

Talking About Anal Cancer

**A Guide for Talking About Your
Diagnosis and Treatment With
Your Cancer Care Team**



Being diagnosed with anal cancer can be overwhelming. This guide can help you take control and have more confident and informed discussions with your care team after a diagnosis.

Inside, you'll find:

- **An overview** of anal cancer and your treatment options
- **Key questions** to ask your doctors and care team
- **A worksheet** to help you identify your goals and priorities
- **Reliable resources** for information and support

Use this guide to get the answers you need and make decisions that feel right for you.

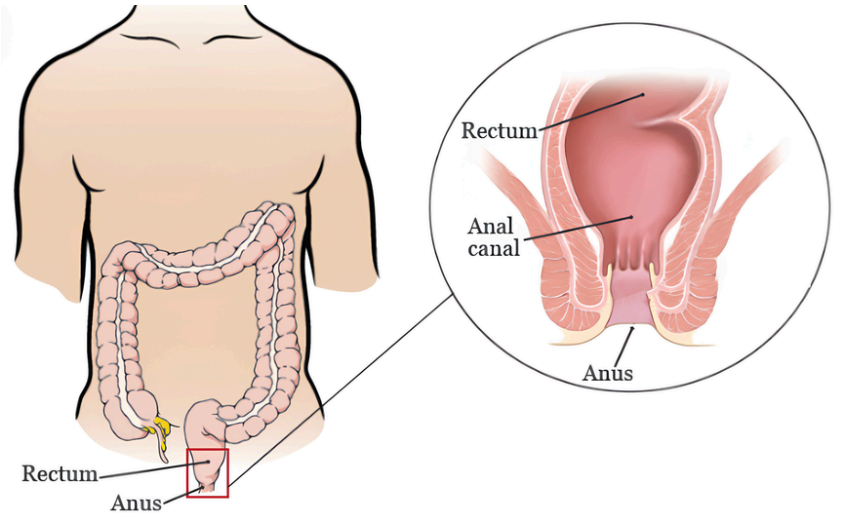


WHAT IS ANAL CANCER?

Anal cancer starts in the tissues of the anus, the opening at the end of the large intestine where stool (poop) leaves the body. The most common type of anal cancer is squamous cell carcinoma. This type makes up 9 out of 10 cases. It starts in the thin, flat cells that line the anal canal. The anal canal connects the anus to the rectum. It is about 1 ½ to 2 inches long. Squamous cell carcinoma can also grow in the perianal skin, or the skin around the anus.

Infection with human papilloma virus (HPV) is the main cause of anal cancer. HPV is the name for a group of more than 200 related viruses. Those that cause cancer are called “high risk” HPVs. The HPV vaccine can help prevent infections from HPVs that cause cancer.

Anal cancer is rare, but cases have been rising over the past several decades. The good news: when found early, anal cancer is often treatable, and many people do well after treatment.




Adapted from Memorial Sloan Kettering Cancer Center





To learn more about anal cancer, visit www.CancerSupportCommunity.org/Anal-Cancer.




TIPS FOR TAKING CONTROL

 Write down your questions before each doctor's visit. Bring a notebook to take notes, or use this resource guide to track your progress over time.

 Bring someone with you to appointments, for support and an extra set of eyes and ears. If you attend alone, take notes or ask if you can record the conversation — always check with your doctor first to make sure recording is allowed.

 Ask your doctor to explain anything you don't understand when they are talking about your cancer. Your doctor should be able to find other ways to help you better understand your cancer and treatment options. Ask if they can provide any printed material to help you and your caregiver(s) understand. You can contact your care team at any time if you want more information or clarity.

 Be proactive about cost. Before starting treatment, take a moment to discuss financial concerns with your care team or financial navigator. You can explore options to manage costs, understand what to expect, and find resources that can help ease the financial burden, so you can focus on what matters most — your care and recovery.

Everyone's cancer experience looks different. Doctors will use different tests and scans to diagnose anal cancer. These tests can also help see if the cancer has spread to other parts of the body and plan treatment moving forward. If detected early, anal cancer can be easier to treat.

QUESTIONS TO ASK ABOUT YOUR DIAGNOSIS

What is the cancer stage?

Where is the cancer located?

Has the cancer spread? Is the cancer considered "advanced"?

What are the different options for treatment?

Does the cancer have a high chance of returning?





WORKING WITH YOUR CARE TEAM

Cancer treatment is complicated. It is always changing as new discoveries are made. You deserve a care team you trust to provide you with the best possible care. Your team can include doctors, nurses, social workers, and other healthcare experts who work together. This is often called “multidisciplinary care.”

Being able to trust your care team and talk openly about your treatment is important. You might have many options for your treatment, so let them know what matters to you. Ask questions, share your worries, and speak up if something does not feel right. You should feel heard and supported during your cancer experience.

GETTING A SECOND OPINION

Getting a **second opinion** allows you to learn whether another medical team agrees with the diagnosis and treatment plan. This can be especially helpful if you feel that your doctor is not addressing your needs or concerns. Other care teams or centers may have different treatment options available to you. They may also offer other supportive care options that are important to you. Do not worry about hurt feelings. It is important that you feel comfortable with your treatment team and plan. But remember, timely cancer treatment is key when deciding to seek multiple opinions.

TREATMENT FOR ANAL CANCER

Treatment for anal cancer depends on:

- The stage of your cancer
- Tumor type (cells)
- Your overall health (including HIV status or immunosuppression)
- Your treatment goals



Below are treatment options your care team may suggest:

Chemoradiation	<p>This is a combination of:</p> <ul style="list-style-type: none">• External beam radiation therapy (EBRT) – The use of high-energy rays to kill or damage cancer cells. External radiation is delivered from a large machine aimed at the anal area.• Chemotherapy – The use of drugs to destroy or damage cancer cells. It is used to shrink tumors, slow cancer’s growth, relieve symptoms, or help people live longer.
Immunotherapy	<p>Immunotherapy uses the body’s natural defenses (the immune system) to find, attack, and kill cancer cells. It may be combined with chemotherapy to treat anal cancer.</p>
Radiation Therapy	<p>Radiation therapy is the use of high-energy rays to kill or damage cancer cells. Radiation may be used for advanced anal cancer — to treat cancer that has spread to the bones, distant lymph nodes, brain, or spinal cord. Radiation can help control symptoms, like pain or bleeding.</p>
Targeted Therapy	<p>Targeted therapy uses drugs to target specific changes in cancer cells that help them grow, divide, and spread. Targeted therapy drugs are designed to be more precise. They fight cancer cells while causing less harm to other cells in the body. There are different types of targeted therapies to treat anal cancer.</p>
Surgery	<p>Most anal cancers are in the anal canal and are treated with chemotherapy and radiation. Surgery may be used with very early tumors or if the cancer comes back or doesn’t go away.</p> <p>Perianal cancer (in the skin around the anus) is more likely to be treated with surgery.</p>



To learn more about these treatment options, visit www.CancerSupportCommunity.org/Treatment-Options-Cancer



WHAT ARE CLINICAL TRIALS?

Consider talking to your care team about clinical trials. Clinical trials are research studies for medicines or therapies that are not yet approved. They help us learn new and better ways to treat cancer. A clinical trial may be part of your treatment plan at any time — it is not a last resort option. A clinical trial may be the only way to gain access to a promising new treatment option.

For more information about clinical trials, visit www.CancerSupportCommunity.org/Clinical-Trials.



KEEPING TRACK OF YOUR SIDE EFFECTS

It helps to learn more about the side effects of treatment before you begin. This way, you will know what to expect. When you know more, you can work with your care team to better manage any symptoms during and after treatment. Report any side effects to your care team as you experience them. This helps your team understand how your body responds to treatment and give options to provide relief.

Below are potential treatment side effects people with anal cancer may experience. Think about how severe they are and how often they have affected you since your last doctor's visit, if at all. Talk to your care team about how to best manage them. They can make recommendations — like which creams can help with skin changes, pelvic floor therapy for bowel and urinary changes, and nutrition support.

	Rarely	Sometimes	Often
Skin changes in the treated area (redness, soreness, peeling)			
Fatigue (feeling very tired) or weakness			
Bowel changes (diarrhea, constipation, urgency)			
Changes in appetite/food taste			
Urinary changes (frequency, burning, blood in urine)			
Nausea			
Fever, which may indicate infection and a sign of low blood counts			



Mouth sores			
Pain (general or in specific area)			
Sexual health changes (vaginal dryness or discomfort; difficulty with erections)			
Difficulty thinking clearly or remembering (brain fog or “chemo brain”)			
Mood changes (feeling worried, anxious, overwhelmed, depressed)			
Other side effects not listed here:			

Fertility Issues. Sometimes, side effects from cancer treatments can lead to fertility issues (the ability to have children). There are steps you can take to address fertility concerns. Talk to your care team about options for sperm banking or freezing your eggs.

There are resources that can help. Visit www.CancerSupportCommunity.org/Cancer-Treatment-Side-Effects for more information on how to manage the side effects of treatment.

PALLIATIVE CARE

Palliative care is a type of support that helps you feel better during or after cancer treatment. A palliative care specialist works alongside your oncologist to help you manage any side effects and feel more comfortable. They focus on relieving symptoms — like pain or fatigue — and optimize your quality of life.

Palliative care is different from hospice care. It is available at any point in the cancer experience. It can be available as early as the time of diagnosis. Palliative care is available for people with any stage of cancer. You can receive it at the same time as your cancer treatment. The goal of palliative care is to help you live as well as possible throughout your cancer experience.



THINK ABOUT YOUR TREATMENT AND PERSONAL GOALS

When you talk to your care team about your treatment options, ask how each one might impact your personal life and goals. If you choose not to receive treatment, think about what kind of care will help you feel comfortable and meet your goals.

Some personal goals may be to:

- Be there for a special event/milestone
- Live as long and as well as you can
- Become an advocate and help others by sharing your experience
- Take part in research

Tell all the members of your care team about your treatment choices and personal goals. Your goals may change over time, and that is OK. Let your care team know if changes happen, so that they can support you in the best way possible.



SETTING YOUR PERSONAL GOALS FOR TREATMENT

Here are some questions for you to consider and discuss with your doctor, as you think about your personal and treatment goals. You may also find it helpful to discuss your goals with your family and loved ones first.

Physical, Emotional, & Sexual Health and Well-Being

- What is most important for you to be able to do and feel?
- What do you want to be able to do physically, during or after treatment?
- What symptoms or side effects do you want to avoid or manage?
- How important is it to maintain your fertility and sexual health?
- What does feeling “emotionally well” look like for you?

Family and Social Relationships

- What is going on in the lives of others that are important to you?
- Are there people in your life that you want to spend more time with or support?
- Are there upcoming family milestones or events you want to be present for?
- How can you maintain meaningful relationships during treatment?
- Who do you want to be involved in your treatment decisions?
- Who do you want to make medical decisions for you if you are unable?



Work/School/Home

- What financial or insurance concerns do you need to consider?
- Do you want or need to continue working or attending school? What kind of support or changes will help you with this?
- What changes could help you balance treatment with your responsibilities?
- What kind of help do you need at home or with daily tasks?

Social Support & Community Involvement

- Are you getting the support you need from friends, family, or community?
- What would good support look like for you right now?
- Is getting or staying involved in your community, advocacy, or support groups important?

Personal and Spiritual Growth

- How are you taking care of yourself spiritually and emotionally?
- What spiritual and wellness practices are important to you? Are there spiritual practices or beliefs that bring you comfort?
- What helps you feel connected to something bigger than yourself?
- What personal or emotional goals do you want to focus on?

Other

- What other cultural, religious, or social considerations are important to you?
- What else is important to you?



QUESTIONS TO ASK YOUR DOCTOR ABOUT TREATMENT & YOUR GOALS

My top goals for treatment are (see answers from above):

What are my treatment options?

What are the benefits and risks of each treatment option that is available for me? What side effects should I watch out for during, immediately after, and long-term after treatment?

How long will treatment last, and how often are visits?

How might this treatment affect my bowel control or bathroom habits? Will I need a colostomy (small opening in the belly connected to a small bag worn outside the body to collect poop)?

Will my ability to have sex or have children change during treatment?

Will I need help at home during and after treatment?

Can I keep working or attending school during treatment?

Are there other treatments options that work just as well but would have fewer side effects or cost less money?

Are there clinical trials that could help me?

The symptoms and side effects that are bothering me the most are (see answers from above):

- These side effects are affecting my daily life in these ways:
- What can we do to manage these side effects?

What can I do to stay active and feel better?

Is there a support group or social worker I can talk to about my experiences?

Who can I talk to if I am feeling overwhelmed or depressed?

How can I manage the stigma or negative feelings around my diagnosis?

What support is available for my caregiver(s)?



FINANCIAL SUPPORT

Even if you have a healthcare plan, cancer treatment and other related costs during your experience can be expensive. Keeping up with costs can be overwhelming. However, there are many resources that can help.

- Talk with your care team and pharmacist about how much your treatment will cost.
- Ask your doctor to refer you to an oncology social worker, financial navigator, or nonprofit organization for help managing financial issues and costs.
- Reach out to your healthcare plan or insurance to find out what resources they have that could help you.
- Find out if there are programs from drug companies that can help pay for your medicines and ask what you need to qualify.
- If your treatment center is far from home, ask if there are assistance programs that can help cover your travel costs.

To learn more about ways to manage the cost of treatment, visit: **www.CancerSupportCommunity.org/Managing-Cost-Cancer-Treatment**.

GETTING SUPPORT

- Think about people in your life who can help (your spouse or partner, friends, neighbors, faith community, support group, or co-workers).
- Make a list of things you need help with (childcare, meal prep, laundry, etc.) and who can help with each task. Consider visiting **www.MyLifeLine.org** to help you stay organized and let friends know what you need.
- Ask your care team about resources for social, emotional, and practical support. You can also ask for a mentor or ask to connect with another person with anal cancer.
- If you search for information online, make sure that you are using trusted websites.

Review the end of this guide to see a list of trusted organizations. Cancer Support Community and many other organizations have helplines, support groups, online discussion boards, and more ways to seek support from others who have cancer.

RESOURCES

ANAL CANCER RESOURCES

Cancer Support Community | CSC-867-5309
www.CancerSupportCommunity.org/Anal-Cancer

HPV Cancers Alliance
HPVCA.org

Anal Cancer Foundation
www.AnalCancerFoundation.org

American Cancer Society

- www.Cancer.org/Cancer/Types/Anal-Cancer.html
- www.Cancer.org/Cancer/Risk-Prevention/HPV/HPV-Vaccine.html

National Cancer Institute (NCI)
800-422-6237
www.Cancer.gov/Types/Anal

NCI's Clinical Trials Registry
800-422-6237
www.Cancer.gov/ClinicalTrials



Cancer Support Community Resources

Cancer Support Helpline® — Have questions, concerns, or looking for resources? Call CSC's toll-free Cancer Support Helpline at CSC-867-5309 (or outside the U.S., toll-free 888-793-9355), available in 200 languages.

Open to Options® — Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

Frankly Speaking About Cancer® — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

Services at Local CSCs and Gilda's Clubs — With the help of over 200 locations, in 50 markets, CSC and Gilda's Club centers provide services free of charge to people impacted by cancer. Attend support groups, educational sessions, wellness programs, and more
www.CancerSupportCommunity.org/FindLocation.

Cancer Experience Registry® — Help others by sharing your cancer patient or cancer caregiver experience via survey at **www.CancerExperienceRegistry.org**.

MyLifeLine® — CSC's secure, online community welcomes anyone impacted by cancer to easily connect with community to reduce stress, anxiety, and isolation. Create a personal network site and invite friends & family to follow your journey. And participate in our discussion forums any time of day to meet others like you who understand what you are experiencing. Join now at **www.MyLifeLine.org**.

Grassroots Network — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at **www.CancerSupportCommunity.org/Become-Advocate**.

This publication is available to download and print yourself at **www.CancerSupportCommunity.org/Anal-Cancer**.

For print copies of this publication or other information about coping with cancer, visit **Orders.CancerSupportCommunity.org**.

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