

# HIV & Cancer

If you or a loved one is living with HIV and has been diagnosed with cancer or is worried about the risk of developing cancer, you may have many questions. You may feel overwhelmed, scared, or confused. This resource aims to answer some of the questions you may have and provide support to navigate this experience.

## WHAT IS HIV?

HIV stands for *Human Immunodeficiency Virus*. When untreated, this virus attacks the cells in the body's immune system that help fight infection. If HIV is not treated, the immune system is weakened. This leads to a higher risk of developing other infections or diseases. This includes certain types of cancer.



While there is currently no cure for HIV, it can be treated, controlled, and managed. HIV medicines, called antiretroviral therapy or ART, help reduce the amount of HIV in a person's blood. This is also known as their "viral load." When people living with HIV take ART, they can suppress the virus.

If HIV is not treated properly, it can develop into AIDS (*Acquired Immunodeficiency Syndrome*). This occurs when a person's immune system is greatly damaged by the virus. A person diagnosed with AIDS is at greater risk of severe illness, infection, and death. Most people living with HIV do not develop AIDS because of ART treatment.

## HIV & CANCER RISK

Risk factors are things that can increase a person's chance of developing a disease. For example, smoking and heavy alcohol use can increase a person's risk of developing

certain diseases. Being diagnosed with HIV is a risk factor for some cancers.

When left untreated, HIV can weaken the body's immune system response. Because of this, it is harder for the body to fight against infections that may later develop into cancer. This places people living with HIV at a higher risk of developing some cancers, including:

- Kaposi sarcoma *due to human herpesvirus 8 (HHV-8)*
- Hodgkin & Non-Hodgkin lymphoma *due to the Epstein-Barr virus (EBV)*
- Cervical cancer *due to human papillomavirus (HPV)*
- Anal cancer *due to human papillomavirus (HPV)*
- Liver cancer *due to the Hepatitis B virus (HBV) and Hepatitis C virus (HCV)*
- Mouth & throat cancer
- Lung cancer
- Skin cancer

People who are diagnosed with both HIV and cancer have lower rates of cancer survival compared to people with cancer who are not diagnosed with HIV. This is especially true if a person's HIV is not treated. Having a weakened immune system, being diagnosed with cancer at a more advanced stage, delaying cancer treatment, and lack of access to proper care and support can all impact a person's prognosis.

## TERMS TO KNOW

**Antiretroviral Therapy (ART):** ART is a form of medication for people living with HIV. This treatment usually involves taking a pill once per day. ART helps reduce a person's viral load.

**Viral Load:** A person's viral load is measured by a lab test. The test shows how much of the virus is present in a person's blood. When a person's viral load is very low and can't be detected in the blood, it is called an *undetectable viral load*. Taking ART consistently can lead to viral suppression or an undetectable viral load. When the virus is suppressed, people living with HIV can lead long, healthy lives.

**HIV-Associated Cancer:** A type of cancer that is more likely to develop in a person living with HIV. This is due to HIV weakening the immune system.

**AIDS-Defining Cancer:** A type of cancer that is a sign that AIDS has developed. These cancers are also called opportunistic cancers. Examples include Kaposi sarcoma, some non-Hodgkin lymphomas, and some cervical cancers.



## LOWERING CANCER RISK

One of the most helpful ways a person living with HIV can lower their cancer risk is by maintaining their prescribed ART regimen. Consistently taking ART can help suppress or lower the viral load until it cannot be detected. This will help keep the virus from damaging the immune system so it can fight against cancer or other diseases.

Getting recommended vaccinations, regular cancer screenings, and limiting exposure to other risk factors can help. Since some cancers can be caused by certain viruses, being vaccinated reduces the chance of an infection. For example, getting the recommended HPV vaccine can help reduce the risk of cervical cancer. Regular screening tests, such as mammogram or colonoscopy, can increase the chance of finding cancer early. Early diagnosis provides more options for treatment, overall cancer care, and survivorship.

Talk to your doctor about your options for vaccinations and cancer screenings.

Limiting exposure to other risk factors can help reduce the risk of developing certain cancers or reduce the cancer's severity. This can include limiting heavy alcohol use, not smoking, and avoiding direct sun exposure without sunscreen.

## CHOOSING YOUR HEALTH CARE TEAM

Cancer treatment can be complex. Recommended treatment options can change with new advancements. Some information about cancer and cancer treatment on the

internet may not always be true. You need a health care team you can trust to work with you and give you the best care.

When choosing your health care team, it is important that you can have honest and open conversations. During appointments, make sure you share your concerns, ask questions, and feel like you are being heard. If you are living with HIV, your health care team should be aware of and understand your diagnosis. It is important to talk with your doctor about your disclosure preferences. Let them know if you would or would not like your HIV status to be disclosed to anyone joining you for your appointments.

Your team may include a number of health care professionals who work together, including:

- **HIV care provider or specialist:** This could be a medical doctor or nurse practitioner. This person will help with managing an HIV diagnosis and ART medication.
- **Physician:** You may see a medical oncologist, surgical oncologist, or a radiation oncologist depending on your type of cancer. Look for doctors who have experience treating your specific type of cancer.
- **Nurse Practitioner/PA/Nurses:** Your oncologist may work with oncology nurse practitioners, physician assistants (PAs), and oncology nurses. Along with your oncologist, they can answer your questions or help you manage the side effects of treatment.



- **Palliative care specialist:** This person helps patients manage difficult symptoms, pain, and side effects. They focus on improving patients' quality of life at the start, during, and after their cancer treatment. It is not only for end-of-life pain management.
- **Patient or nurse navigator/advocate:** Some cancer centers use patient navigators or nurse navigators. They help patients learn about and move through the care system, from diagnosis through treatment and recovery.
- **Social worker:** This person can help you and your family find resources to cope with cancer, treatment, and the costs of care.
- **Psychologist/Cancer Counselor:** Being diagnosed with HIV and cancer can be difficult to deal with. Having a trained professional to talk with can affect your outlook and journey. It may help you find or maintain the energy you need to get through treatment and take the best possible care of yourself.
- **Financial Navigator:** This person provides information and resources to help you and your family manage treatment-related costs. They can offer referrals and help you enroll in financial assistance programs if available.
- **Nutritionist/Dietician:** Some types of cancer affect eating or appetite. A registered dietician can recommend foods to help you eat comfortably and get the nutrients you need.

## GETTING A SECOND OPINION

At any point in your care, you can ask for a second opinion. Many people with cancer get a second or even third opinion from another oncologist or cancer center to confirm their diagnosis and review treatment options. Another hospital or doctor may offer a different treatment, including clinical trials, or more useful support services. They may be a better fit for you in other ways. **Do not worry about hurt feelings.** You can always return to the first doctor if you want. It is also important to remember that timely cancer treatment is key when deciding to seek multiple opinions.

## TREATMENT PLANNING

As you discuss treatment, your doctor should give you the chance to ask questions and make choices along the way. You might help choose the type of treatment, the timing of treatment, or the order of treatments. You may have the option to try a clinical trial. Making these choices is called treatment planning.

Good communication with your health care team and loved ones will make treatment planning easier. Talk with them about your goals, needs, and preferences. Let them know what is important to you. Make sure you understand what your doctors are saying about the stage and location of the cancer, and why one treatment might work better than another. **Don't be afraid to ask questions.** When you have a preference about your cancer treatment, make that preference known. If you feel overwhelmed during an



appointment, ask how you can contact a member of the team after the visit. This way you can share any additional questions or your decision regarding treatment.

## Open to Options®

A service of the Cancer Support Community

If you are facing a cancer treatment decision, the Cancer Support Community's Open to Options program can help you prepare a list of personalized questions to share with your doctor. Our Open to Options® specialists can help you create a written list of specific questions about your treatment plan for your doctor. **Call 888-793-9355 to schedule an appointment or to find a Cancer Support Community near you.**

## TREATMENT OPTIONS

It is important to continue taking your ART treatment while receiving cancer treatment unless your doctor advises you to stop. The HIV specialists and oncologists on your health care team should work together to determine the best treatment options for you. The treatment options will vary depending on the cancer type, stage of the cancer, your overall health, how well your immune system functions, and how you may respond to certain treatments. Your preferences are also important when selecting treatment options.

## QUESTIONS FOR YOUR CANCER HEALTH CARE TEAM

- Can you explain my test results to me?
- When should I start cancer treatment? What happens if I wait to start?
- What are my cancer treatment options?
- Will my cancer treatment team work with my HIV care provider?
- Will this cancer treatment impact my HIV care or medications?
- What are the overall goals of this treatment option?
- Will this treatment option allow me to pursue my personal goals?
- What are the short- and long-term side effects of my treatment?
- What can we do to manage the symptoms and side effects?
- Are there resources available to help me manage the cost of treatment or a financial navigator I can talk with?
- Do you have any resources available for social, emotional, and practical support?
- How can I contact the treatment team if an issue comes up during my treatment?





## CLINICAL TRIALS

Most cancer treatments have been tested in clinical trials to make sure they are safe and effective. Clinical trials are research studies that test new treatments. These studies can also help us learn how to use existing treatments better. It's important to know that:

- If you participate in a clinical trial, you will be part of a research study. You should receive the highest level of care while participating in the trial and your best interests should come first.
- The U.S. Food and Drug Administration (FDA) and local review boards oversee U.S. clinical trials to keep patients safe.
- No one receives a placebo or “sugar pill” in place of effective, appropriate treatments.
- During the trial, you can always ask questions. You also have the right to stop participating at any point.
- Often, the trial pays the costs of the drug being studied. Then, your health insurance and your copay cover “standard” treatment costs. Be sure to ask about the costs to you.
- Some clinical trials may make you ineligible for a future trial or treatment, so make sure to ask questions about this.

If you are interested in a clinical trial, ask your doctor if there may be one right for you as a treatment option. You can also look up clinical trials online if you know the type and stage of the cancer. Learn more here: [www.CancerSupportCommunity.org/Find-Clinical-Trial](http://www.CancerSupportCommunity.org/Find-Clinical-Trial)

## PATIENTS HAVE RIGHT

As a patient, you have rights. Most hospitals and medical centers have a written document called a patient bill of rights and responsibilities. It is often based on the patient bill of rights published by the American Hospital Association (AHA).

Ask a hospital representative for a copy of their patient bill of rights. It may also be posted online or in the building. The list will vary but most begin with the right to be treated with respect. Other rights might relate to privacy, access to information, and participation in research.

Hospitals and cancer centers that conduct research may have a research participant bill of rights. There is a staff person or office that oversee these rights. If you feel that your rights as a patient or as a participant in a clinical trial are being violated, reach out to the office that oversees this.

## COPING, STIGMA, & EMOTIONAL WELLBEING

Dealing with cancer in addition to living with HIV can be difficult to manage and overwhelming. This can cause a lot of emotions to arise. In addition to the seriousness of dealing with both diagnoses, there is also the emotional stress that comes with stigmas associated with HIV and cancer.



Some people in your life may respond in ways you dislike when they learn you have HIV or cancer. Concerns about how people may respond may make someone reluctant to share their diagnosis with loved ones and their health care team. There may also be fear around disclosing one's sexual relationships, which can cause hesitation around seeking cancer treatment overall.

It is important to consider your comfort level and preferences when discussing your HIV status with your treatment team.

**Ask questions** about how your HIV and cancer treatment teams will communicate and if treatment for one will impact the other.

Consider who already knows about your HIV and cancer diagnoses and who, if anyone, you would like to tell. You are the expert in making the best choice in this area. It can be helpful to communicate this with your health care team.

Managing both the emotional and physical impact of two diagnoses can lead to a lot of stress. Some ways to cope and best take care of your mental health include:

- **Take care of your overall health:** Try to eat regularly and get enough sleep. Try to stay physically active, even if that means taking a 15-minute walk. Limit any use of substances, including smoking, alcohol, drugs, and even caffeine. Try not to judge yourself harshly if these changes don't happen right away.

- **Stay connected to others:** It is important to share your feelings with people you are comfortable with and who are important to you. Talking with a counselor or therapist can help you cope with distress, anxiety, and depression. Your treatment team may be able to connect you with a support group with others going through similar experiences. Share your concerns with a health care professional you trust.
- **Do things you enjoy:** Finding things to look forward to, no matter how small, can be helpful and bring a sense of joy. This can include spending time with a friend, watching your favorite show, or trying something new.



## HIV & CANCER INFORMATION AND SUPPORT

Cancer Support Community · 1-888-793-9355 · [www.CancerSupportCommunity.org](http://www.CancerSupportCommunity.org)

AIDS Malignancy Consortium [Clinical Trials] · [www.Amcooperations.com](http://www.Amcooperations.com)

American Cancer Society · 800-227-2345 · [www.Cancer.org](http://www.Cancer.org)

American Society of Clinical Oncology · 1-888-651-3038 · [www.Cancer.net/HIV](http://www.Cancer.net/HIV)

Patient Empowerment Network · [www.PowerfulPatients.org](http://www.PowerfulPatients.org)

## CANCER SUPPORT COMMUNITY RESOURCES

**Cancer Support Helpline®** — Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon-Fri 9am-8pm ET and Sat 9am-5pm ET.

**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 170 locations, CSC and Gilda's Club network partners provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you. [www.CancerSupportCommunity.org/FindLocation](http://www.CancerSupportCommunity.org/FindLocation).

**Cancer Experience Registry®** — Help others by sharing your cancer patient or cancer caregiver experience via survey at [www.CancerExperienceRegistry.org](http://www.CancerExperienceRegistry.org).

**MyLifeLine** — CSC's private, online community allows patients and caregivers to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond. Sign up at [www.MyLifeLine.org](http://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](http://www.CancerSupportCommunity.org/become-advocate).

This publication is available to download and print yourself at [www.CancerSupportCommunity.org](http://www.CancerSupportCommunity.org).

Photos are stock images posed by models.

The Cancer Support Community and its partners provide this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or other health care professionals to answer questions and learn more.

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