

Taking it Step by Step

A GUIDE FOR WOMEN DIAGNOSED WITH GYNECOLOGICAL CANCER



With great thanks

Taking it Step by Step: A guide for women diagnosed with gynecological cancer was envisioned and created by the BC/Yukon Women's Cancer Information & Support Alliance. This group's collaborative effort includes: women with gynecological cancers; the Canadian Cancer Society BC & Yukon; the Gynecologic Tumour Group and Supportive Care Professionals, BC Cancer Agency; Ovarian Cancer Canada Pacific Yukon Region and UBC School of Physical Therapy.

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“The best advice I got was right in the very beginning: Simply take one step at a time. Ask questions until you understand and trust what feels right for you.”



What Is Cancer?

The body is made up of trillions of cells. During normal growth, a cell becomes larger and then divides into two separate cells. After a period of time these cells will divide again. Every cell in our body goes through a life cycle of growth, death and replacement. Each cell contains genetic information as to how fast they grow and divide. The balance between new and old cells keeps our bodies functioning normally. It can take a long time for cancer to develop as several steps and alterations to a cell are usually required before it becomes changed. Usually, many years pass between changes to a cell and cancer developing.

Benign is the term applied to a group of cells or mass which is NOT cancer. Thus, the cells do not spread and are not usually life-threatening. They are small harmless lumps of cells that remain in place.

Cancer cells or tumours consist of **malignant** cells that grow into masses and have the potential to spread to other areas or tissues in the body. Cancers are named after the part of the body where they start. Thus, if you have a gynecological cancer, it has begun in a part of the female reproductive system.

A diagnosis of gynecological cancer means cancer cells are found in the female reproductive system:

- » Uterine/Endometrial
- » Ovarian/Fallopian Tube
- » Cervical
- » Vulvar
- » Vaginal

This guide is divided into sections which give practical information about aspects of the cancer journey. Some sections will give information specific to each type of gynecological cancer, while others will be of a general nature. There are five distinct gynecological cancer sites and each site has many types to it. Keep in mind that each cancer diagnosis is as individual as you and that you may be offered treatments in a different order than described in this guide.

You may find your need for information and support may differ from others. As well you may not need all the information included in this guide, nor read it all at once. Most sections provide resources.

Women of child-bearing age diagnosed with cancer and worried about their future fertility and pregnancy may wish to speak with their doctor about options.

Resources To Learn About Your Diagnosis

BC Cancer Agency Website

www.bccancer.bc.ca

Patient/Public Info > Types of Cancer

Cancer Information Service

Canadian Cancer Society

1.888.939.3333 | www.cancer.ca

Trained information specialists will assist you in accessing information on all aspects of the cancer journey. They also have a complete directory of resources for your community.

Library Services BC Cancer Agency

www.bccancer.bc.ca/Library

- » Abbotsford Cancer Centre Library
604.851.4710 ext. 646825 | 1.877.547.3777
- » Centre for the North Library
250.565.2219
- » Centre for the Southern Interior Library
250.712.3900 ext. 686821 | 1.888.563.7773
- » Fraser Valley Centre Library
604.930.2098 ext. 654576 | 1.800.523.2885
- » Vancouver Centre Library
604.675.8001 | 1.888.675.8001 ext. 8001
- » Vancouver Island Centre Library
250.519.5500 | 1.800.670.3322

Northern BC Cancer Care Navigator 250.565.2813

In Northern BC, a Cancer Care Navigator is available to assist in understanding cancer and treatment options, as well as providing information on travel, accommodations and community-based resources.

Yukon Cancer Navigator 867.393.8853

In the Yukon, a Cancer Navigator is available to assist in understanding cancer and treatment options, as well as providing information on travel, accommodations and community-based resources.

Ovarian Cancer Canada

1.800.749.9310 | www.ovariancanada.org

Offers information, education and support including YOU ARE NOT ALONE: A Guide for Canadian Women Living with Ovarian Cancer.

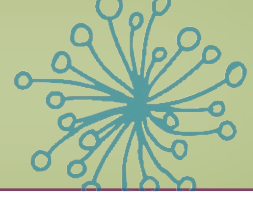


Fertile Future

1.877.467.3066 | www.fertilefuture.ca

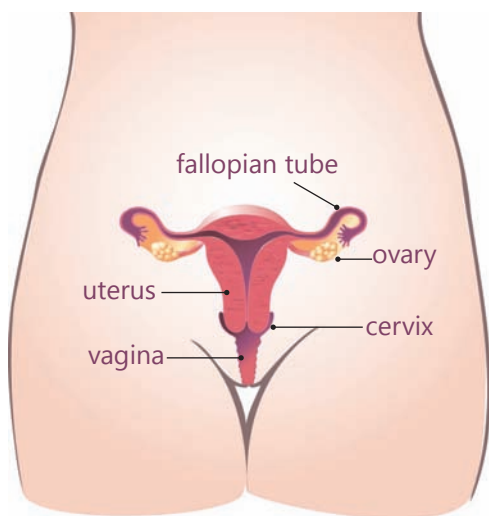
A Canadian network dedicated to providing information, education and financial assistance to cancer patients who wish to pursue fertility preservation.





UTERINE/ENDOMETRIAL CANCER

The uterus (womb) is part of the female reproductive system and is a hollow muscular organ shaped like an upside down pear. The uterus receives a fertilized egg from the fallopian tube and protects the fetus (baby) while it grows and develops. The endometrium is the inner layer or lining of the uterus. Often the terms uterine cancer and endometrial cancer are used together as cancer that starts in the endometrium (lining of the uterus) occurs in the majority of cases. Cancers that start in the muscle or connective tissue in or near the uterus are much less common yet do occur. It is estimated 600 women will be diagnosed with uterine or endometrial cancer each year in BC/Yukon. This is the most common type of gynecological cancer.



Uterine/Endometrial cancer is treated by a team of experts who often use surgery and/or adjuvant (additional) treatments (chemotherapy, radiation therapy) to remove the cancer. Most women have surgery first to remove the cancer and in most cases the lymph nodes in the pelvis are also removed. There are different types of surgery based on your cancer type. In some cases, chemotherapy and/or radiation therapy will be suggested before you have surgery.

In order to make informed choices on which types of treatments are best in your situation, you may wish to learn about the options and

discuss them with your doctor. “**Questions for Your Medical Team**” are found in Section 6 of this guide.

Your gynecologist or family doctor will send your name and information to the BC Cancer Agency Centre or Clinic close to you. The Centre or Clinic will then set up an appointment for you with a **Gynecologic Oncologist** (a specialist in cancer gynecology surgery), a **Medical Oncologist** (specialist in chemotherapy and hormone therapy) or a **Radiation Oncologist** (specialist in radiation therapy and hormone therapy).

Your oncologist will have reviewed your case, possibly discussed it with other doctors, and will recommend a treatment plan tailored to you. Remember that your cancer is as individual as you are. You do not have to make a decision on the spot, unless you feel ready to do so and no medical treatments will happen at the first visit.

Surgery

When diagnosed with uterine cancer, you will be referred to a gynecologic surgeon. Depending on the type and extent of the cancer, your surgery will likely be one of the following which are described below:

- » **Hysterectomy & Bilateral Salpingo-Oophorectomy (BSO)**
- » **Hysterectomy & BSO with Pelvic Lymphadenectomy**

HYSTERECTOMY

In a simple hysterectomy your uterus, cervix and fallopian tubes are taken out. The preferred surgery is a laparoscopically assisted vaginal hysterectomy (LAVH). This uses a laparoscope (thin hollow viewing tube) to guide the removal of the uterus, cervix and fallopian tubes through the vagina (birth canal). This surgery can also be done “abdominally” meaning a larger cut into the stomach wall and the removal of the organs through this incision.

Bilateral Salpingo-Oophorectomy (BSO)

BSO is surgery that removes both ovaries and fallopian tubes. It is usually done at the same time as the hysterectomy for cancer of the uterus.

PELVIC LYMPHADENECTOMY (Lymph Node Dissection)

This is usually done at the same time as a total hysterectomy (in many cases of uterine cancer). The surgeon takes out the lymph node(s) at both sides of the pelvis.

PELVIC EXENTERATION

If cancer has advanced or spread (metastasized) this rare procedure may be done removing any or all of the following: bladder, cervix, uterus, vagina and rectum.

Adjuvant Treatment Options

While surgery is the primary treatment for uterine cancer, **adjuvant** (treatments added to increase the chance of cure) treatments such as radiation, chemotherapy or hormone therapy may be considered, depending on the type and spread of the cancer.

RADIATION THERAPY

Radiation therapy or radiotherapy uses high-energy rays to target cancer cells in one specific area and stop them from growing. Radiation therapy is only available at the BC Cancer Agency centres, thus you may need to travel to receive this treatment. The radiation can come from a machine (external radiation) or from radioactive material placed into or near the tumour or where the tumour was (brachytherapy).

► External Beam Radiation Therapy (EBRT)

Uterine cancer may be treated with external beam radiation therapy. In external beam radiation therapy, a large machine is used to carefully aim a beam of radiation at the tumour and to some of the surrounding tissue. The experience is a lot like getting an X-ray with most of the time spent setting up your body and the machine beam. Treatments are usually given for a few minutes, once a day, 5 days a week for 5 – 7 weeks.

► Brachytherapy

Brachytherapy involves placing a radioactive pellet (radioactive isotope) next to the tumour or in the area where the tumour was removed.

Special hollow tubes (about the size of a large tampon) are placed in the woman through the vagina and the radioactive pellet travels along these tubes to the tumour site. The actual treatment takes less than 15 minutes and the entire process takes about one hour. The tubes are then removed in the clinic. Most people will have 1-5 of these treatments.

These treatments are done on an outpatient basis, and the woman is able to leave the same day, as there is no radiation left by the end of either type of radiation therapy.

CHEMOTHERAPY

Chemotherapy or “chemo” is the use of one drug or a combination of drugs to target cancer cells throughout the body. **Systemic chemotherapy** treats the whole body rather than just one part of it.

- » Cancer cells divide to reproduce themselves and create more cancer cells. Chemotherapy kills cancer cells by stopping their ability to divide and reproduce.
- » Chemotherapy drugs can stop or slow the growth and spread of cancer cells, and can shrink the size of the cancer tumour.

► Intravenous (IV) chemotherapy

Most chemotherapy drugs are injected into one of your veins (given ‘intravenously’) so that they can move around your body through the blood stream. Other drugs can be given in pill form.

You receive intravenous chemotherapy in cycles. This means you will have a chemotherapy treatment in one sitting and then you will have a rest period of days to weeks. Each treatment and rest period make up one cycle. You will likely have more than one cycle of chemotherapy. Your doctor will explain what your chemotherapy plan will be and what you can expect. The length of each chemotherapy treatment period depends on the type of drug and dosages you take. With many types of chemotherapy, 3 – 6 cycles are common.

HORMONE THERAPY

Hormones are chemical substances that are produced by glands in the body or made in a laboratory. **Hormone therapy** is a “systemic” treatment (whole body) that changes the hormone levels in the body. Hormone therapy is used for uterine cancer at the following times:

- » after surgery to destroy any cancer cells left behind and to reduce the risk of the cancer returning
- » as primary (first) treatment for advanced cancer or when the cancer has come back (recurrent)

Resources

Cancer Information Service

Canadian Cancer Society

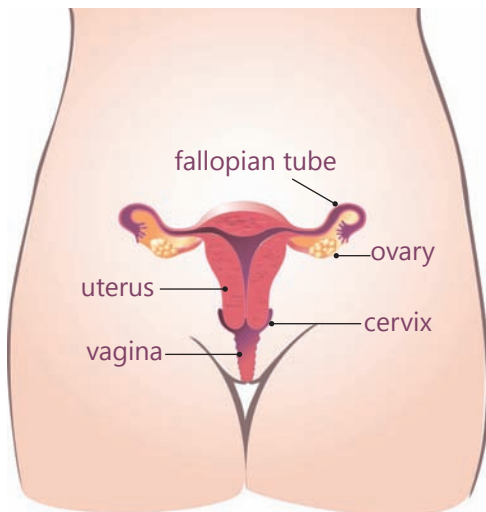
1.888.939.3333 | www.cancer.ca

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- » Eating Well When You Have Cancer
- » Chemotherapy and Other Drug Therapies: A guide for people with cancer
- » Radiation Therapy: A guide for people with cancer
- » When Someone You Know Has Cancer: How you can help

OVARIAN/FALLOPIAN TUBE CANCER

Ovarian cancer begins in the cells of the ovary and, in many cases, the fallopian tubes. The ovaries are two almond-shaped organs attached on either side of the uterus and close to the ends of the fallopian tubes. The ovary produces eggs and the female hormones (estrogen and progesterone). Every month, an egg is released into the fallopian tube which in turn carries it to the uterus. Ovarian cancer is the second most common cancer of the reproductive system. It is estimated 310 women will be diagnosed with ovarian/fallopian tube cancer in BC/Yukon each year.



Ovarian cancer is treated by a team of experts who often use surgery and/or adjuvant (additional) treatments (chemotherapy, radiation therapy) to remove the cancer. Most women have surgery first to remove the cancer and perhaps some of the lymph nodes in the pelvis are also removed. There are different types of surgery based on your cancer type. In some cases, chemotherapy and/or radiation therapy will be suggested before you have surgery.

In order to make informed choices on which types of treatments are best for you, you may wish to learn about the options and discuss them with your doctor. “**Questions for Your Medical Team**” are found in Section 6 of this guide.

Your gynecologist or family doctor will send your name and information to the BC Cancer Agency Centre or Clinic close to you. The Centre or Clinic will then set up an appointment for you with a **Gynecologic Oncologist** (a specialist in cancer gynecology surgery), a **Medical Oncologist** (specialist in chemotherapy and hormone therapy) or a **Radiation Oncologist** (specialist in radiation therapy and hormone therapy).

Your oncologist will have reviewed your case, possibly discussed it with other doctors, and will recommend a treatment plan tailored to you. Remember that your cancer is as individual as you are. You do not have to make a decision on the spot, unless you feel ready to do so and no medical treatments will happen at the first visit.

Surgery

When ovarian cancer is suspected, you will be referred to a gynecologic surgeon. It is usual to not receive a diagnosis of ovarian cancer until after surgery. Surgery may likely be one or more of the following:

- » **Laparotomy**
- » **Unilateral Salpingo-Oophorectomy (USO)**
- » **Hysterectomy with Bilateral Salpingo-Oophorectomy (BSO)**
- » **Omentectomy with Tumour Debulking**

LAPAROTOMY

A surgery called a laparotomy is done for most women to find out the stage of the cancer. The doctor makes a cut into the abdomen and carefully looks at the ovaries and surrounding areas to see if they contain cancer, and will remove as much as possible.

UNILATERAL SALPINGO-OOPHORECTOMY

This surgery removes just one ovary and fallopian tube. This may be used in early stage ovarian cancer or in younger women who wish to have children.

HYSTERECTOMY

In a simple hysterectomy your uterus, cervix and fallopian tubes are taken out. The preferred surgery is a laparoscopically assisted vaginal hysterectomy (LAVH). This uses a laparoscope

(thin hollow viewing tube) to guide the removal of the uterus, cervix and fallopian tubes through the vagina (birth canal). This surgery can also be done “abdominally” meaning a larger cut into the stomach wall and the removal of the organs through this incision.

BILATERAL SALPINGO-OOPHORECTOMY (BSO)

BSO is surgery that removes both ovaries and fallopian tubes. It is usually done at the same time as the hysterectomy.

OMENTECTOMY & TUMOUR DEBULKING

Omentectomy is the removal of the omentum (the layer of fat that hangs over the intestines) and debulking means removal of as much of the disease as possible. For patients with advanced disease, it may be recommended to receive “neoadjuvant chemotherapy.” This means you will receive 3–4 cycles of chemotherapy before a delayed surgery.

Adjuvant Cancer Treatments

The primary treatment for ovarian cancer consists of surgery and chemotherapy. Chemotherapy is considered **adjuvant** (treatments added to increase chance of cure) treatment. Some rare types of ovarian cancer may also require surgery with or without adjuvant radiation therapy.

CHEMOTHERAPY

Chemotherapy or “chemo” is the use of one drug or a combination of drugs to kill cancer cells throughout the body. **Systemic chemotherapy** treats the whole body rather than just one part of it.

- » Cancer cells divide to reproduce themselves and create more cancer cells. Chemotherapy kills cancer cells by stopping their ability to divide and reproduce.
- » Chemotherapy drugs can stop or slow the growth and spread of cancer cells, and can shrink the size of the cancer tumour.
- » Chemotherapy may be given before the surgery (neoadjuvant) or after it (adjuvant).

▶ Intravenous (IV) chemotherapy

Chemotherapy drugs are injected into one of your veins (given ‘intravenously’) so that they can move around the body through the blood stream.

▶ Intraperitoneal chemotherapy

Chemotherapy drugs may be given through a thin tube inserted directly into the abdomen. This is given in addition to standard IV chemotherapy.

You receive chemotherapy in cycles. This means you will have a chemotherapy treatment in one sitting and then you will have a rest period of days to weeks. Each treatment and rest period make up one cycle. You’ll likely have more than one cycle of chemotherapy. Your doctor will explain what your chemotherapy plan will be and what you can expect. The length of each chemotherapy treatment period depends on the type of drug you take. With many types of chemotherapy, 3 – 6 cycles are common.

RADIATION THERAPY

Radiation therapy or radiotherapy uses high-energy rays to target cancer cells in one specific area and stop them from growing. Radiation therapy is only available at the BC Cancer Agency centres, thus you may need to travel to receive this treatment.

▶ External Beam Radiation Therapy (EBRT)

Ovarian cancer may be treated with external beam radiation therapy. In external beam radiation therapy, a large machine is used to carefully aim a beam of radiation at the tumour and the surrounding tissue. The experience is a lot like getting an X-ray, with most of the time spent setting up your body and the machine beam. Treatments are usually given once a day, 5 days a week for 5 weeks.

Resources

Ovarian Cancer Canada

1.877.413.7970 | www.ovariancanada.org

Offers information, education and support, including the 'YOU ARE NOT ALONE' kit – a Guide for Canadian Women Living with Ovarian Cancer.



Cancer Information Service

Canadian Cancer Society

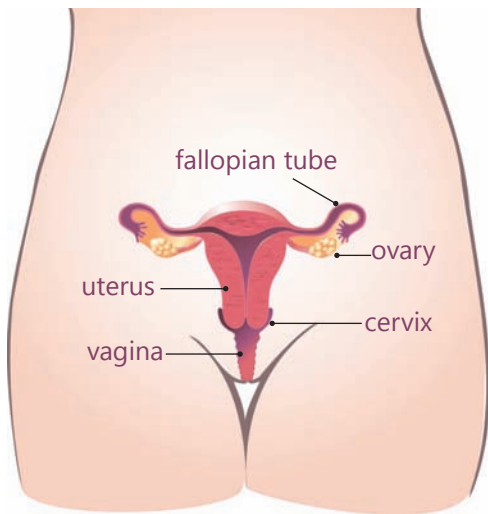
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- » Eating Well When You Have Cancer
- » Chemotherapy and Other Drug Therapies: A guide for people with cancer
- » Radiation Therapy: A guide for people with cancer
- » When Someone You Know Has Cancer: How you can help

CERVICAL CANCER

The cervix is part of the female reproductive system. The cervix is the lower portion of the uterus which connects the main body of the uterus to the vagina. It is used as a channel between the two organs. Cervical cancer begins in the cells of the cervix and it is estimated 140 women will be diagnosed with cervical cancer in BC/Yukon each year. Cervical cancer is in many cases found early thanks to the Cervical Screening Program in BC and the Yukon. It is the third most diagnosed female reproductive cancer.



Cervical cancer is treated by a team of experts who often use surgery and/or adjuvant (additional) treatments (chemotherapy, radiation therapy) to remove the cancer. Most women have surgery first to remove the cancer and the lymph nodes in the pelvis. There are different types of surgery based on your cancer type. In some cases, chemotherapy and/or radiation therapy will be suggested before you have surgery.

In order to make informed choices on which types of treatments are best for you, you may wish to learn about the options and discuss them with your doctor. “**Questions for Your Medical Team**” are found in Section 6 of this guide.

Your gynecologist or family doctor will send your name and information to the BC Cancer Agency

Centre or Clinic close to you. The Centre or Clinic will then set up an appointment for you with a **Gynecologic Oncologist** (a specialist in cancer gynecology surgery), a **Medical Oncologist** (specialist in chemotherapy and hormone therapy) or a **Radiation Oncologist** (specialist in radiation therapy and hormone therapy).

Your oncologist will have reviewed your case, possibly discussed it with other doctors, and will recommend a treatment plan tailored to you. Remember that your cancer is as individual as you are. You do not have to make a decision on the spot, unless you feel ready to do so and no medical treatments will happen at the first visit.

Surgery

While surgery is one way to treat early cervical cancer, **adjuvant** (additional) treatments are used depending on the type and spread of the cancer. Your surgery will likely be one of the following:

- » **Cone biopsy or LEEP (early stage)**
- » **Radical Trachelectomy**
- » **Hysterectomy**
- » **Radical Hysterectomy with Pelvic Lymphadenectomy**

CONE BIOPSY

The doctor removes a cone-shaped piece of tissue from the cervix and cervical canal. The tissue sample is then looked at under a microscope to see if there is cancer. This may be used to diagnose or treat a cervical condition.

LOOP ELECTROSURGICAL EXCISION PROCEDURE (LEEP)

This is more commonly used in “precancerous” lesions of the cervix. LEEP uses a high frequency electrical current for cutting away diseased tissue. Large and deep sections of damaged tissue can be effectively removed and very high cure rates are possible with just one treatment.

RADICAL TRACHELECTOMY

This is the removal of the cervix and tissue around it, while still leaving the body of the uterus intact. A radical trachelectomy with lymphadenectomy is an option for young women with early stage disease who wish to maintain

their fertility. In most cases, the lymph node(s) on both sides of the pelvis are also removed.

PELVIC LYMPHADENECTOMY (Lymph Node Dissection)

The surgeon takes out the lymph node(s) on both sides of the pelvis.

HYSTERECTOMY

In a simple hysterectomy your uterus, cervix and fallopian tubes are taken out. The preferred surgery is a laparoscopically assisted vaginal hysterectomy (LAVH). This uses a laparoscope (thin hollow viewing tube) to guide the removal of the uterus, cervix and fallopian tubes through the vagina (birth canal). This surgery can also be done "abdominally" meaning a larger cut into the stomach wall and the removal of the organs through this incision.

RADICAL HYSTERECTOMY

Complete removal of the uterus, cervix, fallopian tubes and the tissue surrounding the uterus.

Adjuvant Treatment Options

While surgery is often the preferred treatment for early cervical cancer, adjuvant (treatments added to increase chance of cure) treatments such as radiation and/or chemotherapy are used for larger or more widespread cancers.

RADIATION THERAPY

If there is significant risk of lymph node involvement or the cancer in the cervix is large or has spread to tissues next to the cervix, radiation therapy may be used. Chemotherapy is often given **concurrently** (at the same time) to make the radiation therapy more effective. Radiation therapy is only available at the BC Cancer Agency centres, thus you may need to travel to receive this treatment.

► External Beam Radiation Therapy (EBRT)

Cervical cancer is treated with external beam radiation therapy. In external beam radiation therapy, a large machine is used to carefully aim a beam of radiation at the tumour, lymph nodes and the surrounding tissue. The experience is a lot like getting an X-ray, with most of the time

spent setting up your body and the machine beam. Treatments are usually given once a day, 5 days a week for 5-6 weeks.

► Brachytherapy

Brachytherapy involves placing a radioactive pellet (radioactive isotope) next to the tumour or in the area where the tumour was removed. Special hollow tubes (about the size of a large tampon) are placed in the woman through the vagina and the radioactive pellet travels along these tubes to the tumour site. The actual treatment takes less than 15 minutes and the entire process takes about one hour. The tubes are then removed in the clinic. Most people will have 2-5 of these treatments.

After you recover from the anesthesia, you will have a CT scan. This CT scan helps the Radiation Oncologist plan your internal treatment. This takes approximately 90 minutes, during which time you will be in the radiation support section of the radiation department.

These treatments are done on an outpatient basis, and the woman is able to leave the same day, as there is no radiation left by the end of either type of radiation therapy.

CHEMOTHERAPY

Chemotherapy or "chemo" is the use of one drug or a combination of drugs to kill cancer cells throughout the body. Systemic chemotherapy treats the whole body rather than just one part of it. The chemotherapy drugs used to treat cervical cancer are usually given as an injection into a vein (IV Chemotherapy) so they can circulate through the blood stream.

- » Cancer cells divide to reproduce themselves and create more cancer cells. Chemotherapy kills cancer cells by stopping their ability to divide and reproduce.
- » Chemotherapy drugs can stop or slow the growth and spread of cancer cells, and can shrink the size of the cancer tumour.
- » In most cases, low-dose chemotherapy is given, along with radiation therapy to enhance the radiation's effectiveness
- » It may also be used to treat recurrent cancer (cancer that comes back).

Resources

Cancer Information Service

Canadian Cancer Society

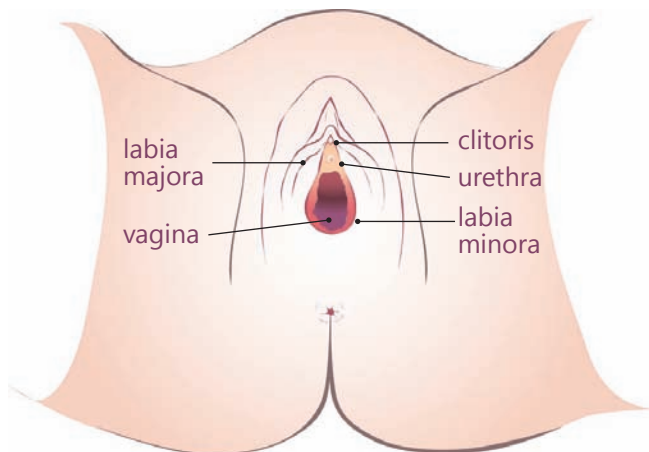
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- » Radiation Therapy: A guide for people with cancer
- » When Someone You Know Has Cancer: How you can help

VULVAR CANCER

The vulva is made up of skin and fatty tissue and includes the opening of the vagina, the outer lips (labia majora), inner lips (labia minora) and the clitoris. Vulvar cancer begins in the cells of the vulva. Cancer of the vulva accounts for less than 5% of all gynecological cancers in BC and the Yukon.



Vulvar cancer is treated by a team of experts who often use surgery and/or adjuvant (additional) treatments (chemotherapy, radiation therapy) to remove the cancer. Most women have surgery first to remove the cancer and perhaps some of the lymph nodes in the groin are also removed. There are different types of surgery based on your cancer type. In some cases, chemotherapy and/or radiation therapy will be suggested before you have surgery.

In order to make informed choices on which types of treatments are best for you, you may wish to learn about the options and discuss them with your doctor. “**Questions for Your Medical Team**” are found in Section 6 of this guide.

Your gynecologist or family doctor will send your name and information to the BC Cancer Agency Centre or Clinic close to you. The Centre or Clinic will then set up an appointment for you with a **Gynecologic Oncologist** (a specialist in cancer gynecology surgery), a **Medical Oncologist** (specialist in chemotherapy and hormone therapy) or a **Radiation Oncologist** (specialist in radiation therapy and hormone therapy).

Your oncologist will have reviewed your case, possibly discussed it with other doctors, and will recommend a treatment plan tailored to you. Remember that your cancer is as individual as you are. You do not have to make a decision on the spot, unless you feel ready to do so and no medical treatments will happen at the first visit.

Surgery

The standard treatment for vulvar cancer is surgery. Your surgery will likely be one of the following:

- » **Wide Local Excision**
- » **Vulvectomy**
 - **Simple Vulvectomy**
 - **Radical Vulvectomy with Lymphadenectomy**

WIDE LOCAL EXCISION

Excision is the type of surgery most often used for early stage vulvar cancer that has not spread to other areas of the body (called superficially invasive). This surgical procedure is for small lesions and removes the cancer, or pre-cancerous areas and also some healthy tissue.

SIMPLE VULVECTOMY

Simple vulvectomy is the removal of all external tissues of the vulva (the skin and the very top layer of fat underneath).

RADICAL VULVECTOMY WITH LYMPHADENECTOMY

This surgery is used if the cancer is more than superficial (on the top skin layer). It involves removing the vulva, labia majora, clitoris, surrounding normal tissue and lymph nodes in one or both sides of the groin.

Adjuvant Treatment Options

Adjuvant (additional) therapies such as radiation therapy and chemotherapy may be used in the treatment of vulvar cancer. It is used if cancer is found in the lymph nodes of the groin, or if surgery cannot totally remove the cancer.

RADIATION THERAPY

Radiation therapy or radiotherapy uses high-energy rays to target cancer cells in a specific area and stop them from growing. Radiation therapy is only available at the BC Cancer Agency centres, thus you may need to travel to receive this treatment. A doctor who specializes in cancer and radiation is called a radiation oncologist. The most common way to receive radiation for vulva cancer is from a machine outside your body that emits an invisible beam. This is called external beam radiation therapy.

► External Beam Radiation Therapy (EBRT)

Vulvar cancer may be treated with external beam radiation. In external beam radiation, a large machine is used to carefully aim a beam of radiation at the tumour and to some of the surrounding tissue. The experience is a lot like getting an X-ray, with most of the time spent setting up your body and the machine beam. Treatments are usually given once a day, 5 days a week for 5-7 weeks.

CHEMOTHERAPY

Chemotherapy or “chemo” is the use of one drug or a combination of drugs to kill cancer cells throughout the body. Chemotherapy treats the whole body rather than just one part of it. Most chemotherapy drugs used to treat vulvar cancer are given as an injection into a vein (intravenous) so they can circulate through the blood stream.

- » Cancer cells divide to reproduce themselves and create more cancer cells. Chemotherapy kills cancer cells by stopping their ability to divide and reproduce.
- » Chemotherapy drugs can stop or slow the growth and spread of cancer cells, and can shrink the size of the cancer tumour.
- » In most cases, low-dose chemotherapy is given along with radiation therapy to enhance the radiation’s effectiveness
- » It may also be used to treat recurrent cancer (cancer that comes back).

You receive chemotherapy in cycles. This means you will have a chemotherapy treatment in one sitting and then you will have a rest period of days to weeks. Each treatment and rest period

make up one cycle. You’ll likely have more than one cycle of chemotherapy. Your doctor will explain what your chemotherapy plan will be and what you can expect. The length of each chemotherapy treatment period depends on the type of drug you take. With many types of chemotherapy, 3 – 6 cycles are common.

Resources

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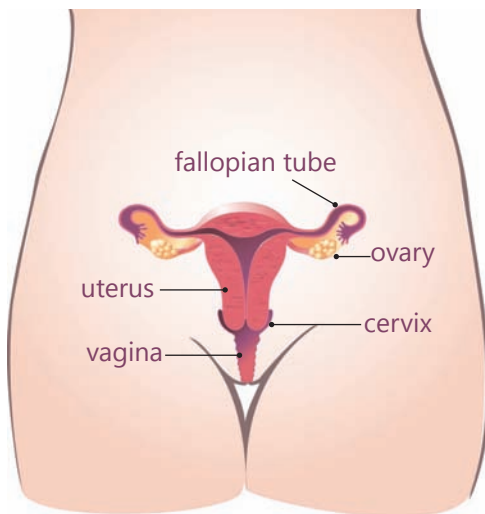
1.888.939.3333 | www.cancer.ca

Go online to download or call and ask for:

- » Eating Well When You Have Cancer
- » Chemotherapy and Other Drug Therapies: A guide for people with cancer
- » Radiation Therapy: A guide for people with cancer
- » When Someone You Know Has Cancer: How you can help

VAGINAL CANCER

The vagina is a hollow tube like passage which connects the cervix (bottom of the uterus) to outside the body. This 3-4 inch tube is known as the birth canal during childbirth. Vaginal cancer begins in the cells of the vagina. Cancer of the vagina is one of the rarest cancers of the reproductive system with less than 1% of gynecological cancers in BC and the Yukon.



Vaginal cancer is treated by a team of experts who often use radiation and chemotherapy treatments to remove the cancer. Surgery is not usually used to treat vaginal cancer. In order to make informed choices on which types of treatments are best for you, you may wish to learn about the options and discuss them with your doctor. **“Questions for Your Medical Team”** are found in Section 6 of this guide.

Your gynecologist or family doctor will send your name and information to the BC Cancer Agency Centre or Clinic close to you. The Centre or Clinic will then set up an appointment for you with a **Gynecologic Oncologist** (a specialist in cancer gynecology surgery), a **Medical Oncologist** (specialist in chemotherapy and hormone therapy) or a **Radiation Oncologist** (specialist in radiation therapy and hormone therapy).

Your oncologist will have reviewed your case, possibly discussed it with other doctors, and will recommend a treatment plan tailored to you.

Remember that your cancer is as individual as you are. You do not have to make a decision on the spot, unless you feel ready to do so and no medical treatments will happen at the first visit.

Surgery

Surgery is not usually used for vaginal cancers. Surgery is used for women that have precancerous changes to the vagina (VAIN 3).

Stage 0 or VAIN 3

This is not vaginal cancer, but could turn into a cancer. Stage 0 is also known as vaginal intraepithelial neoplasia grade 3 (VAIN 3) or carcinoma in-situ (CIS). These abnormal cells are in the skin tissue lining the vagina and have not spread away from this tissue. These abnormal cells are removed by:

- » **Laser Surgery**
- » **Partial or Total Vaginectomy**

LASER SURGERY

This surgery uses a laser beam (a narrow beam of intense light) to remove the tumor. The laser beam is used as a knife, only the cut is bloodless or leaves no bleeding. The laser removes the tumor by burning off the tissue.

VAGINECTOMY

A vaginectomy is the partial or entire removal of the vagina.

Adjuvant Cancer Treatments

If your vaginal cancer is greater than Stage 0 (VAIN3), your medical team will use adjuvant (additional) radiation therapy. Chemotherapy may also be given **concurrently** (at the same time) to make the radiation therapy more effective. With concurrent chemotherapy, this will be given at the BC Cancer Agency Centres.

RADIATION THERAPY

Radiation therapy or radiotherapy uses high-energy rays to target cancer cells in one specific area and stop them from growing. Radiation therapy is only available at the BC Cancer Agency centres, thus you may need to travel to

receive this treatment. A doctor who specializes in cancer and radiation is called a radiation oncologist. The radiation can come from a machine (external radiation) or from radioactive material placed into or near the tumour (Brachytherapy).

► External Beam Radiation Therapy (EBRT)

Vaginal cancer may be treated with external beam radiation. In external beam radiation a large machine is used to carefully aim a beam of radiation at the tumour and to some of the surrounding tissue. The experience is a lot like getting an X-ray, with most of the time spent setting up your body and the machine beam. Treatments are usually given once a day, 5 days a week for 3-5 weeks.

► Brachytherapy (Vaginal Vault Therapy)

Brachytherapy involves placing a radioactive pellet (radioactive isotope) next to the tumour or in the area where the tumour was removed. Special hollow tubes (about the size of a large tampon) are placed in the woman through the vagina and the radioactive pellet travels along these tubes to the tumour site. The actual treatment takes less than 15 minutes and the entire process takes about one hour. The tubes are then removed in the clinic. Most people will have 1-5 of these treatments.

These treatments are done on an outpatient basis, and the woman is able to leave the same day, as there is no radiation left by the end of either type of radiation therapy.

CHEMOTHERAPY

Chemotherapy or “chemo” is the use of one drug or a combination of drugs to kill cancer cells throughout the body. Chemotherapy treats the whole body rather than just one part of it. Most chemotherapy drugs used to treat vaginal cancer are given as an injection into a vein (intravenous) so they can circulate through the blood stream.

- » Cancer cells divide to reproduce themselves and create more cancer cells. Chemotherapy kills cancer cells by stopping their ability to divide and reproduce.

- » Chemotherapy drugs can stop or slow the growth and spread of cancer cells, and can shrink the size of the cancer tumour.
- » In some cases, low-dose chemotherapy is given along with radiation therapy to enhance the radiation’s effectiveness
- » It may also be used to treat recurrent cancer (cancer that comes back).

Resources

Cancer Information Service

Canadian Cancer Society

1.888.939.3333 | www.cancer.ca

Go online to download or call and ask for:

- » Eating Well When You Have Cancer
- » Chemotherapy and Other Drug Therapies: A guide for people with cancer
- » Radiation Therapy: A guide for people with cancer
- » When Someone You Know Has Cancer: How you can help



After a diagnosis of cancer is made, it is important to determine the extent or stage of the cancer before deciding on the treatment plan. A **pathology report** is a detailed picture of the cancer cells as seen by the naked eye and under a microscope. In many cases, a full pathology report is not ready until about 2 weeks after the cancer biopsy or surgery. While having tests and waiting for results can feel long and frustrating, the complete description of the cancer is needed.

Grade Of Cancer

Grade refers to the appearance or look of the cancer cells under the microscope. It describes how different they have become from what a normal cell looks like.

Stage Of Cancer

There are two systems used together to classify cancer. TNM is a type of classification system used to describe the extent of the cancer's involvement in your body. The second classification used is Spread of Cancer which uses a 1-4 scale system to describe the location of the cancer in your body.

TNM

T (Tumour) describes the site and size of the main (primary) tumour

N (Node) describes involvement of lymph nodes

M (Metastasis) relates to the cancer spread (metastasis) in the body

SPREAD OF CANCER	
STAGE 1	cancer is present and within the primary tumour site
STAGE 2	cancer has spread into nearby tissues, but not into the lymph nodes
STAGE 3	cancer has spread past the primary site and into the lymph nodes
STAGE 4	cancer has spread to other or distant areas in the body

Your **oncologist** (cancer doctor) will use the information in the pathology report to:

- » choose the best treatment for you
- » suggest if a clinical trial exists for you
- » estimate your chance of recovery

Questions To Ask About Your Pathology Report

- » Where did my cancer start?
- » What is the grade or how aggressive is my cancer?
- » What is the stage or extent of my cancer?
- » Has the cancer spread to my lymph nodes?
- » Has the cancer spread (metastasized) to other or distant areas of my body?
- » Do I need more tests before treatment can start?
- » What are my chances for having children?
- » Can you give me an idea of my chance of recovery or survival?

Chance Of Recovery

The **chance of recovery** or survival rate is often used by doctors as a way of discussing a person's **prognosis** (how cancer will affect a person). Some patients with cancer may want to know the survival statistics for people in the same situation, while others may not find the numbers helpful.

Survival rates are often based on past outcomes of large numbers of people who had the disease, but they cannot forecast what will happen in any one person's case. Factors may affect a person's survival, such as their overall health, the treatment they receive, and how well their cancer responds to treatment.



Tips For Meeting With Your Medical Team

As you move into your cancer journey, it is important to keep your own medical information, test results and appointments, not just for yourself but for your medical care team as well. You may choose to become informed about tests and procedures that have been offered to you as well as being able to ask questions of your doctors. See “**Questions for Your Medical Team**”, in Section 6 in this guide.

HELPFUL TIPS

- » **Write down questions before seeing your doctor. Ask questions until you understand what is being said.**
- » There may be many oncology (cancer) experts on your care team. Record names and telephone numbers on this page.
- » You are encouraged to have a family member or friend accompany you to doctor’s visits to take notes on your behalf.
- » You may choose to use a blank calendar to record your medical visit times. Or, you may find keeping a journal helpful.
- » Be sure you ask for copies of all your test results. Keep all records and reports in one place.
- » You can ask for a second opinion should you not feel comfortable with the information you are given.

Resources

www.caringbridge.com

www.mylifeline.org

www.lotsahelpinghands.com

Websites designed to help families and friends stay connected and help to manage their loved ones care needs.

Your Medical Team Contacts

Your treatment plan may or may not include all types of oncology experts. Women with a cancer diagnosis are always able to access supportive care services such as counselling, nutrition and library services at the BC Cancer Agency, regardless of your treatment plan or where you live.

Cancer Navigator

Surgeon

Medical Oncologist

Radiation Oncologist

Nurse

Counsellor/Social Worker

Dietitian

Pharmacist

Other



There will be many visits with health care professionals at various time of your journey. It is important to get all the information you require to make informed decisions. It is okay to ask questions, over and over again until you feel you understand all aspects of what is being presented. Below are some questions you may wish to consider asking.

Before Surgery

- » What are my options for surgery?
- » Are there clinical trials I should think about?
- » I want to have children. Is this still an option?
- » How long does it take for the surgery?
- » What do I need to do to get ready for surgery?
- » How long will I be in the hospital after surgery?
- » Will I have drains?
- » Will I have stitches/staples?
- » Will I go into menopause due to the type of surgery?
- » How long after surgery before I can be intimate with my partner?

After Surgery

- » What pain or body stiffness can I expect and how long will it last?
- » Are there side effects to the pain medication?
- » How can I access home support?
- » When can I take a shower or bath?
- » What activities should I avoid?
- » When will my pathology report (a detailed report of the cancer removed) be ready?
- » When and how do I get referred to the Cancer Centre?
- » When will I be able to return to work?
- » Will I need physiotherapy?

About Chemotherapy

- » What are my options regarding the drug types? Who pays for the drugs?
- » Are there clinical trials I should think about?
- » Where do I go for my treatment?

- » Can I have someone come with me? To drive me home?
- » How will chemotherapy be given? How often? Over what time period?
- » Is it safe to take my herbs or vitamins while having chemotherapy?
- » What are the short-term side effects?
- » What are the long-term side effects?
- » Will I lose my hair? If so, how soon will that be?
- » Can I work while I am having chemotherapy?

About Radiation Therapy

- » What is radiation therapy like? Will it hurt?
- » Where do I go for treatments?
- » Are there clinical trials I should think about?
- » What are the short-term side effects?
- » What are the long-term side effects?
- » Will radiation therapy affect any other organs?
- » Is it safe to take my herbs or vitamins while having radiation therapy?
- » Can I have someone come with me? To drive me home?
- » Can I work while I am having radiation treatments?

Resources

Cancer Information Service

Canadian Cancer Society

1.888.939.3333 | www.cancer.ca

Go online to download or call and ask for:

- » Chemotherapy and Other Drug Therapies: A guide for people with cancer
- » Radiation Therapy: A guide for people with cancer

Fertile Future

1.877.467.3066 | www.fertilefuture.ca

A Canadian network dedicated to providing information, education and financial assistance to cancer patients who wish to pursue fertility preservation.



There are still many basic questions about getting through the cancer journey, especially for those that must travel distances to their cancer clinic. The following questions are most commonly asked by patients and family members. Answers to these questions, contact numbers and referrals are found by using the resources listed below.

The closest cancer centre is 200 km away.

Where do I stay during my treatment?

- » Canadian Cancer Society Lodges
- » Local Hotels at discount rates
- » Family and friends homes

How am I going to pay for all of this?

- » Financial Support Programs (Supportive Drugs, Accommodation, Transportation)
- » Provincial and National programs

I need help getting to the cancer clinic for my treatments.

- » Volunteer Driver Programs
- » Travel Assistance Program
- » Northern Health Connection Bus

I need help at home.

- » Home care
- » Community resources

What if my cancer treatments cause me to lose my hair?

- » Canadian Cancer Society Wig Banks
- » Look Good Feel Better Program
- » Local wig shops

Resources

Cancer Information Service

Canadian Cancer Society

1.888.939.3333 | www.cancer.ca

Trained information specialists will assist you in accessing information on these aspects of your cancer journey. They also have a complete directory of resources for your community available online, as well as over the phone.

Northern BC Cancer Care Navigator

250.565.2813

In Northern BC, a Cancer Care Navigator is available to assist in understanding cancer and treatment options, as well as providing information on travel, accommodations and community-based resources.

Yukon Cancer Navigator

867.393.8853

In the Yukon, a Cancer Navigator is available to assist in providing information on travel, accommodations and community-based resources.

Patient and Family Counselling Services

BC Cancer Agency

1.800.663.3333 ext 2194

www.bccancer.bc.ca

» **Patient/Public Info** » **Coping with Cancer**

Go online to download or call and ask for:

- » Financial Information for Cancer Patients



Being diagnosed with cancer can be scary and confusing. Being aware that this diagnosis affects your emotional and spiritual self, as well as your body is important. You may feel the need for help and there is support that exists. Some first steps to taking care of yourself are probably things you already do. Explore the resources in this section for ways to get support.

Breathe deep

The first, last, and most important step to remember is to breathe...long, deep breaths. Breathing helps you clear your mind and brings your heart rate down.

Refocus

Allow yourself to take a few steps back from your situation and view it from this slightly different view...you may be able to see more clearly what is happening, and know what is in your control and what is not. Make one decision at a time.

Acknowledge your feelings

Expressing your feelings is an important part of this journey. Something intimate and major has happened to you which will impact most, if not all, aspects of your life. This will likely evoke powerful feelings of fear, anxiety, sadness or anger. A sense of relief, calm, and comfort may follow when you express your emotions, both positive and negative.

Choose effective coping skills

Cancer is stressful! Take stock of the coping skills in your personal "tool kit." It may seem like your familiar, everyday ways of dealing with "stress" are just not doing the trick. Think about what has worked well in the past and helped you deal with stress or anxiety.

Seek the support of others

Who are you going to reach out to for support? Family, neighbours, friends and co-workers may want to help, but may not know how. Be open with your family and friends as to how they can help you.

Resist information overload

Do your "homework." Become informed about your diagnosis in a way that is helpful to you. Be careful not to get overloaded and overwhelmed with information or others stories. **Remember your journey is unique and some people's experiences will not be useful.**

Resources

You may find a sense of comfort in talking or connecting with others who share similar experiences, either in person, online or over the telephone. Know that everyone's cancer and experience with cancer is unique.

Coping With Cancer Section BC Cancer Agency

www.bccancer.bc.ca

» **Patient/Public Info** » **Coping with Cancer**

Basic self-care skills are found in the "Emotional Support" online.

Cancer Connection Canadian Cancer Society

1.888.939.3333 | www.cancerconnection.ca

A peer support program which matches you with a trained volunteer who has had a similar cancer experience. Volunteers listen and offer support over the telephone. As well, a trusted online community for patients, their family and friends.

Cancer Chat Canada

www.cancerchatcanada.ca

A website with online professionally-led support online support groups for women with cancer.

Eyes on the Prize (US)

www.eyesontheprize.org

A website with online support groups for gynecological cancer.

**Patient and Family Counselling Services
BC Cancer Agency**

www.bccancer.bc.ca

» **Patient/Public Info** » **Coping with Cancer** »
Emotional

Professionally led support groups and individual counselling for women, caregivers and children. Check the monthly calendars online for cancer centre groups or call:

- » Abbotsford Cancer Centre
604.851.4733
- » Centre for the Southern Interior
250.712.3963
- » Centre for the North, Oncology Social Worker
250.565.2863
- » Fraser Valley Centre
604.930.4000
- » Vancouver Centre
604.877.6000 ext. 2194
- » Vancouver Island Centre
250.519.5525

(Centre for the North opens November 2012. Call 250.565.2000 after this date to be connected to the centre.)

Ovarian Cancer Canada

1.877.413.7970 | www.ovariancanada.org

Offers support groups and networking information sessions both in-person and over the telephone.

Cancer Information Service

Canadian Cancer Society

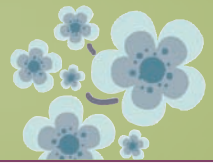
1.888.939.3333 | www.cancer.ca

Go online to download or call and ask for:

- » Living with Cancer: A guide for people with cancer and their caregivers
- » When Someone you know has Cancer: How you can help



"I thought about cancer constantly. I was obsessing and scared all the time. I could not function well. I finally found help to sort things out. Talking with others and finding out they have the same fears and concerns was reassuring."



Follow-Up Plan

After your treatments at the cancer centre or clinics are complete, you will be provided with a follow-up plan to ensure your health is monitored on a regular basis. Your follow-up plan will depend on the type of gynecological cancer you had, as well as the surgery and other cancer treatments you have gone through. Ask your medical team for a copy of your specific plan details.

Transitioning To Cancer Survivor

We all have our own ways of coping with the challenges and issues that arise in our lives. You may be surprised by the feelings and emotions which surface after you have ended your cancer treatments. Common themes include: trying to “find yourself”, taking a new look at your life and spiritual ideas, as well as changes to your body and energy. Some women have said the end of treatment can bring with it a feeling of being “left on their own at the edge of a cliff afraid to take a step forward”. It is important to realize there will be a point that you will transition from being an active patient to living as a survivor (a person who has gone through a cancer experience).

Take Back Control

While everyone varies in how much medical information they need, want and find helpful, you may wish to know more about your cancer. Once treatment is over, you may want to create your own program for wellness, to take control of your overall health. This ability to take control may assist in dealing with issues such as fatigue and sadness – the physical and emotional side of cancer. See the **“Making Healthy Choices”** Section in this guide.

Fatigue

Fatigue is the kind of chronic tiredness that a good night’s sleep does not seem to help and its effects may last longer than you expect. This can lead to frustration or longing for the energy you

used to have. Fatigue can often be managed and energy can be regained over time. In the meantime, choose how you use your limited energy in your day-to-day tasks.

Getting Clear On Life’s Priorities

Many patients tell us that cancer has allowed them to clean house, to clear the clutter in their lives of both people and things. Some take a clear look at their relationships with others, change careers that no longer fit, stop activities that are no longer rewarding, or simply vow to be more selective in how they spend their time and energy. The bittersweet gift of cancer is to perhaps value life more intensely – and to be committed to not wasting a moment. Many women report they begin to pursue heartfelt moments which make them feel good!

Making Sense, Finding Meaning

For some women, there is great comfort in drawing on personal spiritual beliefs. Some refer to a higher purpose in their lives. Perhaps cancer has lessons to teach us? Exploring those lessons and your own beliefs may be something you are drawn to. Even people who are not spiritual, report feeling they have been given a “second chance” at living their lives and do so with gusto.

Connection and Support

Often survivors tell us that they have a renewed appreciation for their relationships with friends and family. There is an intimacy which may develop by connecting and speaking with others who have travelled this journey. Support groups, one-on-one peer conversations and in some cases, professional counselling can assist you in coping with your new life.

Brain Fog (Chemo Brain)

Some people, whether due to the stress of the cancer experience or due to the toxicity of the drugs, may experience brain fog. Brain fog is defined as: difficulty in thinking, memory loss

(forgetting names), not being able to focus for long periods and having trouble doing one or more tasks at a time. Brain Fog is usually temporary and you may find some of the resources in this section helpful.

Recurrence

For many, dealing with the fear of recurrence (the cancer coming back) is too much. For those that come to some peace or resolution about living with this fear, it seems that “action may be the best antidote for anxiety”. You may wish to take control of factors which you can have control over such as: diet, exercise and stress. Try to “let go” of the rest. It may help to connect and talk openly with other cancer patients who understand your feelings as they have been there too.

Resources

Library Services

BC Cancer Agency

1.888.675.8001. ext 8001

www.bccancer.bc.ca/Library

Excellent Books:

- » Picking up the Pieces by Sherri Magee & Kathy Scalzo
- » Dancing in Limbo by Glenna Halvorson-Boyd
- » Your Brain After Chemo by Daniel Silverman & Idelle Davidson
- » Intimacy after Cancer: A Woman’s Guide by Sally Kydd & Diane Rowett

Vocational Rehabilitation Services

BC Cancer Agency

www.bccancer.bc.ca

» **Patient/Public Info** » **Coping with Cancer** »

Emotional

Vocational Rehabilitation counselling includes helping patients access resources, developing a plan to return to work or remain employed during treatment and assists with understanding insurance benefits and services. Counselling related to life planning and goal setting is also available, as well as information available online.

Patient and Family Counselling Services

BC Cancer Agency

www.bccancer.bc.ca

» **Patient/Public Info** » **Coping with Cancer** »

Emotional

Professionally led support groups for women, caregivers and children. Check the monthly calendars for regional cancer centre groups or call:

- » Abbotsford Cancer Centre
604.851.4733 | 250.565.2863
- » Centre for the Southern Interior
250.712.3963
- » Fraser Valley Centre
604.930.4000
- » Vancouver Centre
604.877.6000 ext. 2194
- » Vancouver Island Centre
250.519.5525

(Centre for the North opens November 2012. Call 250.565.2000 after this date to be connected to the centre.)



“As a woman, I thought what made me a woman had been taken away. I was worried that making love would feel different after my treatment. My partner and I were able to talk to each other openly about our anxieties and slowly as time passed our sex life returned to what it was before my diagnosis.”

Because a person’s self-esteem, and more importantly their “sexual self-esteem” plays a large part in sexual health, it is not unusual for women to experience a drop in sexual desire, frequency and satisfaction. Research has shown that a woman’s feelings about herself, including her mood, self-esteem, confidence, and sexual self-esteem, likely account for more of her sexual willingness than hormones and physical factors. Thus, even when post-treatment healing has settled, many women are left with changes to their sexual selves.

But it is a difficult topic to discuss. How does one raise with their physician that they feel “less of a woman” when it seems the most important concern was removal of the cancer? Unfortunately, cultural taboos around discussing sexuality, especially in cancer survivors, result in many women (and their partners) suffering in silence. Although sexual problems do diminish with time in some survivors, sexual challenges may persist in a large majority of women, sometimes for years. But an end to cancer should not mean an end to a satisfying sex life.

Sexual difficulties are not an uncommon consequence of gynecological cancers and their treatments. These sexual difficulties include a loss of libido (less interest in sex or sexual drive), arousal difficulties (such as vaginal dryness), and decreased orgasmic ability or sensations. In fact, studies estimate that at least half of women with gynecological or breast cancers experience

distressing sexual effects as a result of cancer treatments. The ways in which cancers and their treatments affect sexuality are complex as surgeries can damage nerves and blood vessels needed for optimal sexual function.

Chemotherapy and adjuvant (additional) drugs also have their own costs to you in terms of altering the hormonal setting that might affect sexuality. Radical vaginal surgeries may lead to pain with penetration, a loss or change of sensations, and altered sexual experience for a woman’s partner. Many women tell us the psychological impact of cancer and its treatment such as changes in well being, mood, anxiety and body image, may be even more damaging to their sexual life.

Sexuality remains an important aspect of quality of life for many cancer survivors and there are a few aids available. The BC Cancer Agency, in collaboration with researchers in the University of British Columbia’s Sexual Health Laboratory, are leading an online treatment for gynecological cancer survivors who have sexual difficulties.

This program “Online Psycho-education for Sexual Difficulties in Cancer Survivors” (OPES) is unique and totally free of charge. OPES is a 12-week program that helps individuals become aware of, and change, those thoughts, feelings, and behaviours that may be contributing to, or maintaining sexual difficulties and altered sense of self following cancer. Topics include body image after cancer, education on sexual anatomy, challenging thoughts and sex therapy exercises to do with a partner. In essence, these programs facilitate getting on with life after cancer by continuing to get it on in the bedroom!

Women need to feel empowered to raise sexual concerns and challenges in their sexual self-esteem with their medical team. In doing so, this sends a clear message that sexuality is a fundamental part of your quality of life.

Resources

Library Services

BC Cancer Agency

1.888.675.8001 ext 8001

www.bccancer.bc.ca/Library

Excellent books:

- » Woman Cancer Sex by Anne Katz
- » Intimacy after Cancer: A Woman's Guide by Sally Kydd & Diane Rowett
- » Sexuality and Fertility by Leslie Schover

OPES Program

604.875.4111 ext. 63994

www.opescancersexhealth.ca

A 12 week online program to assist people with cancer with sexual health issues.

Sexual Health Clinic Research Project Centre for the Southern Interior, Kelowna BC Cancer Agency

250.712.3963

A pilot project to provide cancer patients with access to professionals who have expertise in sexual health. The clinic is open one half day a month.

Cancer Information Service

Canadian Cancer Society

1.888.939.3333 | www.cancer.ca

Go online to download or call and ask for:

- » Sexuality and Cancer: A guide for people with cancer





NUTRITION

Eating well is important all through life, but is really important after a cancer diagnosis. Good nutrition will help to keep you strong through your treatment and help with healing and recovery. Everyone's cancer experience is unique in regard to treatment-related side effects.

If you are not experiencing any symptoms that prevent you from eating well, then try to eat a diet that is balanced with a variety of foods by following "Eating Well with Canada's Food Guide." This guide provides advice for good eating habits and may reduce the risk of certain types of cancer, as well as other chronic illnesses such as heart disease, diabetes and obesity.

Sometimes, the side effects of cancer treatment may prevent you from eating well for a brief period of time and leads to unwanted weight loss. In this case, you can consult with a Registered Dietitian at your cancer centre to help you make the right food choices to keep you well nourished and as healthy as possible.

In the case of advanced cancer, you may have little interest in eating and drinking. This loss of desire to eat can be a natural part of the cancer process. Despite this, it can still be quite upsetting and lead to emotions such as frustration and sadness. Comfort food and choice should be the focus at this time to improve quality of life. Special diets may need to be relaxed and may not be needed at this time.

Toward a Healthy Diet

Canada's Food Guide lists their diet recommendations based on serving size or "weight", while other guides will describe "portion" sizes. The following are some average servings/portion sizes to consider when planning your meals. It is suggested that your dinner plate should consist of:

- » ½ plate raw or cooked veggies
- » ¼ plate whole grains
- » ¼ plate protein

The following examples might be useful to help you with understanding the average portion size or weight.

Protein



Fish, chicken, pork, meat and tofu
1 serving=3 ounces=a deck of cards

Vegetables & Fruit



Vegetables (raw or cooked)
1 serving=1 cup=a softball

Fruit
1 serving=1 apple=a tennis ball

Whole Grains



Pasta and rice cooked
1 serving=1/2 cup=a tennis ball

Bread (whole grain)
1 serving=25 grams=a piece of bread

Fats, Oils & Snacks



Butter and oils (olive, canola, peanut)
1 serving=1 tablespoon=2 scrabble tiles

Low fat milk and yogurt
1 serving = 1 cup

Nuts or seeds
1 serving = ¼ cup = 1 handful



Resources

HealthLink BC

Call 8-1-1 | www.healthlinkbc.ca

Speak to a Registered Dietitian by phone regarding diet and nutrition.

Canada Food Guide

1.800 O-Canada (1.800.622.6232)

www.healthcanada.gc.ca/foodguide

Act Now BC

www.actnowbc.ca

A web resource for healthy lifestyle information.

Nutrition Services

BC Cancer Agency

www.bccancer.bc.ca

» Patient/Public Info » Coping with Cancer »

Nutrition

- » Abbotsford Cancer Centre
604.851.4733
- » Centre for the North Cancer Care Navigator
250.565.2813
- » Centre for the Southern Interior
250.712.3963
- » Fraser Valley Centre
604.930.4000
- » Vancouver Centre
604.877.6000 ext. 2194
- » Vancouver Island Centre
250.519.5525

(Centre for the North opens November 2012.
Call 250.565.2000 after this date to be connected
to the centre.)

Cancer Information Service

Canadian Cancer Society

1.888.939.3333 | www.cancer.ca

Go online to download or call for:

- » Eating Well after you have Cancer: A guide to good nutrition
- » Eat Well, Be Active: What you can do

EXERCISE

Exercise or physical activity plays an important part in health and well-being. In cancer survivors, research has shown that exercise during and after treatment helps to improve energy levels and mood. Any activity is better than no activity. During treatment, you may not feel like being active and that is okay. Do what you can, when you can. One example for an activity goal might be to go for a 10-30 minute walk every day or every other day.

A common question is “Does being physically active improve my survival?” At this point, there is some early evidence that being more physically active can improve survival in breast and colon cancer, but more research is needed to confirm this. To date, there is very little research on the link between physical activity and survival in gynecological cancers. In a recent study on women who were not overweight, “survival was better for women who reported more than 2 hours of physical activity a week compared to those who did less than 1 hour a week.” Further research is needed to confirm this finding.

However, there is a wealth of research showing gynecological cancer survivors who are physically active have a better quality of life, are less tired and have a better ability to interact in their world. Being physically active also lowers your risk of other diseases, such as heart disease and diabetes, and helps with controlling body weight. While more research is needed to understand the role of physical activity in cancer survival, physical activity has many health benefits.

For Women With Gynecological Cancer

- » After surgery, follow the advice of your surgeon or health care professional about when and how to start exercise.
- » Keep track of changes in your body that perhaps are not right.

- » If you notice swelling of the abdomen, groin or legs, stop exercising and talk to your doctor. Swelling could be a sign of lymphedema or other health concerns.

Tips To Prepare For Physical Activity

- » Check with your doctor to see what activities are best
- » Consider working with an exercise professional to develop a plan. Check your local community centre or go to a physiotherapist
- » Start slowly and progress gradually! Start with light activity and build your strength from there
- » Do activities that work for you and you feel safe doing
- » Do a light warm-up before starting any activity
- » Do as much as you feel comfortable with
- » Rest when you need to
- » Drink water often
- » End each session by stretching

Resources

Your Local Community Centre and Fitness Clubs

Provides a variety of accessible physical activities as well as personal trainers.

Physical Activity Line PAL

1.877.725.1149 | www.physicalactivityline.com

A free BC resource for practical and trusted physical activity and healthy living information.

Act Now BC

www.actnowbc.ca

A web resource for healthy lifestyle information.

RESOURCES FOR LYMPHEDEMA

Physiotherapy Association of BC

604.730.9193 | www.bcphysio.org

Physiotherapists have expertise in “lymphatic drainage” for lymphedema swelling and building exercise plans for persons with an illness.

Dr. Vodder’s International School

www.vodderschool.com

This website includes an international “Find a Therapist” and “Find a Garment Fitter” sections for those dealing with lymphedema.



“Walking is defined by some sources as ‘moving at a regular pace by lifting and setting down each foot in turn, never having both feet off the ground at once.’ Who thinks about the definition of walking? If there is one thing I can begin to do to get outside and exercise – it’s this! I find it has lifted my spirits and made me stronger as I go further and longer each week.”



You may be considering using therapies beyond conventional cancer treatments to improve your health. These types of therapies will be referred to as complementary and alternative medicine (CAM).

Complementary therapies are products and practices **used along with** conventional medical treatment.

Alternative therapies are products and practices that are **used instead of** conventional treatments.

Some examples of CAM therapies are:

- » Natural health products (herbs, vitamins and herbal supplements)
- » Physiotherapy
- » Massage therapy
- » Acupuncture
- » Traditional Chinese medicine
- » Traditional Aboriginal medicine
- » Healing touch

People are used to hearing about the research that supports regular cancer treatments. This research clearly lays out what is known about the treatment and what the expected benefits are, as well as possible risks.

Research about CAM is in the early stages. For example, for many natural health products, only cell or animal research exists. Women may ask if they can trust these results and if it can be applied to their situation. How can someone living with cancer make an informed decision when there are few credible (trustworthy) human research results available? There may also be little known about the risks associated with the CAM therapy you are considering. It can be hard to know where to begin.

How To Make Safe CAM Therapy Choices

You may wish to consider the following points **before** deciding to use CAM therapies or before you visit a CAM health care provider.

Ask your doctor about using CAM while you are in treatment

In many cases it is preferred that you stop your CAM therapies while you are undergoing treatments for cancer. For example, grapefruit juice can slow or speed up how your body uses a chemotherapy drug. This means you could end up with a higher or lower level in your body than desired.

Think about your goals for using the CAM therapy

Does the therapy have the ability to help you reach your goals? Remember that goals may be physical, emotional, and/or spiritual. Be careful of therapies that claim to “cure” your cancer.

Find out about the risks and benefits of the CAM therapy

Think about the research behind the therapy. How trustworthy is the information given? It is important to balance and consider what is known, as well as what is **not** known about a therapy. Also, make sure to consider what a safe dose of the therapy is. More is not always better!

Check out the training, credentials and experience of the CAM health care provider

As well, the costs of using CAM therapies are in many cases not covered in your medical insurance plan(s). Consider whether you can afford to participate in a therapy.

What CAM services are available in your local community?

BC Cancer Agency centres and local hospitals may offer mind-body and exercise therapies. Don't forget to also ask to see the Registered Dietitian or Pharmacist if you have questions about your diet or the safety of a natural health product.

Once you have made your decision about taking a CAM therapy, it is important to tell your oncologist and family doctor. Knowing all the therapies you are using, including CAM, allows health care providers to provide care that is complete and safe. It is also important to have a plan about how you will monitor your use of a CAM therapy to see if it is meeting your goals and not causing any bad side effects.

CAM therapies can be an important part of your overall experience with cancer. Make sure you have the support and information you need to make a decision that is right for you!

Resources

Integrative Medicine Services

Memorial Sloan Kettering

www.mskcc.org/mskcc

This website includes an easy-to-search database of natural health products and information on individual CAM therapies.

CAMEO (Complementary Medicine Educations and Outcomes Program)

BC Cancer Agency

1.800.663.3333 x 675960

www.bccancer.bc.ca/cameo

CAMEO currently offers a range of CAM support programs and resources, all within the context of research, to allow these services to be evaluated. These include: credible information about CAM therapies, one-on-one decision-making support, education courses, booklets and other tools, such as a CAM Use Diary.

Cancer Information Service

Canadian Cancer Society

1.888.939.3333 | www.cancer.ca

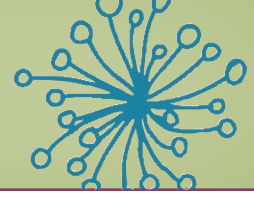
Go online to download or call for this booklet:

- » Complementary Therapies: A guide for people with cancer

“After the dust had settled from surgery, chemo and radiation, I knew that it was my job to keep my body in optimum health.

I learned how to choose other therapies that were good for me and worked together with my medications.”





Is There More Cancer In Some Families Than Others?

Many families include at least one person who has had cancer because cancer is common and there are many types. In large families, it is not un-common for more than one person to have had cancer. Sometimes there are more people with cancer than expected in a family. This may be due to common risk factors in the lifestyle or environment that family members share such as diet or smoking. In a small number of families we see a pattern of cancers that may be called "hereditary cancer."

What Is Hereditary Cancer?

Most cancers are NOT hereditary. Less than 10% of all cancers are related to a specific **gene mutation** that is passed down in a family.

A gene mutation is a change that prevents the gene from working properly.

Some ovarian cancers and some endometrial cancers may be hereditary; cervical cancer is unlikely to be hereditary.

GETTING GENETIC TESTING FOR HEREDITARY CANCER?

- » **Talk to your doctor about your concerns.**
- » Talk to your relatives to find out if anyone else is looking into this already.
- » Genetic testing in BC is offered by referral for genetic counselling to the BC Cancer Agency Hereditary Cancer Program.
- » Genetic testing usually starts with a blood or tumour tissue sample from an eligible person who has had cancer.
- » If a specific gene mutation is found, then testing is possible for other interested family members.

OVARIAN CANCER

Most ovarian cancer is NOT hereditary. Up to 10% of high-grade serous ovarian (or fallopian tube or primary peritoneal) cancers may be related to an inherited BRCA1 or BRCA2 gene mutation. This means all women with these

types of diagnosis are eligible for genetic counselling and testing. The chance of having hereditary ovarian cancer is higher if your family history also includes:

- » another woman with ovarian cancer (includes fallopian tube or peritoneal cancers)
- » breast cancer in close female relatives (male or female)
- » Ashkenazi Jewish heritage

Ovarian cancer can also be part of Lynch Syndrome, but that is less common.

ENDOMETRIAL CANCER

Most endometrial cancer is NOT hereditary,

Up to 10% of endometrial cancers are part of a hereditary cancer syndrome known as "Lynch Syndrome." Genetic testing for Lynch syndrome may be offered if your family history includes:

- » Other women with endometrial cancer
- » Close relatives with colorectal cancer and/or other related cancers

Endometrial cancer may also be seen in some other rare hereditary cancer syndromes.

Resources

Hereditary Cancer Program

BC Cancer Agency

1-800-663-3333 or 604.877.6000 ext. 2325

www.bccancer.bc.ca/hereditarycancer

The Hereditary Cancer Program accepts referrals in our Vancouver, Victoria and Abbotsford offices. We provide genetic counselling appointments to Surrey, Prince George and Kelowna centres and by video-conference to many other BC/Yukon communities.

In Our Genes

www.inourgenes.ca

Information and support for anyone at risk or diagnosed with hereditary breast/ovarian cancers

Lynch Syndrome International

www.lynchcancers.com

Information and support for persons with Lynch syndrome.



“Regardless of the choices we’ve made or the experiences we’ve had, facing the end of our life is a certainty for all of us. We’ll likely find ourselves needing to adjust to new situations that feel foreign, difficult and unpleasant.

At some point, your doctor may say that your cancer has advanced and ‘treatments are no longer working’ or your ‘cancer is incurable’. Your experience during this transition will be greatly influenced by the quality of information you have, how prepared you feel, and the support and resources available to you.

Hospice palliative care, sometimes called end-of-life care, is a special kind of care designed to help you cope in the face of life-limiting illness, by living each remaining day to the fullest and to help your loved ones go on with their lives forever changed. Hospice palliative care strives to support you as the decision maker in your care. Good hospice palliative care involves meeting your physical, emotional, spiritual and practical needs in ways that are sensitive to your individual beliefs and culture.

Rather than a place, hospice palliative care is a philosophy – a program of care and support that envelops you and your family in your community. Care may take place at home, in a residential care facility, in a hospice, or in a hospital, depending on your needs and choices. Anticipatory grief support (counseling to deal with grief when you know there will be a loss, but it has not yet occurred) is often of value to your family members and friends.

Bereavement services are also an important component, offered to your family and friends in need of support as they continue with their own lives after a loss of a loved one. Caregiver support is offered in many communities. Generally, these free services for family members

and loved ones are provided by community hospice societies.

Seeking hospice palliative care as soon as possible can assist you and your family in preparing for these challenges. Typically, anyone who has been given an approximate prognosis of 6-12 months to live can register for hospice palliative care.

Access to the full scope of services varies considerably depending on where you live. Regardless of where you live, a hospice palliative care program is made possible through collaborative partnerships between Regional Health Authority’s Home and Community Care Nursing and Home Support services, hospitals, extended care facilities, home-like residential hospices and community hospice societies.

For more information on resources in your community, you can talk with your doctor, ask your home care nurse or contact your local hospice society.

FINANCIAL RESOURCES

BC Palliative Care Benefits Program

The BC Palliative Care Benefits Program supports individuals of any age who have reached the end stage of a life-threatening disease or illness, and who wish to receive palliative care at home. Your family physician will apply for this on your behalf. Under the program, eligible patients receive:

- » coverage of approved medications used in palliative care through PharmaCare BC Palliative Care Drug Plan
- » approved medical supplies and equipment through the local health authority

Compassionate Care Leave Program

All employees can take up to 8 weeks of compassionate care leave to look after a family member who is gravely ill. The Canada Labour Code guarantees your job security and you apply for this program in the same manner as you would for Employment Insurance (EI). This program allows for a percentage of your pay to cover you during this leave. This leave of absence can be shared by

two or more people when looking after the same family member, but the total amount of leave taken between all can not exceed 8 weeks in total.

Resources

Speak Up – Start the conversation on end-of-life

www.advancecareplanning.ca

It is not easy to think about the care you would like to receive at the end of life, but it is important. Making your wishes known ensures that you—and those who care about you—can make the right decisions.

Palliative Care Team BC Cancer Agency

www.bccancer.bc.ca

Each of the BC Cancer Agency's sites has a symptom management and palliative care team to assist patients and their families who are having problems with their symptoms or dealing with the knowledge that the cancer is not curable. These teams are made up of doctors, nurses, counsellors, pharmacists and nutritionists to help patients work through physical and emotional hurdles.

- » Abbotsford Cancer Centre
604.851.4733
- » Centre for the North Cancer Care Navigator
250.565.2813
- » Centre for the Southern Interior
250.712.3963
- » Fraser Valley Centre
604.930.4000
- » Vancouver Centre
604.877.6000
- » Vancouver Island Centre
250.519.5525

(Centre for the North opens November 2012.
Call 250.565.2000 after this date to be connected to the centre.)

Yukon Palliative Program

1.800.661.0408 | www.hss.gov.yk.ca

Yukon Ministry of Health and Social Services offers support services including medical and nursing support.

BC Hospice Palliative Care Association

1 877 410-6297 | www.hospicebc.org

This organization maintains a directory of community hospices and other resources both online and over the phone.

BC Bereavement Helpline

1.877.7792223

www.bcbereavementhelpline.com

A non-profit, free, and confidential service that connects the public to grief support services within the province of BC. •



BC Cancer Foundation is proud to provide funding for the Women’s Gynecological Cancer Guide.

BC Cancer Foundation

The BC Cancer Foundation is the bridge that connects philanthropic support and research breakthroughs in cancer knowledge. As the fundraising partner of the BC Cancer Agency and the largest charitable funder of cancer research in this province, we enable donors to make contributions to leading-edge research that has a direct impact on improvements to cancer care for patients in British Columbia. We fund with the goal of finding solutions.

As an independent charitable organization, we raise funds exclusively for the BC Cancer Agency that support innovative cancer research and compassionate enhancements to patient care.

**Our Vision:
A world free from cancer**

With philanthropy and research working together, we can achieve our vision of a world free from cancer. As partners in discovery, philanthropy provides the fuel that enables research to make revolutionary advances in knowledge. Both partners are needed to spark change. The impact this partnership has for cancer patients in BC is momentous.

**Our Cause:
Supporting world-renowned research in B.C.**

Exciting discoveries provide evidence that leads to new clinical options. Translating discoveries from the researcher’s bench to the patient’s bedside is the quickest and most effective way to impact cancer care. This translation happens on an ongoing basis at the BC Cancer Agency. It is what makes it an international leader in cancer research.

**Our Partner:
The BC Cancer Agency, an internationally recognized, province-wide cancer control organization**

The BC Cancer Agency provides a province-wide, population-based cancer control program for everyone in BC and Yukon. It delivers the full spectrum of cancer care. World-class expertise is found across the BC Cancer Agency in various clinical programs and research platforms.

**Our Donors:
Are leading the way in helping us advance our cause**

Because of our unique relationship with the BC Cancer Agency, we can directly connect donors to outcomes. We can show you a return on your investment and partnership right here in BC – discoveries made possible because of donor-supported research taking place at the BC Cancer Agency. You provide the funds that fuel research.



Yes, I want to become a Partner in Discovery

Enclosed is my gift to the BC Cancer Foundation for:

\$50 \$100 \$250 \$500 Other Amount \$ _____

Monthly Giving Option:

On the 1st or 15th of each month I would like to give \$ _____

I have enclosed a cheque marked "void" or provided my credit card information below.

Monthly donors can change or cancel their gift at any time by contacting the BC Cancer Foundation.

I have enclosed my cheque made payable to: BC Cancer Foundation

I prefer to use my credit card: VISA MasterCard Amex

Card Number: _____ Expiry Date (mm/yy): _____

Name on Card: _____ Signature: _____

Home Address: _____

City: _____ Province: _____ Postal Code: _____

Phone: _____ Business: _____

Email: _____

Please send me *Partners in Discovery*, the BC Cancer Foundation's monthly e-newsletter, to my email address above.

I would like a free subscription to *Vim & Vigour*, the BC Cancer Foundation's quarterly magazine, sent to my mailing address above.

BC Cancer Foundation Provincial Office
150-686 W. Broadway
Vancouver, BC V5Z 1G1
604.877.6040
TOLL FREE: 1.888.906.2873



Charitable Business Number: 11881 8434 RR0001

You can also donate online at www.bccancerfoundation.com

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Taking It Step By Step

A Guide For Women Diagnosed With Gynecological Cancer