

AYA

FAQS

ANSWERS TO
YOUR QUESTIONS



Children's Hospital
of Philadelphia®

Cancer Center



If you are an adolescent or young adult (AYA) with cancer, you probably have many questions. We understand that not everyone wants to ask their questions out loud, so we've compiled a list of those that are often asked. If your question is not on this list, or if you want more information, please ask a trusted member of your healthcare team, such as a doctor, nurse practitioner, nurse or social worker.



Is this my fault?

No! Nothing you did or did not do caused your cancer. Nothing your parents did or did not do caused your cancer.

Why am I at a children's hospital when I'm not a child?

Though we may not know why children/adolescents/young adults get cancer, we do know that there are many ways to treat it. Pediatric cancer is treated differently than adult cancer, and that is why it makes sense for you to be treated here. It can be tough feeling like you are the oldest one here, but you're not the only one. Talk with your child life specialist or social worker about groups and opportunities for you to connect with other patients around your age.

Is what I tell my medical team confidential?

If you are over 18, everything is completely confidential – that is, it will not be shared with your parents. For your safety, we do have to tell your parents/guardian about any abuse or if we have concern for risk of harm to yourself or others. Our priority is always your health and safety. If you are under 18, your parents/legal guardians do have some access to your medical information. If you are over 14 years old, information about most sexual or mental health issues will stay confidential. Ask a trusted team member if you have a specific concern about your privacy.



What do I do about missed school/work?

If you are in school, your social worker will work with you and your family to make a plan for you to continue to do schoolwork as you are able, and will help make sure that cancer has as little impact as possible on your progress in school.

If you are employed, you may qualify for the Family Medical Leave Act, which allows you to take up to 12 weeks (either all at once or broken up) off of work per year without fear of losing your job or your benefits.

I already have cancer, so what's the harm in smoking?

A lot! Some of the therapies we use to treat cancer can have effects on the heart or lungs, and so can tobacco (in all forms, including traditional cigarettes, e-cigarettes/vaping, and hookah pipes). To protect your heart and your lungs and to decrease your risk of getting other cancers, you should NEVER use any tobacco products.



cancer.chop.edu/aya

Is it okay to drink alcohol while I'm on treatment?

Alcohol may interact with some of the chemotherapies or other medications you take for your cancer treatment. For example, you may feel more tired or confused when drinking while you are on other medications. Alcohol can also affect the liver, which may lead your healthcare team to have to do additional testing and/or change your chemotherapy dosing. You should be honest with your care team about your current or planned alcohol use, so you can discuss the specific interactions with your treatment plan.

What's the deal with marijuana during cancer therapy?

Oncology doctors sometimes prescribe a medicine called marinol or drabinol for nausea, which contains the main ingredient in marijuana. This is taken as a pill. These medicines help many patients to control their nausea and increase their appetite. You should let your team know if you are using marijuana on your own (again, because it involves your health, not because they are police officers!). If you have symptoms like nausea, and marijuana is helping, it's important for your medical team to know so they can better treat your symptoms.

Can I still drive?

Great question! Your doctor will tell you if you should avoid driving at any time during treatment (after procedures and for other reasons).

If you have been told that it is OK to drive, make sure to avoid driving after taking any medicines that may make you tired or feel loopy (such as ativan, Benadryl or marinol).

Can I get a tattoo or body piercing?

Yes, but timing is important. You should not get a tattoo or body piercing when your white blood cells are low because you have a higher risk of infections. Do not get a tattoo/piercing when your platelets are low because you have a high risk for bleeding. To avoid any of these problems, your healthcare team may suggest that you wait until you finish therapy before you get a tattoo/piercing.



Does having cancer mean I can't have sex?

No – but there are important things to think about! There may be times when your blood counts are low and having sex may put you at risk for infection (low white blood cells) or bleeding (low platelets). Your healthcare team can talk with you about times when you may be more at risk.

Any skin breakdown (open cuts/sores on the skin) is a risk for infection. Do not have oral sex if you have skin breakdown or thrush (white coating on your tongue/mouth).

Always protect yourself with a condom or dental dam.



If I have sex, could my partner get sick?

Cancer is not a contagious disease. Your partner can't catch it from close contact such as touching, hugging, kissing or sex.

However, there are many infections that are spread by sexual activity. These are referred to as sexually transmitted infections (STIs).

When your white blood cell count is low, you are at greater risk for infection, so if you are going to be physically intimate with someone, always use a condom or other barrier method to protect yourself. Getting an STI while on therapy is a very serious issue.



**Can I get pregnant if I'm on treatment?
Can I get someone pregnant if I'm on
treatment?**

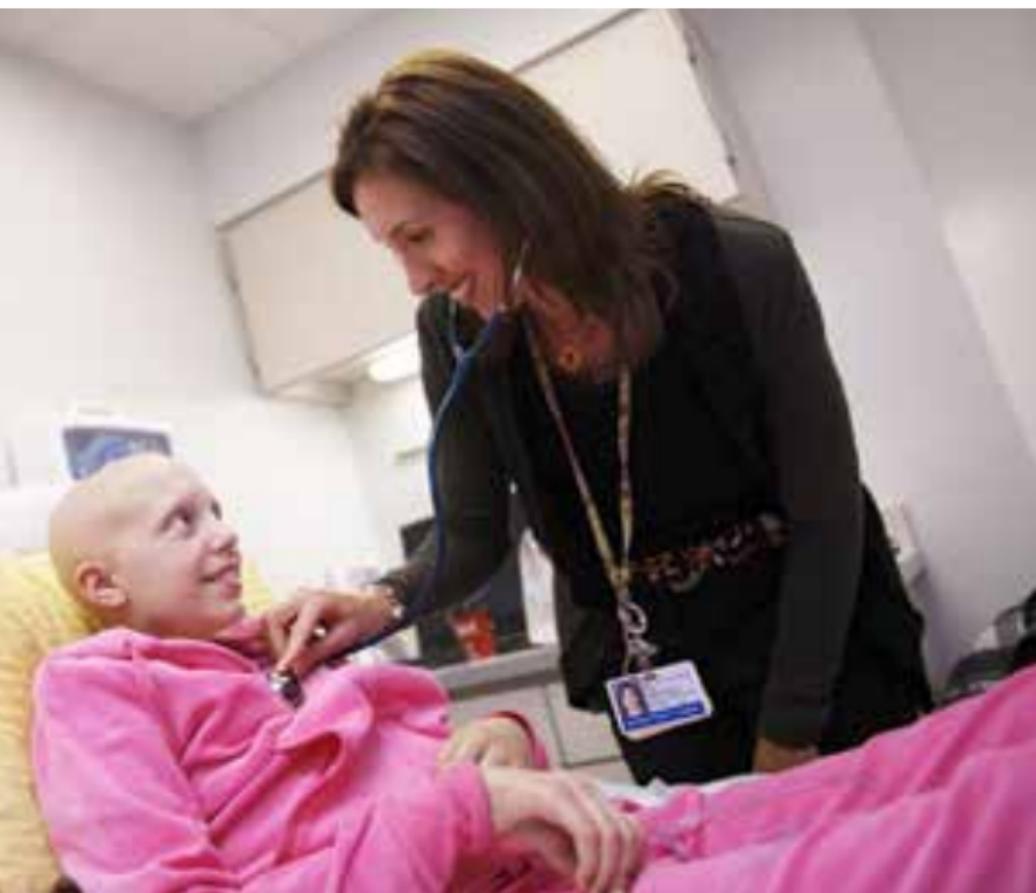
Yes. While some cancer therapy can affect short- and long-term fertility (the ability to have children), women can get pregnant even while on and off treatment.

It is very possible for a man receiving cancer treatment to get a female partner pregnant, whether he is on or off therapy.

Being pregnant when you have cancer can be very dangerous for both the pregnant woman and the developing baby. It is very important to use protection if you're sexually active to prevent pregnancy during treatment, with birth control medicine and condoms.

Why does my doctor need to know about my sex life?

As an adolescent/young adult, sexuality is a very important and normal part of your life. If you are sexually active, it is important that you can talk to your doctor about your questions, concerns and behaviors. Your doctor knows the treatment that you are getting and can talk to you about any risks related to your treatment plan.



Why is my menstrual period irregular?

Cancer therapy can change the timing, length or heaviness of your period. If you are having changes in your period, you should talk to your team about it. Some young women might be started on birth control (regardless of whether or not they are sexually active) to stop menstrual periods because they are at risk for increased bleeding when a platelet count is low.



I have a central line, g-tube or other implanted device. Can I still be intimate with another person?

Yes. While many teenagers and young adults feel differently about their body while undergoing cancer therapy because of weight loss, weight gain, central lines and/or feedings tubes, you can still be intimate with another person. You must still take care of your central line or feeding tube as you were taught.



What can I do about my hair loss?

Coping with hair loss can be difficult. Talk to your child life specialist or social worker about your feelings. Some people choose to wear wigs, hats, scarves and other head coverings. Some AYA patients have said that – with the support they receive from staff, friends and family – they feel empowered to be bald.

If you lose your hair from chemotherapy or radiation, it usually comes back shortly after your treatment is finished. Sometimes hair comes back a bit different in texture (curlier or straighter) or in a different color.



Who can I talk to/what can I do about how I'm feeling?

Your mental health is just as important as your physical health! Many people who are going through treatment find that they are more sad or frustrated than usual. There are many people at CHOP who can help you, including social workers, psychologists and child life specialists.

Sometimes it helps to hear from someone who has been through what you're going through and who can understand how you're feeling. There are organizations that can connect you with other adolescents and young adults who have gone through similar diagnoses and treatments. CHOP participates in a podcast that discusses some of these issues (find the podcast at chop.edu/ayacancerchat or on iTunes).

How do I tell my friends or co-workers about what I'm going through?

It is up to you to decide who you will tell about your cancer. Some people give a play-by-play of all their appointments and treatments on social media; others keep things very private. Most people are somewhere in the middle. Some people find it helpful to tell a few of their closest friends first before telling a larger circle of people. Do what works best for you. Your social worker or child life specialist can help you choose the best way to share your story.





Will my friendships change? Will I lose my friends?

Your friends may not know how to react when they learn that you have cancer. They may not know what to say to you or may be afraid of saying the wrong thing or upsetting you. Tell your friends how they can help you. Ask them to tell you what is going on at school. Let them know you want to talk about things other than cancer. Ask them to keep calling or texting, even if you don't always feel like talking or can't always respond. Ask them to invite you to things, even if you can't always go — you'll go when you can. Ask them not to take it personally if you can't talk or hang out because you don't feel well.



AFTER CANCER

The point of all of this treatment is for you to get on with your life. So what else can you do to stay healthy after cancer treatment?

- Continue regular medical follow-up.
- Eat well and exercise.
- Get recommended vaccines.
- Prevent other cancers by protecting yourself from the sun, getting cancer screenings and not smoking.
- Pay attention to your emotions. Sometimes, finishing treatment is harder than being on treatment.



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