

# Gynecologic Cancers: Your Journey

A guide for people
with gynecologic cancer
made by people with
gynecologic cancer























## Understanding your diagnosis

#### **Endometrial (uterine) cancer**

Endometrial cancer is the most common gynecologic cancer.

This cancer starts in the cells of the uterus, also known as the womb.

#### Vaginal cancer

Vaginal cancer starts in the vagina, also known as the birth canal.

The vagina is a hollow, muscular tube. It is located between the bottom of the uterus and the outside of the body.

Vaginal cancer is rare and few people will be diagnosed with it.

### **Vulvar cancer**

Vulvar cancer starts in the vulva, the outer part of the genitals for people with a vagina.

Skin and fatty tissue make up the vulva. It includes the opening of the vagina, the outer lips (labia majora), inner lips (labia minora) and the clitoris.

Vulvar cancer is rare and few people will be diagnosed with it.

#### Ovarian cancer

Ovarian cancer can start in the cells of the ovary or fallopian tubes.

The most common ovarian cancer starts in the fallopian tubes but grows on the ovaries.

The ovaries make eggs. There is one ovary on each side of the uterus.

#### Cervical cancer

Cervical cancer starts in the cells of the cervix. This is the narrow, lower part of the uterus connected to the vagina.

The human papillomavirus (HPV) is the main cause of cervical cancer.

## Did you know?

In 2020, the
World Health Organization
announced its global plan to
eliminate cervical cancer.
This plan to get rid of cervical
cancer includes bold targets for
HPV vaccination, screening
and treatment.

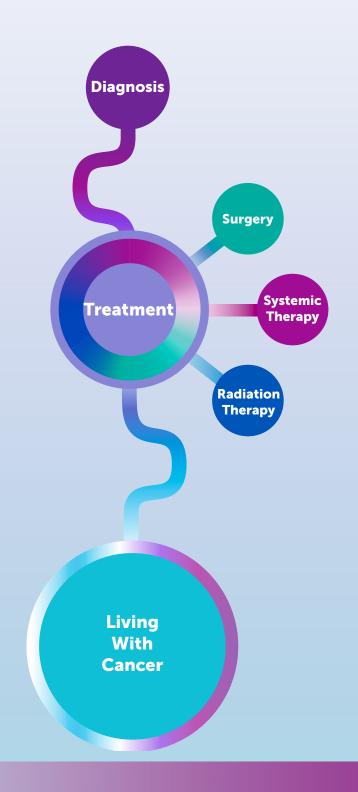
## Your journey

We have collected information. resources and useful personal stories that can help to support you on your cancer journey. This document reflects the experiences of people with gynecologic cancer in B.C.

Cancer is so much more than the statistics. There is an amazing village of survivors, healthcare workers, researchers, and advocates, that help to make the journey ahead manageable and filled with new hope.

Nancy Cleveland, Ovarian Cancer Survivor

There are many links in this document. Click on the underlined text to open them when you are ready.



## Timing of treatment

Everyone's cancer is unique and so is their treatment. If you have any questions or concerns about your treatment, please talk to your BC Cancer healthcare team.

### Team-based care

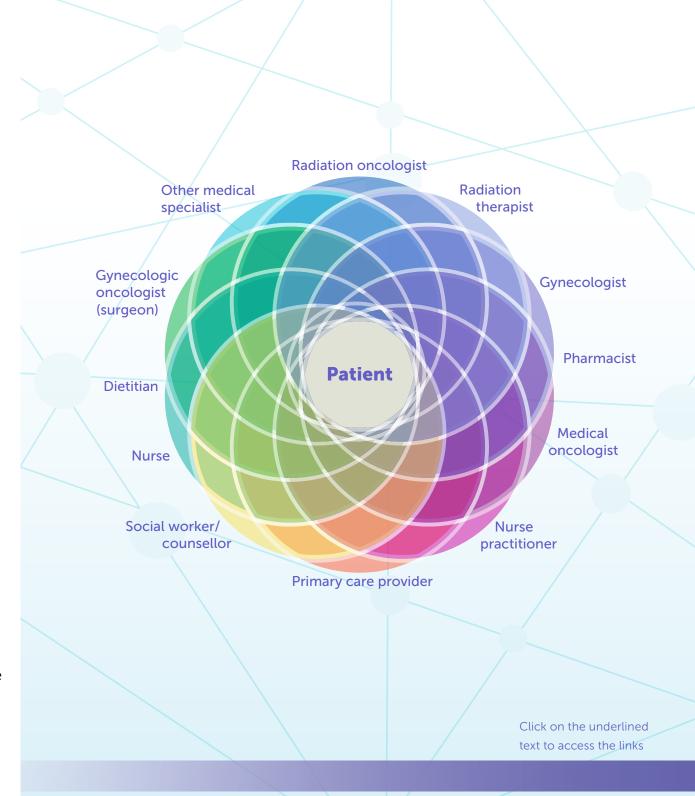
People with gynecologic cancers get team-based cancer care. The team has many people on it: gynecologic oncologists, radiation oncologists, nurses, pharmacists and many others. Together, they work hard to give you high quality care.

## Supportive Care

BC Cancer has support services to help you throughout your cancer journey.

These include Art Therapy, Nutrition, Pain and Symptom Management, Patient & Family Counselling, Psychiatry, Speech Language Pathology, Spiritual Health and Vocational Rehabilitation.

People with gynecologic cancers have also found other ways to support themselves during their treatment. Some examples include exercise, yoga, massage therapy, spiritual practices and meditation.



## Province-wide care

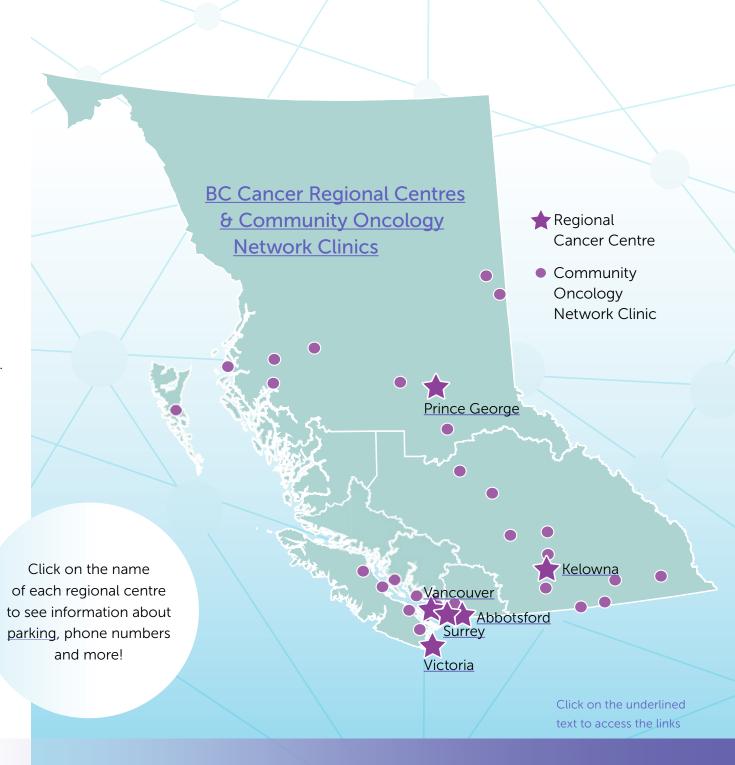
BC Cancer regional centres and community clinics serve people with cancer in B.C. A network of healthcare providers is available to all. This means you will get excellent care, no matter where you live in B.C.

#### Tailored treatment

Everyone's cancer is unique and so is their treatment. You may have one or more of each treatment type. The timing of treatments is different for each person. Your healthcare team will tailor your treatment to meet your needs.

Treatment depends on many things:

- What you want
- Cancer type
- Cancer stage
- Cancer grade
- Age
- Other healthcare concerns



# Types of cancer treatment **Surgery Systemic Treatment Therapy Radiation Therapy**

## **Surgery**

Surgery can be an important part of treatment. Surgeons will often take out the tumour and other parts, such as ovaries or fallopian tubes. Your healthcare team will tell you how to prepare for surgery.

# 80

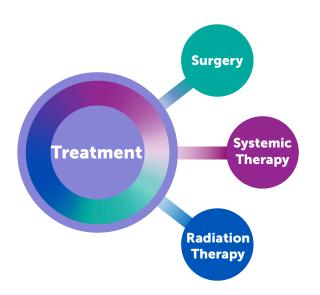
#### Common surgeries are:

- Hysterectomy removing the uterus
- Bilateral salpingo-oophorectomytaking out the fallopian tubes and ovaries
- Radical hysterectomy taking out the uterus, cervix, ovaries, fallopian tubes and part of the vagina
- Vulvectomy taking out parts of the vulva

## **Preparing for surgery**

You may need to travel to Vancouver or Victoria for surgery.

Check the resource pages (pages 14-18) for support for your stay.



## Radiation therapy

Radiation therapy uses high energy x-rays to kill cancer cells and shrink tumours. We direct x-rays at the tumour. When passing through our bodies, x-rays can also harm nearby healthy cells. This is what causes side effects.

Radiation therapy includes:



#### **External radiation**

A machine outside your body aims radiation at the tumour.



## Internal radiation (brachytherapy)

We put the radioactive source inside your body. The source may go inside the tumour or close to it.

## Systemic therapy

Systemic therapy includes any medication that travels through your blood to damage or destroy cancer cells. The medication can also affect healthy cells in your body. This is what causes side effects.

Systemic therapy includes:



### Chemotherapy (drugs)

We inject drugs into your body or infuse them through an intravenous (IV) drip. You may also get pills to swallow.



## Hormone therapy

Some cancer cells need hormones to grow. Hormone therapy stops your body from making the hormone or stops the cancer cells from using the hormone to grow.



## Immunotherapy

A special type of cancer treatment that trains your body's immune system to fight your cancer.

Through our commitment to gynecologic cancer research in B.C., we are not only improving treatments and quality of life for those living with and beyond gynecologic cancer, but we are also preventing many gynecologic cancers before they start.

Dr. Gillian Hanley, Ovarian Cancer Researcher

## The role of research

## **Clinical trials**

Clinical trials are research studies that test how well new treatments work and how safe they are. A lot of research is done to make sure these new treatments are safe, effective and improve outcomes. These studies also test new ways to diagnose and prevent cancers.

All of the treatments we use right now were tested in clinical trials.

You may be able to take part in a clinical trial. This is always voluntary. You do not have to join a trial. If you do not take part, your care will not change. Please talk to your healthcare team about clinical trials.

# Gynecologic Cancer Initiative

The Gynecologic Cancer Initiative (GCI) is a network of doctors, scientists, patients and community members.

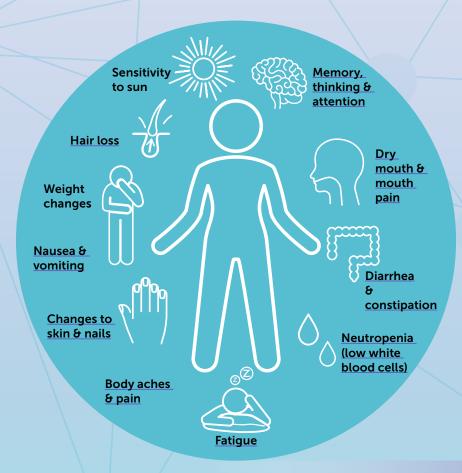
They are working on a goal to reduce the incidence (how many cancers), death and suffering of gynecologic cancers by 50% by 2034.



# Common side effects during cancer treatment

Your healthcare team will explain any side effects you may have during treatment. They will help you manage them. Your body may react differently to each treatment. You may have different side effects each time.

Common side effects include:



For information and support during and after your treatment, check out the following:

- <u>Emotional Support</u>
- Exercise Support
- Nutrition Support
- Pain and Symptom Management Clinics
- Radiation Therapy Side Effects
- Symptom Self-Check Tool
- Systemic Therapy Side Effects
- BC Cancer Abbotsford Support
- BC Cancer Kelowna Support
- BC Cancer Prince George Support
- BC Cancer Surrey Support
- BC Cancer Vancouver Support
- BC Cancer Victoria Support

Cancer treatment
may lower the number of
white blood cells in your blood.
This can make it difficult to fight
infection. Your healthcare team will
help you manage this. You can help by
watching for signs of infection,
helping to prevent infection and
practicing good food safety.
Ask your healthcare team

if you have questions.

# Living with cancer

After your cancer treatment, you will start a new phase of your cancer journey: "living with cancer".

Living with cancer is a process. As you move into this phase, you may feel lost or confused. Cancer may also continue to affect parts of your life.

During this part of your journey, your primary care provider may have a larger role in managing your health. If you have questions, know that you can reach out to your healthcare team.

The following pages talk about some of the things you may experience in this phase.



## Mental health

Cancer may affect your mental and emotional health. Healing takes time.

Everyone has different emotions after finishing cancer treatment. Anything you are feeling is normal.

Some common emotions include fear of recurrence, guilt, confusion, anger and anxiety. These emotions might be stronger after your treatment.

## Fear of cancer recurrence

The fear of recurrence (cancer coming back) is normal and common.

This fear can greatly affect your mental health. You may also feel uncertain, worried and anxious.

Many people have these feelings a lot more right after cancer treatment. The feeling many come and go. You may still have a fear of recurrence many years after your cancer diagnosis.



## Sexual health

Gynecologic cancer and its treatments may affect sex and intimacy.

Your feelings and attitudes about intimacy may change during your cancer journey.

The physical side effects of treatments may change your body and your feelings about your body.

This might affect your sexual health and ability to take part in sexual activity.

## Premature menopause

Gynecologic cancer treatments can cause early (premature) menopause.

The symptoms of menopause can affect your quality of life. These symptoms might include hot flashes, trouble sleeping and emotional changes.

We can control premature menopause with hormone replacement therapy. Without proper treatment, premature menopause can cause long-term health risks.



I didn't realize how little
I knew about menopause until I
experienced it prematurely when I
was 33. After advocating for myself,
I learned that the fatigue, brain fog,
and insomnia I struggled with were
all related to premature menopause.
With the right support and hormone
replacement regime, I began
to feel more like myself.

Nicole Keay, Cervical Cancer Survivor & Patient Partner

## **Fatigue**

Fatigue is a feeling of extreme tiredness or lack of energy. Some signs of fatigue include feeling weary, exhausted and heavy.

Trouble sleeping after cancer treatment can cause fatigue.

There are things you can do to help manage your fatigue. These include exercise, proper <u>nutrition</u> and using supportive care resources.

## Peripheral neuropathy

Neuropathy is damage that affects the long nerves in your body. Long nerves go from your spinal cord to your arms, hands, fingers, legs, feet and toes.

Symptoms can include feelings of tingling, numbness, unpleasant sensation when touching or being touched, and problems with balance.

Click on the underlined text to access the links

# Memory, thinking and attention

Cancer treatment can cause long-term thinking and memory problems. This is known as "chemo brain" or "chemo fog".

This can happen during cancer treatment, but it can also be a long-term side effect.



Every patient journey is unique, like a fingerprint, and not all paths through a cancer diagnosis are the same. I could not truly understand symptoms like fatigue, memory loss and/or fog, and nerve damage called neuropathy until I experienced it myself. There is a wealth of information out there with support for each of us as we navigate these turbulent and unknown waters.

Debra Walker, Ovarian Cancer Survivor & Patient Partner

# Resources for your journey

You are not alone in your journey. There are many BC Cancer and community resources to help you. They are available to you whenever you are ready.

These resources are for every person with cancer in B.C., no matter where you live. Many services are available virtually. Call your closest BC Cancer centre to learn what is available for you.

You can use some of these services yourself. For others, you need a referral from a doctor or nurse. If you are interested in any of these services, talk to your healthcare team.



This icon means that the service offers virtual/online options to patients.



BC Cancer – Abbotsford



BC Cancer - Surrey



BC Cancer – Vancouver



BC Cancer – Kelowna



BC Cancer – Prince George



BC Cancer - Victoria

## Health and wellbeing

## **Finding community**



Many organizations support people with cancer. Support includes services, information, resources, online forums and groups and webinars. These organizations can also connect you with other people with gynecologic cancer.

- Canadian Cancer Society
- Ovarian Cancer Canada
- Gynecologic Cancer Initiative

# Gynecologic Cancer Initiative Patient and Family Advisory Council

The Gynecologic Cancer Initiative
Patient and Family Advisory Council
is a group of patient and family partners.
They share their voice in gynecologic
cancer research in BC. This group helps
to advance our knowledge of gynecologic
cancers and improve the patient experience.

This icon means that the service offers virtual/online options to patients.

Click on the underlined text to access the links

#### **GOSH Podcast**





The Gynecologic Oncology Sharing Hub (GOSH) creates a space for real discussions on gynecologic cancers.

The podcast was inspired by Nicole Keay, a patient partner and cervical cancer survivor. Episodes share stories of people with gynecologic cancers. Researchers and healthcare staff talk about their work to improve the lives of people with gynecologic cancer.

## **BC Cancer Network of Patient &**Family Partners



A network of patients, families and loved ones who have experience with cancer. They use their experience to improve care for people with cancer in BC. Our partners work with BC Cancer staff on committees, working groups and research projects. Partners also help create patient education materials.

## **Beyond the Stories**



Beyond the Stories is a video series that shares information on gynecologic cancer prevention, diagnosis, treatment and survivorship. This series is for patients. Patients with gynecologic cancer helped make the series. Topics include preventing ovarian cancer, hereditary cancers and endometrial cancer.

### **Inspire Health**



Programs and services to enhance quality of life, health and wellbeing of people living with cancer and their families.

All services are free. You do not need a referral.

Services include: exercise therapy, stress management, nutrition and counselling.

Kelowna: 250.861.7125 Vancouver: 250.734.7125 Victoria: 250.595.7125

## **Emotional support**

## **BC Cancer Patient and Family** Counselling



We offer counselling services and support programs to people with cancer and family members. Counselling can help you cope with emotions and concerns. We have individual and group programs.

Services include: counselling, art therapy, Chinese support group, mindfulness-based stress reduction, return to work group and many more.

Abbotsford: 604.851.4733

250.712.3963 Kelowna:

Prince George: 250.645.7330

Surrey: 604.930.4000

Vancouver: 604.877.6000 x 672194

Victoria: 250.519.5525



## Look Good, Feel Better Workshop



Cancer treatment can change how you look. These workshops can help you feel beautiful and vital. You will learn how to manage changes to your appearance. Workshops are free.

Learn about skincare, cosmetics, wigs and hair alternatives.

Call: 647.776.5111

## **Callanish Society**

Programs to strengthen your spirit while living with cancer. Many services are free or by donation.

Services include: counselling, art therapy, massage therapy, healing circles.

Call: 604.731.0633



This icon means that the service offers virtual/online options to patients.

## Managing Symptoms and Side Effects

# BC Cancer Pain and Symptom Management and Palliative Care



This program helps improve the quality of life for people living with cancer and their caregivers. Specialists in these clinics help with pain control and coping with other physical problems related to cancer. They also help with care planning and give you emotional and social support. All people with cancer are welcome at any time during your cancer journey.

Abbotsford: 604.870.7470 (press #4)

Kelowna: 250.712.3959

Prince George: 250.645.7313

Surrey: 604.930.2098 x 654322

Vancouver: 604.877.6000 x 672752

Victoria: 250.519.5656

# Vancouver Coastal Health Gynecologic Oncology Survivorship Clinic

This clinic improves the quality of care before and after gynecologic cancer surgery. It also offers hormone therapy support and education.

Services include: menopause management and support when making decisions about surgery to prevent cancer.

Contact: 604.875.4111 x 20153

## Pelvic floor physiotherapy



Cancer treatment can affect your pelvic floor muscles. Physiotherapy can help your pelvic muscles get stronger and help them work better. This can improve bladder and bowel control, sexual function and quality of life. Physiotherapy can help people after gynecologic surgery or those with pelvic pain. There are physiotherapists who specialize in this type of treatment.

#### **BC Cancer Oncology Nutrition**



BC Cancer registered dietitians can help you with nutrition at every stage of your cancer journey. They can help if you are having eating challenges during your cancer treatment. There are also group classes you can join.

Abbotsford: 604.851.4733

Kelowna: 250.712.3963

Prince George: 250.645.7330

Surrey: 604.930.4000

Vancouver: 604.877.6000 x 2013

Victoria: 250.519.5525

# Sexual Medicine and Menopause Clinic at BC Centre for Vulvar Health

This clinic helps people with cancer who have concerns about sexual health and managing menopause.

Services include: menopause management, sexual discomfort, sexual self-image, relationship communication and lower desire, arousal and orgasm.

Contact: 604.875.5022, press 3



This icon means that the service offers virtual/online options to patients.

## **Practical support**

#### **Fertile Futures**



A Canadian non-profit organization that gives fertility preservation information and support services. They support people with cancer and oncology professionals. This is not a fertility clinic, but they work with clinics across Canada...

Their 'Power of Hope' program helps lower the cost of fertility preservation.

#### Work & school



BC Cancer has counselling and support groups to help you with concerns about work and school. Counsellors can help you with changing jobs and returning to, maintaining or finding new work. They can also help you with staying in school during treatment or going back to school. More information here.



### **Financial information**



BC Cancer has a financial information booklet. Read about programs and services to help lower costs that come with having cancer. These include medical and non-medical costs. This information can help if you have to travel for treatment.

## **Transportation and lodging**



The programs below can help with transportation and lodging (if you have to travel for cancer treatment):

- Volunteer Cancer Drivers Society
- Transportation Assistance Program
- Hope Air
- Canadian Cancer Society Lodges
  (locations in Vancouver,
  Victoria, Kelowna and
  Prince George)

BC CAN CER

for Cancer





#### More information

- Patient guide
- Interpreters
- Indigenous Cancer Control
- BC Cancer Library



This icon means that the service offers virtual/online options to patients.

## Contact information

BC Cancer Centres		BC Cancer Pharmacies		BC Cancer Patient and Family Counselling	
BC Cancer – Abbotsford	604.851.4710	BC Cancer – Abbotsford	604.851.4709	BC Cancer – Abbotsford	604.851.4710
BC Cancer – Kelowna	250.712.3900	BC Cancer – Kelowna	250.712.3952	BC Cancer – Kelowna	250.712.3900
BC Cancer – Prince George	250.645.7300	BC Cancer – Prince George	250.645.7306	BC Cancer – Prince George	250.645.7300
BC Cancer – Surrey	604.930.2098	BC Cancer – Surrey	604.930.4002	BC Cancer – Surrey	604.930.2098
BC Cancer – Vancouver	604.877.6000	BC Cancer – Vancouver	604.877.6135	BC Cancer – Vancouver	604.877.6000
BC Cancer – Victoria	250.519.5500	BC Cancer – Victoria	250.519.5510	BC Cancer – Victoria	250.519.5500

For general questions about health, contact your physician or other healthcare professional directly for advice.

You can also speak to a healthcare professional any time, day or night, by calling 8.1.1 or visiting <u>HealthLinkBC</u>

Deaf or hearing-impaired (TTY): 7.1.1