



If you are reading this, the chances are you or a loved one has experienced an anal cancer diagnosis. This diagnosis can bring with it more questions than answers. This fact sheet is intended to answer some of your basic questions about anal cancer. We encourage you to contact us with any and all questions and concerns that may not be covered in this fact sheet. We are here for you.

## What is Anal Cancer?

Cancer that develops in the cells and tissue of the skin lining either the inside or outside of the anus is called anal cancer. The anus is an opening to the outside of the body below the rectum from which stool exits the body. It is the last part of the gastrointestinal tract. Some confuse anal cancer for rectal cancer due to the proximity, but the two diseases and treatments of the diseases are different. Colorectal cancer, for example, is primarily adenocarcinoma, and anal cancer is usually squamous cell carcinoma (SCC).

## Anal Cancer Fast Facts

- ⊗ Approximately 7,200 people will be diagnosed with anal cancer in the US in 2014 and about 1,200 in the UK.
- ⊗ It is estimated that over 93% of anal cancer cases are caused by human papillomavirus (HPV).
- ⊗ Nearly all adults will have HPV at some point in their lifetime. Frequently HPV goes away on its own, although for some it can remain dormant in the body for decades causing cancers to surface later in life. A small percentage of HPV infections develop into cancer.

## Anal Cancer Risk Factors

- ⊗ HPV infection
- ⊗ A history of cancer or precancer in the cervix, vagina or vulva
- ⊗ Weakened immune system
- ⊗ Transplant recipient
- ⊗ HIV-positive
- ⊗ Age: Individuals 50 -80 years of age
- ⊗ Smoking
- ⊗ Sexual contact

## Risk Factors

According to the World Health Organization a risk factor may be “any attribute, characteristic or exposure of an individual that increases the likelihood of developing a disease or injury.”

## What are the symptoms of anal cancer?

Individuals who have anal cancer may experience these symptoms before diagnosis:

- ⊗ Bleeding or discharge from the anus
- ⊗ Anal itching
- ⊗ Abnormal bowel habits including constipation or narrowing of the stools
- ⊗ A lump near or in the anus
- ⊗ Anal pain or pressure



It is important for people who have anal cancer symptoms to discuss screening options with their health care provider. Although these symptoms may indicate the presence of anal cancer, some individuals with anal cancer may be asymptomatic. Utilize yearly examinations, annual check-ups, or other screening times as occasions to talk to your provider about screening and as opportunities to screen for anal cancer. Individuals with anal cancer risk factors should discuss screening with their providers. Some doctors may misdiagnose anal cancer for hemorrhoids. If your hemorrhoids persist and after treatment they do not disappear, speak to your doctor about a more detailed examination or ask for a referral to a specialist.

## What are the screening methods for anal cancer?

It is important to note that there have not been sufficient studies to prove what approach is best for screening for anal cancer. However, providers may use one or all of these methods.

- Anal cytology (anal pap test) - similar to a cervical pap test. Used to detect abnormal cells that may be the precursor to anal cancer.
- HRA (high resolution anoscopy) - a microscope used to examine the anus to identify abnormal cell growth.
- DARE (digital anorectal exam) - a manual exam in which a doctor places her/his gloved fingers in one's anus to feel for abnormalities.

Who should ask their physician about being screened for anal cancer? Scientists are still considering who should be regularly screened for anal cancer. Ultimately, any of the risk factors listed above may lead to an increased need for screening.

## What tests are used to diagnose anal cancer?

If a provider thinks a patient may have anal cancer, he/she will perform a biopsy. A biopsy is a test in which a tissue sample is collected from the area in question and then examined to diagnose cancer.

## What other tests and exams may be used after an anal cancer diagnosis?

A 'workup' (a series of tests) may be completed by one's medical team. These tests will help a provider decide what treatment option is best, identify the exact location(s) of the cancer and determine the stage of the cancer. The tests described below are part of the National Comprehensive Cancer Network's (NCCN) guidelines for squamous cell carcinoma anal cancer. Here are some tests that may be ordered:

- Blood work
- CT scans
- MRI on one's pelvis, abdomen or chest
- PET scan depending on the information gathered during the other tests and examinations
- Anoscopy (see definition above)
- For women, it is recommended that they receive a gynecological exam including a cervical pap test
- HIV testing



An anal cancer diagnosis can be both confusing and daunting. Anal cancer is uncommon and it is important to have a physician working with you who is familiar with the disease. After a diagnosis, one may want to get a second opinion to verify diagnosis, pathology, staging, and to discuss treatment options. Getting a second opinion does not mean you do not trust your doctor and it does not mean that you cannot be treated by the first doctor one sees. A second opinion is a way for individuals facing a diagnosis to gain confidence in their treatment protocol and get as much information as possible.

## Anal Cancer Types

There are three types of anal cancer: squamous cell carcinoma, adenocarcinoma and malignant melanoma. Treatment options vary depending on the type of anal cancer you have.

- **Squamous cell carcinoma (SCC)** starts in the outer lining of the anus. Approximately 80% of anal cancers are squamous cell carcinoma. Cloacogenic carcinoma, which occurs between the anus and the bottom of the rectum, is often considered a subcategory of squamous cell carcinoma. Basal cell carcinoma is in the perianal tissue and another subcategory of squamous cell carcinoma. Anal SCC results from HPV most of the time.
- **Adenocarcinoma** is either in the lining of the anus near the rectum or in the anal glands that produce mucous. It often arises from the rectum and is frequently treated as a rectal carcinoma.
- **Malignant melanoma** occurs in the cells of the skin of the anal lining responsible for pigment and makes up  $\leq 2\%$  of anal cancers. Malignant melanoma is a skin cancer.

## When do individuals diagnosed with anal cancer need colostomies?

Some individuals diagnosed with anal cancer will require a colostomy. A colostomy involves a surgery that redirects bowel movements to an opening, called a stoma, in the abdomen. Bowel movements exit the stoma into an appliance bag that is placed on one's abdomen that may be attached with adhesive and/or a belt.

For some, a colostomy due to anal cancer is temporary. Other individuals will live with a colostomy for the rest of their lives. For individuals who are diagnosed with anal cancer, an already stigmatized disease, having a colostomy may be particularly difficult. It is important for individuals with a colostomy to remember that after a period of adjustment they will be able to participate in many of the same activities as before having a colostomy. There are specialized colostomy nurses and various support groups for those with colostomies.

## How is anal cancer treated?

Treatment options vary depending on the stage and the type. The treatment descriptions here are based on general guidelines, but this does not reflect medical advice. You should talk to your medical provider about the best treatment options for you.

It should be noted that these treatment regimens are primarily for squamous cell carcinoma. The below description is according to National Comprehensive Cancer Network guidelines. The three treatments for anal cancer are surgery, chemotherapy, and radiation. Radiation and chemotherapy are the standard for stages I-III and are usually used in conjunction with one another (often called 'chemoradiation'). This treatment



regimen is referred to as the Nigro Protocol. Stage IV cancers are usually addressed with chemotherapy alone first.

## Surgery

Surgery is typically used for early stage anal cancer in which the tumor is extremely small and localized. Some experts may refer to this as superficially invasive. During surgery, the area in which cancer is present is excised (removed). If tests after the surgery show that there is no evidence of disease, the individual will be observed by his/her doctors. If the tests after surgery show that anal cancer is still present, the patient will undergo further treatment which may include another excision or chemotherapy and radiation.

## Chemotherapy

Chemotherapies are a class of drugs that kill cancer cells and prevent them from multiplying. Anal cancers between stage I-III are often treated with mitomycin and 5-fluorouracil (5-FU) in addition to radiation. Other chemotherapies that may be used for stage IV cancers include platinum based therapies like cisplatin. For individuals with stages I-III, chemotherapy is administered twice, once at the beginning of radiation and then again at five weeks of radiation. Before treatment, a temporary central venous catheter ('CVC') or peripherally inserted central catheter ('PICC') may be placed on an individual to receive chemotherapy. These tools allow for the chemotherapy to be infused for 96 to 120 hours at a time. Recently, chemotherapy for anal cancer has been administered to some in pill form. Common side effects for these drugs include, but are not limited to: decreased white blood cells, decreased red blood cells and/or platelets, nausea, vomiting, mouth sores, hair loss, neuropathy and fatigue. Individuals taking these drugs should talk to their doctors about possible side effects and tell their doctors if they experience these or other side effects.

## Radiation

Radiation for anal cancer involves an external beam of radiation that is directed towards the location of the cancer to shrink tumors and kill cancer cells. For individuals with anal cancer stages I-III, radiation is typically five days a week for five to six weeks. Individuals receiving radiation may not experience side effects at the beginning of treatment, but should expect to feel them as the treatment progresses and for a period of time after treatment. This is because radiation therapy has cumulative effects, meaning they build up over time. During radiation it is important to take care of your skin and drink liquids.

Side effects may include: skin irritation, GI and anal discomfort, pain during bowel movements and while urinating, fatigue, diarrhea and nausea. Women may experience side effects unique to their anatomy, including: vaginal pain, irregular vaginal discharge and closure of the vagina through the accumulation of scar tissue called stenosis. Side effects unique to male anatomy may include erectile dysfunction and impotence. Both men and women may experience narrowing of the anus, which may make bowel movements difficult. Similarly, individuals undergoing pelvic radiation for anal cancer may have GI and sexual dysfunction that lasts throughout their lifetime. Due to the location of the cancer and the radiation, individuals may experience a weakened pelvis and an inability to use their sphincter. Individuals receiving radiation can expect to feel the



effects for a few weeks after completing radiation. Please talk to your radiation oncologist about your specific treatment and side effects, as they vary from person to person. Ask your doctors about mitigating radiation side effects. Management aides may include moisturizers, dilators, pelvic rehabilitation and a referral to a sex therapist who is familiar with pelvic radiation side effects.

## Emerging Medicine

Immunotherapies are a developing classification of interventions for cancer that seek to harness the power of an individual's immune system. The thought behind immunotherapies is that one's immune system can be 'taught' to defend the body against cancer. Immunotherapies would enable one's immune system to destroy targeted cancer cells while keeping healthy cells safe, something other cancer therapies are unable to accomplish. Please remember, however, that the role of immunotherapy remains in clinical trials and as of yet it is not FDA approved.

## What happens after treatment?

Once treatment has concluded, individuals should expect to see their provider regularly for follow-up visits. These visits may include physical exams as well as tests to determine the presence or absence of anal cancer. At first, these visits typically occur every three months and gradually change to every six months over a two-year period. Some guidelines suggest three to six month screening intervals for up to five years after treatment. Generally, if a recurrence happens, it is in the first two years after treatment.

## Support During and After Treatment

Anal cancer is considered uncommon with an incidence rate in the US of 1.8 in 100,000 people. In 2014, around 7,200 people will be diagnosed with anal cancer in the US and 1,200 people in the UK. Due to its rarity and the stigma associated with it, it is extremely important for those with anal cancer to reach out to others in the community for information and support. Anal cancer does not need to be isolating. The HPV and Anal Cancer Foundation has a Peer to Peer Support Program specifically for individuals diagnosed with anal cancer and their caregivers. For more information on this and other support services, please visit us at: [www.analcancerfoundation.org](http://www.analcancerfoundation.org)

For a glossary of terms, please see our Common HPV and Anal Cancer Terms page.

These fact sheets were reviewed by an oncologist, an infectious disease doctor, and a nurse.