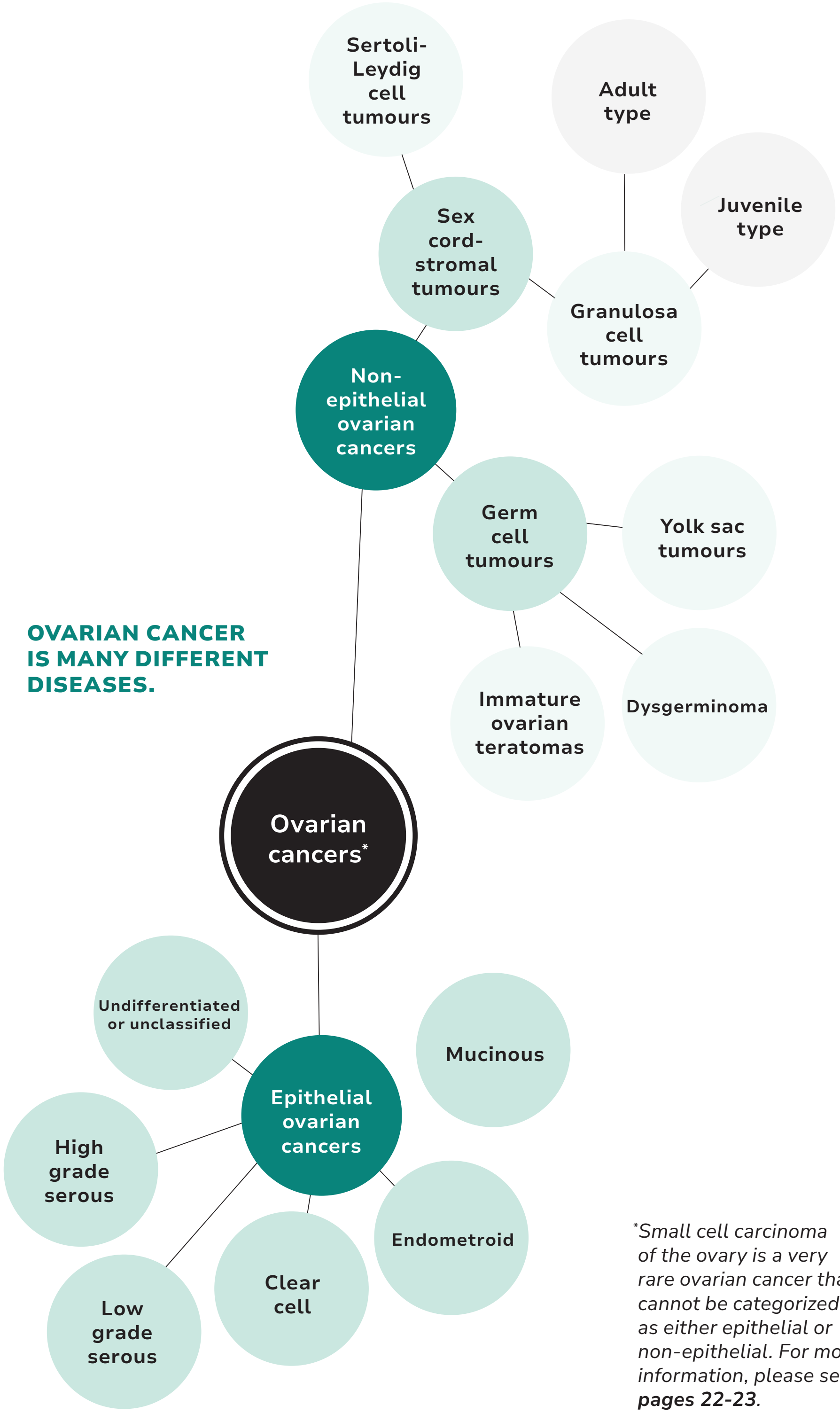
Zejula: the brand name of the PARP inhibitor, niraparib. It prevents (or inhibits) cancer cells from repairing their damaged DNA, therefore increasing cancer cell death.

APPENDIX 03

TYPES OF OVARIAN CANCER



OVARIAN CANCER IS MANY DIFFERENT DISEASES.



Small cell carcinoma of the ovary is a very rare ovarian cancer that cannot be categorized as either epithelial or non-epithelial. For more information, please see **pages 22-23.*

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