Chapter 1

Anal Cancer Basics

Angela G. Gentile

The word “cancer,” or the term “Big C” as some of us know it, is all too familiar. Most of us learn at a very young age how cancer can rob us of our relatives, friends, neighbors or acquaintances. We hear about it on the news, how cancer is something to be “fought” and “prevented.” Cancer is one of the leading causes of death in North America, with one in every three women and one in every two men affected. One in two Canadians will develop cancer in their lifetime, and one in four will die from it. Not all types of cancer are fatal, and the good news is that people who are diagnosed with cancer are living longer thanks to modern-day medicine.

Cancer is an umbrella term used to describe over 100 types of diseases that cause the body’s healthy cells to develop into abnormal cells which can grow and spread. These tumors, blood, or bone diseases can cause other problems, and some eventually spread throughout the body or “metastasize.” When cancer metastasizes, it is challenging to treat. When vital organs such as the lungs or liver are affected it becomes life-threatening.

Everyone is at risk of developing cancer, even people who live a healthy lifestyle and avoid risk factors such as smoking, drinking alcohol, and inhaling toxins like asbestos. Researchers are learning more about cancer and its causes, but unfortunately, no one is immune. Every age, race and gender can develop cancer; however, in Canada, 89% of those diagnosed with cancer are 50 and older. The longer we live, the more chances we have of developing life-threatening illnesses such as cancer and heart disease. There is no cancer cure-all, but fortunately we have some very effective treatments to keep it in check.

The most commonly diagnosed forms of cancer in those 50 and older are lung, colorectal, breast (in women), and prostate (in men). Lung cancer is the leading cause of cancer deaths in both men and women. People who smoke are at high risk for lung cancer.

Anal Cancer is Rare

Although rare, anal cancer is on the rise—especially in women aged 50-69 (Van Dyne et al., 2018). The reason for the increasing rate of anal cancer is not fully known (Ahmedin et. al, 2013). In 2013, 580 Canadians were diagnosed with anal cancer. The American Cancer Society estimates there will be about 8,580 Americans diagnosed with anal cancer in 2018. About 65% of these new cases will be in women, with the average age at diagnosis being in the early 60s. Our lifetime risk of developing anal cancer is estimated at 1 in 500 people (versus 1 in 9 for breast cancer and 1 in 11 for lung cancer).

Experts agree that human papillomavirus (HPV) infections are linked to the development of certain cancers such as anal, cervical, sexual organs, mouth, and throat. The HPV and Anal Cancer Foundation states, “Nearly all sexually active adults will have at least one type of sexually transmitted HPV at some point in their lifetime. It can be transmitted through skin-to-skin contact during sexual activity. HPV can be spread without engaging in sexual intercourse” (HPV: The Facts). It is estimated that HPV causes 93% of anal cancer.

Anal cancer affects the gastrointestinal tract and is often mistaken for rectal cancer. The anal canal is the lowest part of the colon,

located in the area between the rectum and the anus (butt hole). The anal canal houses the anal sphincter muscles, which are responsible for holding back feces (poop) before it leaves the body.

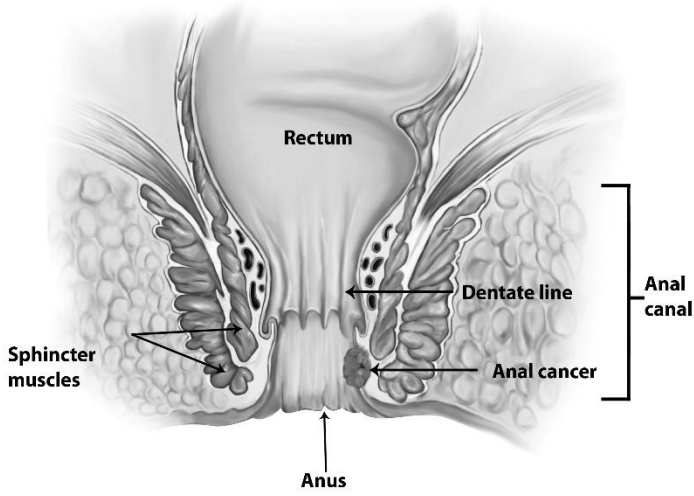

Figure 1. Anal Cancer (Tumor) and Surrounding Anatomy

Growths and abnormal cells can develop in the anal area. People who have anal warts are more likely to be diagnosed with anal cancer. Pre-cancerous conditions called low-grade anal intraepithelial neoplasia (AIN) or high-grade anal squamous intraepithelial lesions (SIL) are also known as dysplasia. High-grade SIL is the more serious of the two and needs to be watched closely.

In anal cancer, a tumor or a malignant (cancerous) lump starts developing in the anal canal. If it is large enough, it may begin to interfere with bowel movements. Growths can also be on the outside of the anus.

There are different types of anal cancer, the most common being “squamous cell carcinoma,” which is often (but not always) related to the human papillomavirus (HPV). Cancer can develop 20-30

years after exposure to HPV. HPV is also responsible for other cancers found in the cervix, mouth, throat and neck.

The other types of anal cancers are called cloacogenic carcinoma, adenocarcinoma, basal cell carcinoma and melanoma. The type of cancer cells found in the anal area can be determined by a biopsy, where the cells are examined under a microscope.

Farrah Fawcett, the late actress and sex symbol, died of anal cancer in 2009. She realized there was stigma and shame attached to this type of cancer, so she did her best to advocate and educate others. She shared her story in the media, and there is now a Farrah Fawcett Foundation to honor her legacy. We address stigma and shame throughout this book.

What I Have Learned About Anal Cancer

I have endured treatment and I am a survivor of anal cancer. During my cancer encounter and sharing with others, I learned about symptoms, diagnosis, treatment, and recovering from treatment. Concerned about some of my symptoms, I did what most computer-literate people do—I Googled it. I was experiencing some of the signs of anal cancer, which made my heart sink. I remember the moment I told my daughter, "I think I have anal cancer."

Symptoms of Anal Cancer (American Cancer Society):

- Rectal bleeding
- Rectal itching
- A lump or mass at the anal opening
- Pain or a feeling of fullness in the anal area
- Narrowing of the stool or other changes in bowel movements
- Abnormal discharge from the anus
- Swollen lymph nodes in the anal or groin areas

Some people experience no symptoms. Often, symptoms are misdiagnosed as hemorrhoids, even by doctors. Anal fissures, fistulas, abscesses, and anal warts can also be causes for some of these symptoms, so it is vital to get assessed by a doctor.

Diagnosing Anal Cancer

Diagnosing anal cancer can be done in a few ways. For me, the digital rectal exam (DRE) helped with the diagnosis. A DRE is a simple procedure that can be done at the doctor's office. The doctor inserts a lubricated, gloved finger into the anus, and feels for any abnormalities or blood. If a lump or blood is found, the doctor can order or perform more tests, such as a colonoscopy, endoscopy, anoscopy, CT scan, MRI, PET scan, and biopsy (as mentioned previously). I had everything except the endoscopy and anoscopy. Blood tests, urine tests, and physical examination of the abdomen and surrounding areas are also usually performed. Sometimes an anal or vaginal Pap test is also done (a small sample of cells are removed and examined under a microscope). The rigid proctosigmoidoscope (defined as a thin, lighted instrument to examine the rectum and lower part of the colon) is also something that may be used to help the doctor see the insides of the lower part of the colon, rectum, and anal canal.

Based on all the tests and exams, the doctor will know what kind of cancer it is and what stage it is. There are four stages of any cancer diagnosis. The stages are dependent on the size and spread of cancer. Stage 1 cancer is early, and stage 4 is when cancer has grown and spread throughout the body. I was diagnosed with squamous cell carcinoma of the anal canal, stage 3, as I had one affected lymph node.

Anal cancer rarely spreads (metastasizes) to distant organs in the body, but when it does, it usually affects the liver or the lungs. The spread is generally through the blood supply, tissues, or lymph system. (This is what happened to Farrah Fawcett.)

The medical exam will also include some medical history. The specialist (for me, it was a colorectal surgeon) will want to know more about your overall health and medical history in order to make some decisions about how to treat the cancer. There may also

be a need for a second opinion, as some people need that reassurance. A doctor or a person with cancer can request a second opinion.

What Are the Risks Associated with Anal Cancer

Many people who have not heard or read about anal cancer may want to know how they got it. Mayo Clinic has listed lifestyle and other risk factors linked to anal cancer:

Who is at Risk for Anal Cancer:

- Those 50 and older.
- Those having had four or more sexual partners over a lifetime (increases HPV infection risk).
- Those who engage in anal sex, especially receptive anal sex (men who have sex with men are at high risk).
- Smokers may be at increased risk of anal cancer.
- Those with a history of cancer. Women who have had cervical, vulvar, or vaginal cancer have an increased risk.
- Those infected with the human papillomavirus (HPV). This sexually transmitted infection, which causes genital (including anal) warts can also cause anal cancer.
- Those who have used drugs or have conditions that suppress your immune system. Transplant patients or people with human immunodeficiency virus (HIV)—the virus that causes acquired immune deficiency syndrome (AIDS)—have an increased risk of anal cancer.

Although it's an embarrassing area to show the doctor, warts in the genital and anal areas should be assessed, and preferably removed (they can be "burnt off" in the doctor's office).

Here is a note about HPV getting into the anal canal. Women are taught to wipe from front to back. My gynecologist tells me HPV can be spread to the anus and surrounding area by performing this common daily habit (Ladies—dab, don't wipe!).

The colorectal surgeon also said that many people are infected with HPV, and they never go on to develop cancer. Additionally, HPV can be transferred from mother to baby during childbirth.

I also wonder if there is a genetic component to this, as my grandmother was diagnosed with vulvar cancer in her later years.

How Can Anal Cancer Be Prevented—It Can't Be, *Butt* . . .

Mayo Clinic's website also states there is "no sure way" to prevent anal cancer. There are ways to reduce the risk, however, including the following:

- Practice safer sex. For those who want to reduce their risk of anal cancer—abstaining from sex, using a condom during sex, using a condom or dental/oral dam during oral sex—can help protect against HPV or HIV infection. Both increase your risk for anal cancer.

- Stop smoking. Smoking increases your risk of anal cancer. Don't start smoking, and quit if you currently do. Doctors have solutions to help you kick the habit.

- Prevent via vaccination against HPV. There are currently two vaccines on the market that are given to boys and girls. Speak to your child's healthcare team about this vaccine. Younger adults are also encouraged to get the vaccine, up until their early twenties.

- HPV vaccination may help reduce the risk of anal cancer recurrence. The research is ongoing in this area as it is fairly new. The results for men have been promising. (As an aside, I have been vaccinated after treatment, after much encouragement from my gynecologist and family doctor.)

Early Detection is Your Best Bet

Early detection measures are strongly recommended for anyone who falls into the risk categories. This may mean a regular anal Pap test, a digital rectal exam, a colonoscopy, and investigation of any abnormal or painful symptoms in the anal area. I would suggest that if you suspect it's more than a hemorrhoid, request more tests until

the doctor has been able to rule out anal cancer. Unfortunately, hemorrhoids are a very common initial misdiagnosis which allows for more time to pass without prompt, critical treatment. Insist on further investigations such as a biopsy or rigid proctoscope examination.

At times someone may be diagnosed with "precancerous" cells as well as dysplasia. Anal precancer, or "anal intraepithelial neoplasia," has its own kind of treatment such as laser ablation or topical chemotherapy. Polyps (clumps of often abnormal cells) in the colon are also found to be linked to cancer. Regular follow up and treatment, as recommended by your doctor, can help prevent the growth, development, and spread of cancer.

Treating Anal Cancer

Average prognosis (likely outcome of the disease and its treatment) for someone diagnosed with anal cancer is about a 67% chance of survival for five years. After five years, close monitoring is usually not required. Treatment usually consists of a combination of radiation and chemotherapy. Surgery (removing the tumor) is often not the first option for treatment.

The Canadian Cancer Society defines radiation therapy as high doses of radiation (energy moving through space) used to destroy cancer cells, slow down cell growth, and shrink tumors. Daily treatments damage the cancer cells over and over again. The cancer cells don't have a chance to repair themselves between treatments, so eventually, they die.

Chemotherapy is a drug therapy used to destroy cancer cells or slow their growth. It can be in liquid form (given intravenously) or in pill form (taken by mouth). Also known as chemo, it is often given in combination with other anticancer drugs or agents.

The "Nigro Protocol" is the most common and successful treatment for the majority of anal cancer cases. It consists of 30 days of pelvic radiation, with the targets being the tumor and lymph nodes, if present, and two rounds of chemotherapy. For me, it was mitomycin (a.k.a. Mitomycin-C) and fluorouracil, commonly known as "5-FU." There are variations of this protocol; some have

more or fewer radiation treatments and different types of chemotherapy. This treatment has been used since the 1970s, as a better or more successful treatment plan has yet to be discovered.

The surgeon explained chemotherapy "sensitizes" the tumor and helps the radiation do its job more efficiently by shrinking or destroying the tumor. In addition to the intravenous chemotherapy treatments, there will be a number of blood tests, so many opt to have a peripherally inserted central catheter (PICC), which is a semi-permanent opening for injections and other needle procedures, inserted into the arm. Alternatively, one may get an implanted central vascular access device (CVAD) or port, which is a long tube placed in a large vein in the upper chest, under the skin. A catheter, or small tube, connects the port to the vein.

Unfortunately, radiation to the pelvic region is perhaps the most brutal of all cancer treatments, but it is also very effective. Dr. Foster Lasley, a radiation oncologist, states, "Anal cancer is different from other types of pelvic radiation because I am radiating so low and hitting very sensitive areas that have rich innervation. I would probably agree with anal carcinoma being probably the most brutal thing I do in terms of acute side effects. On a scale of 1-10, I'd give it a 9.5. I reserve 10 for those wacky, terrible cases I see sometimes."

> TIP: The National Comprehensive Cancer Network has a thorough "Clinical Practice Guidelines" for Anal Carcinoma, found at (Login required): www.nccn.org/professionals/physician_gls/PDF/anal.pdf.

Your Team

The person with anal cancer will need an oncology or healthcare team of professionals working together to optimize treatment and keep side effects to a minimum. Side-effect management is essential, and many people will experience radiation burns to the pelvic area (including anal, perianal, genitals, groin), and will require pain management, skin treatments, and other symptom management.

Team members may include the radiation oncologist and nurse, the radiation team, the chemotherapy doctor (medical oncologist), colorectal surgeon, your family doctor, the on-call weekend and evening team, social worker, dietician and more! You may also consider having a psychologist or psychiatrist help you with emotional and mood problems if they arise.

> A support group is a group of people with similar disease or concerns who help each other cope by sharing experiences and information.
>
> –National Cancer Institute

Your supports (practical, emotional, and informational) will hopefully include family members, friends, support groups (whether in-person or online), and other people diagnosed with cancer.

Side Effects of Treatment

Anal cancer treatment (radiation, chemotherapy, and sometimes surgery) usually takes about six weeks from start to finish. There are numerous side effects to watch for, some being very serious.

Neutropenia is very common in people being treated for cancer, as chemotherapy depletes the immune system, which consists of white blood cells. White blood cells help the body protect against infections and foreign invaders. Neutropenia is a life-threatening condition determined through a blood test and can come on very suddenly. When the person becomes neutropenic, physicians address the issue. Check out *chemocare.com* for more info on side effects of chemotherapy.

It is critical for someone diagnosed with neutropenia to not expose oneself to anything that could cause an infection, as the body cannot fight it. For example, I was advised to postpone my visit to the dentist when my white blood cell count was low.

Severe fatigue (tiredness) often comes with radiation. This fatigue can impact a person even when radiation is used to treat a small area of skin cancer on the tip of someone's nose. However,

Dr. Foster Lasley, a radiation oncologist, states there isn't a reasonable biological explanation for this. He tells his patients to stay as active as possible, and post-treatment, he expects people to feel about 50% better after one month and 80% better by three months. It may take up to a full year before they are back to their prior energy level. He adds that anal cancer is particularly brutal when it comes to some other side effects, so that timeline is sometimes skewed a little further out. This fatigue can also affect one's mood, and although it doesn't cause depression, it can certainly make it worse. If fatigue is an issue, it's always important to talk to the medical team, as there could be other explanations for it.

Side effects vary, and there is quite a range. For example, I know of some people who hardly missed a day of work. Some have minimal side effects. While others lose their hair, my hair thinned. I remember having "chemo brain" or "chemo fog"—a very common state of distraction, or not being quite "with it" while on chemotherapy. For example, I couldn't remember which finger I wore my wedding ring on—was it the right or left hand?

A full list of radiation or chemotherapy side effects can be obtained from your healthcare team. The pharmacist gave me an excellent overview of the chemotherapy I was receiving, and the radiation team gave me some handouts on pelvic radiation side effects to watch for (like losing your pubic hair!). The pharmacist warned me about mouth sores as a side effect of chemotherapy, too.

Recovering and Healing After Treatment for Anal Cancer

Although the treatment is completed in about six weeks, often there is a lengthy recovery process. Depending on each person's response to radiation and chemotherapy, people who work may need to take some time off. It may take up to a year to feel ready to go back to work. In the short term, responsibilities may need to be delegated to others. There are psychological and physical changes that can affect a person's outlook, priorities, and mood.

During and after treatment, it's important to do as much as you can and get moving. It can help reverse some downward momentum—

even if it's just walking to the mailbox or pushing a shopping cart for support.

There may be unexpected things that happen. I experienced "stranding" and fibrous tissue in the anal canal and vaginal walls. Fat stranding is best described as folds of fat that are thickened and inflamed due to radiation injury. I also experienced vaginal stenosis (narrowing of the vagina). It is suggested that ALL women who have pelvic radiation use a vaginal dilator daily to PREVENT vaginal narrowing or stenosis. Stiff hips and groin can also result. There can be unexpected injuries or trauma, also known as "collateral damage," to the surrounding organs and skin tissues. Some end up with pelvic radiation disease also known as radiation-induced injury (interestingly, pelvic radiation disease is not commonly recognized in the USA). Pelvic floor physiotherapy can help with improving some of the after-effects of radiation. Treatment can make a woman go into menopause. I've heard it said that radiation to the pelvis is like putting your private parts and organs into a microwave oven. It all gets fried. But this is what is needed to destroy the cancer cells.

There are ways to combat and heal from many, but not all of these after-effects. It takes time, patience, commitment, and work. Late effects can also happen, as radiation has come to be known as "the gift that keeps on giving." For example, if lymph nodes in the groin have been zapped, lymphedema, or swelling of the legs can occur even years later.

Exploring Alternative Options

When I was diagnosed, I also explored other treatment options. I read about alternative medicine, but I was not convinced there was a better way to go. One woman shared her story about a cannabis oil (marijuana) cure for her anal cancer. After I did some research, I was not convinced it would treat my condition, so I stuck with the original plan. I had a friend look into alternatives for me, but she couldn't come up with anything else. I asked a Facebook friend to connect me with someone who took the natural route as she "knew so many." She never got back to me.

There are many alternative remedies for pain relief, including cannabis, Chinese herbs, natural supplements, etc. Also, many have found relief from TENS (Transcutaneous Electrical Nerve Stimulation) units, which run a non-painful, mild electric current through electrodes placed on the skin. Home remedies such as warm baths in baking soda and essential oils can offer comfort. Meditation, massage, and chiropractic adjustments can also provide some people relief. (More on this in a later chapter on Integrative Medicine.)

Abdominoperineal Resection with Permanent Colostomy

One option for those who have no success with chemoradiation treatment (or for those with the melanoma or adenocarcinoma type of cancer) is to have surgery to remove the tumor. The tumor could be removed if it is suitable for this type of operation. If the mass is large or has grown deeper into the tissues, a more intensive surgery called abdominoperineal resection (APR) may be required. If the sphincter muscles don't work correctly (a loss of controlling bowel function, for example) or the tumor compromises the anus, this is an option. It results in a permanent colostomy. (Colostomies can also be temporary if the doctor deems it a necessary procedure to manage pain or other problems with functioning.)

With APR surgery, the anus is closed up (a.k.a. "Barbie butt") and a colostomy is necessary. A colostomy is a permanent hole made in the abdomen. The colon is connected to it, and the feces (poop) is emptied into a bag outside of the body instead of through the anus. The vast majority of those who have had these procedures report that after a period of adjustment (diet/maintenance/emotions), they live very active, healthy, happy lives.

Clinical Trials May Be Available

Another option for people who don't respond to the standard treatment for anal cancer, or who have an advanced form of cancer, is to explore the possibility of clinical trials. Participating in a clinical trial is a way to help researchers test the effectiveness of new treatments and drugs. People volunteer for these studies and report on the efficacy of the treatment and any side effects. Dr. Cathy Eng, who is a Gastrointestinal Oncologist at the MD Anderson Cancer

Center in Texas, USA, has been the principal investigator in some of these studies. For example, immunotherapy (prevention or treatment of disease using substances that stimulate the body's immune response) is an emerging science in the area of cancer treatment. There are always new treatments being developed and tested, so you can ask your doctor about clinical trials you may be considered for. You can also check online at *ClinicalTrials.gov*.

The Integrated Cancer Care Approach is Best (in my opinion)

I highly recommend hospitals or cancer centers that promote and encourage an integrated approach to care. These are centers with clinicians, doctors, and specialists practicing orthodox or allopathic (traditional) medicine who are also open to helping a patient decide on complementary therapies that may help, such as massage, yoga, meditation, prayer, and support groups. Those who do not have access to such centers can create networks to benefit from an integrated program.

For some people, acupuncture has helped relieve the symptoms of nausea associated with cancer treatment. Unfortunately, many complementary and alternative therapies lack scientific proof of effectiveness. Others prove to be no more helpful than a placebo. A placebo effect means relief has been brought about not by a medicinal reaction, but by the person imagining it is going to work—relief resulting from the brain "convincing the body." I am of the mindset that if it doesn't harm, and it doesn't interfere with standard treatment, and it's not breaking the bank, it's worth a try. If the service or product comes with a money-back guarantee, that's even better! Some of these integrated centers offer a variety of programs for free as part of their comprehensive care approach. I believe the body-mind-spirit approach is necessary to help one through a traumatic and life-threatening cancer ordeal. (More on the integrative approach in a later chapter.)

Post-Treatment Follow Up and Monitoring

Once treatment ends, and there is an "all clear," "no evidence of disease (NED)" or "cancer-free" declaration by the specialist, a follow-up plan is made. You will be seen by a surgeon, a radiation

I may be disease-free, but I am not free
from my disease. –Angela G. Gentile

oncologist, a medical oncologist, or other specialist for regular monitoring for a specified amount of time, which could be years. These regular visits, which could be every three months, six months, or something along those lines can cause people anxiety and fear of recurrence. Waiting for the results of tests such as CT scans can cause "scanxiety" for some. The anxiety caused by the time it takes to wait for results can create fear of an abnormal result.

On my initial six-month follow-up exam, the doctor stated he saw "No Evidence of Recurrent Disease." I jokingly and happily announced, "So I am a NERD!" (I've also since heard NERD can mean "No Evidence of Residual Disease.")

Finding a "New Normal"

An anal cancer diagnosis is not a death sentence. It can be overcome with early detection, proper diagnosis, standard treatment combined with complementary or integrated approaches, and a team of professionals and other supports. Participating in cancer rehabilitation programs, which may include exercise, yoga, support, etc.; planning a trip; or getting a puppy are examples of things that can help you move forward. Most people say they must find a "new normal" after a cancer diagnosis, as it often has a profound way of changing a person's mental attitude, outlook, and priorities. Some people retire, change jobs, or find an entirely new purpose in helping others who have also experienced cancer. Living well with or after cancer takes some effort. You can do it.

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RESOURCES:

American Cancer Society (*cancer.org*)

Canadian Cancer Society (*cancer.ca)*

Centers for Disease Control and Prevention (*cdc.gov*)

ChemoCare (*chemocare.com*)

The Farrah Fawcett Foundation
(*thefarrahfawcettfoundation.org)*

The HPV and Anal Cancer Foundation
(*analcancerfoundation.org)*

Mayo Clinic (*mayoclinic.org*)

National Cancer Institute (*cancer.gov)*

National Comprehensive Cancer Network Guidelines for Anal Carcinoma (Login required)
(*nccn.org/professionals/physician_gls/PDF/anal.pdf*)