



AYA

Q&A

This booklet aims to answer some of the questions you may have when faced with a cancer diagnosis as an Adolescent or Young Adult (AYA).

QUESTIONS AND ANSWERS

What is an AYA?

AYA is an abbreviation for Adolescents and Young Adults. We know that being an AYA with cancer comes with a different set of challenges than young children or older adults. You experience your diagnosis and treatment in a unique way.

Our AYA program at Connecticut Children's aims to serve you in the best way possible, making life with cancer a little less overwhelming and easier to navigate.

What is in this booklet?

We know that you may have had a lot of questions when you were told you had cancer. You may not feel comfortable asking some of these questions out loud to your care team or maybe you haven't even thought of them yet. We asked AYAs in our program to reflect on things they wanted to know and have answered their questions for you here. Please use this as a jumping off point to continue discussions with your care team.



Who is my “Care Team”?

You will often hear us refer to your primary “Care Team” in our cancer center. This is a group of our team members who will get to know you very well throughout treatment. They see you as a whole person and are interested in your physical, mental and emotional well-being.

Members of your care team include:

Attending Physician

This is your main doctor. They have had extensive training, completing medical school, residency and a fellowship in pediatric/AYA cancer and blood disorders. They are often referred to as an **Oncologist**, a doctor who specializes in diagnosing and treating cancer. They oversee your care and determine what treatment you will receive.

Fellow

This is a doctor who has completed medical school and residency and is now completing additional training specifically in pediatric/AYA cancer and blood disorders. They help decide what treatment you need and work with the team to carry out the plan.

Advanced Practitioner

You will likely have a primary Nurse Practitioner (APRN) or Physician Assistant (PA). These are advanced level medical providers who can treat and prescribe medications for pediatric and AYA patients. In our clinic, they work as part of the medical team to coordinate your care and carry out your treatment plan.

Nurses

Nurses are crucial to carrying out your treatment plan. They will be with you in clinic and inpatient, giving you your medications, making sure you tolerate medications well and providing lots of education and support. Nurses will help coordinate your visits and your care at home and in the hospital.

Child Life Specialists

It may sound funny to you that you have a Child Life Specialist on your team when you are not a child, but rest assured, your Child Life Specialist has training in adolescents and young adults, too. They can help explain medical things to you in non-medical language, prepare you for any procedures or surgeries and provide you with support and distraction during your treatment. They can also help connect you to other supportive services like massage therapy, pet therapy, etc.

Social Workers

Our social workers have many different functions, including providing emotional support, connecting you to resources, and helping to communicate with your school or work. If you have worries about how cancer will fit into your life, financial concerns, etc.— they are your go to!

Psychologists

Psychologists are available to you at the beginning, during and even after treatment to provide support, evaluate and treat any mental health concerns. Our psychologists have specialized training in emotional well-being for AYAs with a cancer diagnosis. Mental health is an important part of your overall health!

Who else will take care of me?

Residents

Residents are doctors that have completed medical school and are now training specifically in pediatric medicine. You will likely meet our resident team while you are staying overnight in the hospital. They work with your Oncology providers to take care of you.

Patient Care Assistants (PCA)

Patient Care Assistants are usually the first people you see once you are checked in for an appointment. They will take your vital signs and show you to the room where you will be seen by your care team in the outpatient clinic. When you are on the inpatient unit, they will take your vital signs frequently throughout the day to make sure you are staying healthy during your treatment.

Physical Therapists

Depending on your needs, you may meet physical therapists. They help you strengthen your body before a surgery or recover after treatment. You can see them inpatient or in the outpatient physical therapy clinic.

Surgeons

You will likely meet a surgeon during your treatment. If you need a central line (like a port-a-cath or a broviac) to safely deliver your chemotherapy and other medications, they will be the ones to place it. If you need additional surgeries like biopsies or a tumor removed, it will be done by a surgeon.

Registered Dietitians

Registered dietitians are specially trained to help you understand how food fuels and supports your body. During your therapy, they may make recommendations for types and amounts of foods or supplemental nutrition your body needs.

Other

There may be many other professionals you meet along your journey, including occupational therapists, pharmacists, respiratory therapists, nurse educators, etc. Depending on your treatment course, you may also meet doctors from other specialties, including cardiology, nephrology, endocrinology, infectious disease, pulmonology, and audiology. This is all to say we have a VERY big team of people that are well-equipped to take care of you and of all aspects of your well-being.



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Why **cancer**?

Why am I **here**?

What's **next**?

Q: Out of thousands of people, why did I get cancer?

A: It is very common to wonder why out of all of the people in the world, you were the one that got diagnosed with cancer. Unfortunately, in most cases, we cannot tell you why you have cancer. The most important thing to remember is that cancer is no one's fault--not yours, not your parents or caregivers. It is not something you did or didn't do that caused cancer.

Q: How can I get more information about my treatment plan?

A: Members of your care team, including your oncologist, advanced practitioner and nurse can provide you with information about your treatment plan. Everyone feels comfortable with different levels of information. If you feel you need more details regarding your treatment, please always ask.

Q: Can I ask a doctor or a nurse a confidential question?

A: If you are 18 years or older, everything can be confidential – that is, it will not be shared with your parents—if that is your wish. However, the exception to that rule is if we are concerned about any abuse or risk of harm to yourself or others. If you are under 18 years of age, your parents or legal guardians have access to your medical information. The exception is, if you are over 14 years old, information about most sexual or mental health issues will stay confidential.



Q: Am I going to die?

A: It is very normal to be questioning this when you are faced with a cancer diagnosis. Your care team will be able to provide you more information about your specific situation. Your team may be able to tell you how larger groups of patients similar to you in age and diagnosis have done with treatment. Please rest assured, our team has expertise in your condition, and our goal at diagnosis is to cure your cancer.



**Ask us...
we are here
to help.**

**Q: What did I do to deserve this?
Is this my fault?**

A: Cancer is not your fault. There is nothing you did or did not do to cause cancer. Cancer is not fair, and it is not fair that you are dealing with this diagnosis. We will do everything we can to help support you throughout your treatment.

**Q: What happens if
I don't take my
cancer meds?**

A: Each diagnosis is different, but what we do know is that following your treatment plan is very important, including taking your oral medication. Following your treatment plan offers you the best chance of cure. If you are having difficulty taking your medications, or have concerns about how to take them, please speak with your care team.



Q: Is my cancer contagious?

A: Cancer is not contagious. It is not something you can pass along to friends or family members.

**Q: Why am I in a children's hospital
if I am not a child?**

A: At Connecticut Children's, we are experts in cancers that primarily effect younger people. Even though you are not a child, your cancer is one that we have expertise in. We treat many adolescents and young adults in our program.

Are there things I can't do during treatment?

Q: Can I still do my normal activities?

A: It depends. Our goal is for you to still be able to do as many of your normal activities as possible, however, most patients find it difficult to continue their day-to-day life without some changes. A lot of this will depend on your specific cancer type, treatment needs and how you are feeling. Make sure that you tell your doctor about the activities that are most important to you so that they can try to help you figure out how to keep doing the things you enjoy and make your life meaningful.

Q: Can I still drive?

A: Your doctor will tell you if there are times that you should not drive, such as after procedures. You will also need to be careful and avoid driving after taking any medications that can make you sleepy or cloud your judgment (such as Marinol, Ativan, Benadryl, etc.).

Q: Is it ok to drink alcohol (if I am old enough)?

A: Alcohol may interact with some of your chemotherapies and other medications that you take for your cancer treatment. This can alter how well these medications work and also increase the side effects (such as affect how well your liver works). You should talk to your care team about your current alcohol use so that you can learn about specific interactions and risks, and how to keep yourself safe.

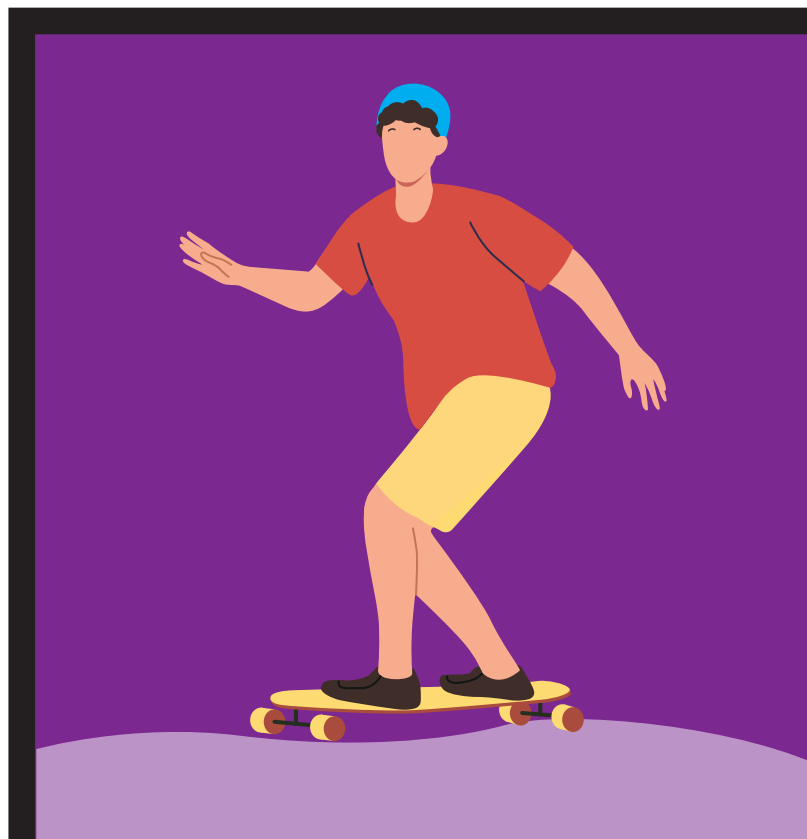


Q: I already have cancer—is there harm in smoking? Vaping?

A: Yes! We know that tobacco can have serious effects on the lungs and other body organs. Unfortunately, some of the therapies we use to treat cancer can also have effects on the heart or lungs, which makes them even more sensitive to the negative effects of tobacco. There are no safe forms of tobacco, including traditional cigarettes, e-cigarettes/vaping, and hookah pipes, etc. To protect your heart and your lungs and to decrease your risk of getting other cancers in the future, you should NEVER use any type of tobacco product.

Q: Can I use marijuana during cancer therapy?

A: You may have heard that marijuana can help patients with cancer deal with nausea and decreased appetite, which is true! However, using marijuana on your own can lead to further health problems, especially when undergoing



cancer treatment. If you are interested, you should speak to your care team. Doctors can prescribe a medicine called marinol or dronabinol for nausea, which contains a medicine similar to the main ingredient in marijuana. These medicines help many patients to control their nausea and increase their appetite. While we don't recommend finding marijuana sources on your own, if you do, please let your doctor know so that they can take the best care of you. Please note, it is never okay to smoke/vape marijuana.

Q: Why not smoke/vape marijuana?

A: Many types of cancer treatments can cause damage to your lungs as a side effect. Unfortunately, in order to cure the cancer, it is necessary to continue with these treatments. For this reason, it is very important to do everything that you can to keep your lungs healthy. Both smoking and vaping can cause serious damage to lung tissue, and make you more susceptible to the harmful side effects of chemotherapy and other cancer treatments on your lungs. This is why we advise you not to smoke/vape during or after treatment.

Q: How can I continue to be physically active while undergoing treatment?

A: The American Cancer Society says that people receiving chemotherapy who also exercise experience many benefits, including shorter hospital stays, less fatigue and emotional distress, better sleep, increased self-esteem and confidence and fewer side effects. It is important to note that people undergoing chemotherapy often feel too weak to start or continue in an intense exercise program, but lighter activities such as walking, stretching and light weight training may be okay. Even a little bit of activity can go a long way. Plus, many stretching and weight-training exercises can be tailored to your capabilities and done while sitting or lying down.

Your care team can help you figure out how you can safely remain physically active during treatment. This may include meeting with a physical therapist. It is important to know that problems can happen when you push yourself too hard, so you want to make sure that you are paying close attention to your body.

Q: Can I get a tattoo or body piercing?

A: Yes, but timing is important. When your white blood cells are low, you are at high risk for infection and are not able to heal well therefore this is not a good time to get a tattoo or body piercing. 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, talk to your care team. It may be safest to wait until you finish therapy before getting a tattoo or piercing.



Q: Why does my care team need to know about my drug and alcohol use?

A: All drugs have the potential to interfere with your cancer treatment. If you have taken any drugs in the past or currently take drugs, even if only occasionally, it is important that you tell your care team. This includes use of marijuana, hallucinogens, cocaine, amphetamines, opiates, anabolic steroids, inhalants, methamphetamine and tobacco. Not telling them is very risky. These drugs can change the chemistry of the cancer treatment and make it less effective or too toxic.

Q: Can I travel? Can I leave the state/country when I'm on treatment?

A: Travel may be possible and you should talk to your care team to determine if a specific trip would be safe for you to go on. This will depend on your specific cancer and cancer treatment as well as risk for serious side effects. With any travel, you would want to make sure that you have access to expert oncology care nearby in case of an emergency.

What about my social life?

Q: How do I meet other people my age who are going through similar things?

A: Connecticut Children's and other organizations offer ongoing AYA activities both at the hospital, in the community and virtually. Please speak with your social worker or care team about these opportunities. Some past local events have included paint nights, sporting events and dinner at a local restaurant. There are also dedicated AYA spaces in clinic and on the inpatient units to check out as well.

Q: Who can I talk to about how I am feeling?

A: Social workers, Child Life Specialists and psychologists at Connecticut Children's are available to help support you during your treatment. They can check in on you (and your family) when you are in clinic or admitted. In addition, our psychologists can schedule outpatient appointments to provide a confidential space to discuss your concerns. Please let us know how we can be most supportive.

Q: How do I explain to my friends what I am going through?

A: We believe that being honest with your friends is the best way to let them know what you are going through. You don't have to share every detail if that is not comfortable but covering major topics like hair loss, feelings of fatigue and ways they can help you stay healthy (good hand washing, not visiting when they are sick) might be important.

Q: Will I lose my friends or feel disconnected and isolated?

A: Friends are often unsure how to respond when they hear about your cancer diagnosis. They worry they will do or say the wrong thing. The best thing you can do is to tell them how to be helpful. Sometimes you will want to hear about school or work and other times it may be too much. Encourage your friends to reach out and to continue to include you in things. Even if you can't participate, let them know just being asked helps you feel connected. Invite one or two friends over for a movie night or ask them to check in regularly via text or social media. Your friends want to do the right thing but may need some guidance from you.

Q: Will people feel bad for me?

A: Everyone's situation is different but you have the ability to set the tone for how people respond to you. Often people show their sadness and compassion toward you because it's hard to see someone they care about going through a difficult time. You may not want people feeling sorry for you but being open to the caring and support of others can go a long way in helping you through treatment.

Q: How do I maintain a sense of independence?

A: As an AYA, cancer can be challenging because you find yourself relying on your parents at a time in your life when you are trying to become more independent. Other AYAs have found it helpful to be upfront and ask for some space on days when they need it. Let your parents and friends know you will ask for help but would like to try and do as much as possible on your own.

What about **school** and/or **work**?



Q: Will I still be able to go to school or work?

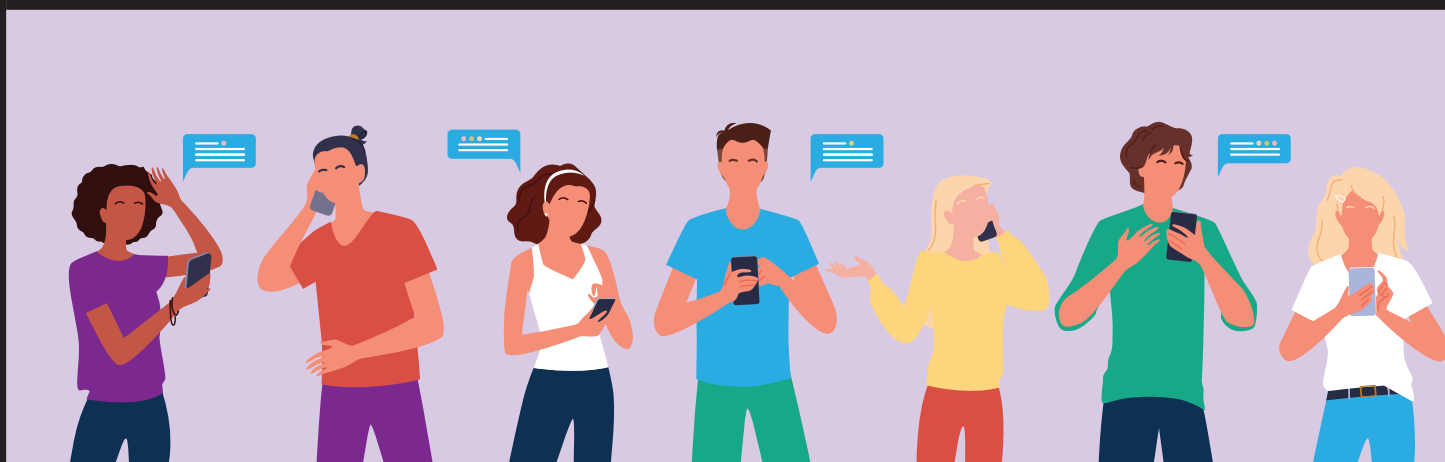
A: If you are currently in high school, we will work with you and your school to help ensure you remain up to date with your school work. This can be done with a home tutor, by attending school or a combination of both. If you are attending college, your care team can offer some suggestions based on your treatment plan and course load.

Many college students choose to take time off until treatment is complete.

If you are working, you may be eligible for FMLA (Family Medical Leave Act) that allows 12 weeks off for treatment and appointments. Please talk to your social worker for additional information.

Q: Do I have to tell my boss or coworker?

A: The decision to share your diagnosis is a very personal one. If you will be requesting a medical leave of absence from work, you will be required to disclose that you have a medical condition to have the leave granted. How much you choose to tell coworkers is up to you. There is no right or wrong answer....whatever feels comfortable is the way to go. The Cancer + Careers website is a great resource for navigating work related issues.



Are there side effects of treatment?



Q: What is chemotherapy?

A: Chemotherapy or “chemo” as you will hear it called, is the word used to describe any type of medication that is used to treat cancer. There are many different types of chemotherapies, and these may come as drugs you take by mouth (a tablet or liquid) or that are infused into your body through an IV or central line. Your particular chemotherapy plan is referred to as your treatment protocol.

Q: Does chemo hurt?

A: Most chemotherapy agents do not directly cause pain. Your care team will review all side effects of your chemotherapy with you during your initial treatment plan review and at any point during your therapy that you request. More common side effects of chemotherapy agents are nausea and fatigue, though each chemotherapy medication has a unique list of side effects.

Q: I hear nausea is common in cancer treatment—what can I do to help avoid that?

A: Unfortunately, nausea is a common side effect of chemotherapy medications. The good news is that we have many medications that can help with nausea. Your care team will prescribe you anti-nausea medications that they feel are appropriate to your chemotherapy protocol, but your nausea plan can always be adjusted if it is not working for you. If you feel your nausea is not well controlled with the medications you have been given, please let your care team know.

Q: Will treatment make me tired?

A: Every individual is different, but most treatment plans will, at some point, cause fatigue. Take breaks and rest when you need it...and on days you feel great, do those activities that you love.

Q: Is medical marijuana an option for helping with chemo side effects?

A: Medical marijuana use (without smoking or vaping) may be an option for many young adults over the age of 18 undergoing cancer therapy. Let your primary care team know if you are interested in learning more.

Will I need to **change what I eat?**

Q: Should I change my diet during treatment?

A: For most treatment plans, there are not specific dietary changes that we recommend. Cancer therapy often causes side effects, such as nausea and vomiting that may cause weight loss. Your team may recommend frequent snacking or higher calorie foods to help maintain your weight. High protein options may be encouraged if you are healing from a surgery or radiation therapy to aid in the recovery process. We have registered dietitians that work closely with us who are able to provide you more nutritional guidance should you or your care team request it.

Q: Are there any restrictions or foods I shouldn't eat during treatment?

A: There may be foods or dietary restrictions for your specific protocol. Please ask your care team for any specific dietary guidelines.

Q: Will my appetite or tastes changes during treatment?

A: Many times, chemotherapy can affect your eating habits. Things that used to taste good to you may not anymore. You may also crave new foods. If you have concerns about your diet, you may speak with a nutritionist or dietitian to help figure out what works for you.





Am I **at risk** for getting infections?

Q: Am I more at risk for infections while on treatment?

A: The vast majority of chemotherapy protocols do affect your immune system, which is the part of your body that fights infection. There will be times that your immune system will be the lowest—usually 7-14 days following an intensive chemotherapy cycle. Your team will tell you if you are at high risk for infection and will give you guidelines for limiting your exposure to illness (for example not going to a crowded movie or store when your counts are very low).

Q: Do I really need to go in to the Emergency Department if I have a fever?

A: Yes! If you are on treatment and have a central line, you must go to the Emergency Department or be seen in clinic with any fever (temp of 100.4 -100.9 twice in one hour, or immediately if your temp is 101 or higher). Because your immune system is weaker during chemotherapy, a small infection can turn into a BIG deal very quickly. You will need to have blood cultures drawn to make sure no germs are in your bloodstream, and you will need to receive IV antibiotics to help protect you from getting very sick. If not treated, fevers can lead to severe illness and even death.

Q: What are good ways to avoid infection when interacting with other people or groups?

A: Washing your hands is the most effective way to prevent infections that spread from one person to another. Carrying hand sanitizer or having a mask with you are other good ideas. If you know a friend is sick, it is best to not spend time with them. Use virtual ways to keep in touch until they are feeling better.

Will my appearance **change**?

Q: How will my appearance change? How do I cope with major body transformations – hair loss, weight loss, weight gain?

A: Cancer and treatment can have an impact on your appearance. Hair loss is the most significant for many. Some AYAs choose to wear hats, scarves or a wig while others become comfortable with their hair loss as treatment progresses and don't wear anything at all. Just like hair loss, weight gain and loss are temporary, but we can appreciate that it doesn't make it any easier when it is happening. Talk to your care team about your feelings and ways to cope with side effects of treatment.

“Today you are you!

That is truer than true!

There is no one alive

who is you-er than you!”

- Dr. Seuss

**Q: Am I going to lose my hair?
How long do I have before I lose
my hair? Will it grow back?**

A: Most patients who receive chemotherapy experience hair loss. It usually takes two to three weeks after your first chemo treatment to notice. Many patients choose to cut their hair short or shave it off while some wait until it falls out on its own. Your hair will typically start to grow back soon after treatment ends

Q: Where can I get a wig?

A: Talk to your social worker. They will be happy to let you know what options are available. Depending on your age, diagnosis and insurance, there may be different programs and options available to you.

How will treatment affect my fertility and sexual health?

Q: How will this affect my fertility? How do I deal with that?

A: Your cancer treatment may affect your fertility (ability to have children in the future). Before you start treatment you will meet with the Fertility and Sexual Health Team to talk about your risks for developing problems and potential ways to preserve your fertility.

Q: Can I still have sex during cancer treatment?

A: Yes, but there are several important things for you to know.

There may be times when your blood counts are low and having sex may put you at high risk for complications. For example, it's not safe to have sex when your white blood cell counts are low because you are at high risk for infections. It also may not be safe when your platelets are low (platelets help your blood to clot) because that increases your risk of serious bleeding. Like the skin lining in your mouth, the lining of the vagina and anus are thin and can be easily irritated and torn, which can result in problems like bleeding and severe infections when your counts are low. Your care team can talk to you more about when you may be most at risk and how to best protect yourself.

During treatment, it is possible for a small amount of chemotherapy or other medications to pass into the fluid inside the vagina or into semen. It is best to wait at least 72 hours after chemotherapy before having sex to protect your partner from exposure. We also recommend always using a barrier method like condoms.

Q: If I have sex, could my partner get sick?

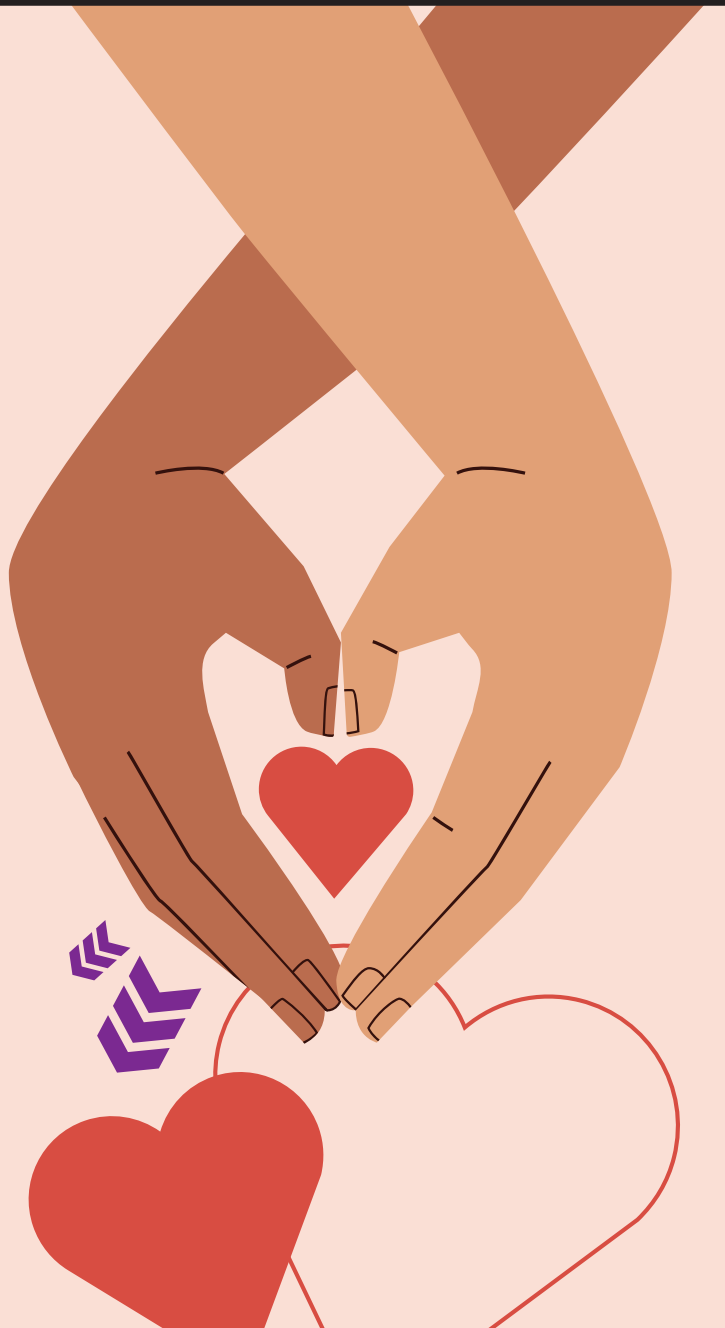
A: Fortunately, cancer is not a contagious disease. This means that your partner can't catch it from being in close contact and through doing things such as touching, hugging, kissing or sex. What is important to remember is that there are many types of infections that are spread by sexual activity, often called sexually transmitted infections (STIs). Remember that when your white blood cell count is low, you are at higher risk for infections. Therefore, 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 can be very serious and even life-threatening.

Q: Is birth control safe during treatment?

A: This will depend on your cancer and cancer treatment, as well as the type of birth control you use. Your care team can help you decide what birth control is best for you. Remember, not all birth control methods protect against STIs, so you will still want to use additional protection, like condoms, if you are going to be physically intimate with a partner.

Q: Can I get pregnant or get someone pregnant if I am on treatment?

A: Yes. While some types of cancer treatment can affect fertility (the ability to have children), it is still possible to get pregnant during and after cancer therapy (even if periods have stopped). It is also possible to get your partner pregnant while on treatment or after chemotherapy. Being pregnant when you have cancer can be very dangerous. It is very important to use protection (condoms and another form of birth control) if you have sex to prevent pregnancy during treatment.



Q: How will my period change?

A: Sometimes cancer therapy can change the length or heaviness of your period. It is important to talk to your care team if you notice changes. Sometimes birth control may be used to stop periods during treatment, especially if they are very heavy and lead to significant blood loss (this can happen when the platelet count is low).

Remember that even though your periods may stop or come less often during cancer treatment, it is still possible to get pregnant.

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

A: Sexuality is a very important and very normal part of life for an adolescent/young adult. Your care team's job is to keep you as healthy as possible during treatment as well as to provide you with information about any risks to your health, including risks to your sexual health. Whether or not you are having sex, it is important for you to be able to talk to your care team about any questions or concerns you may have about your sexual health.

Q: If I have a central line, g-tube or other implanted device, can I still be intimate with another person?

A: Yes, you can still be intimate with another person despite any devices. However, you must still take care of your central line or g-tube as you were taught. Ask a member of your care team if you have any questions.



AYA Words of Wisdom

(from former patients who get it)

Hi! We hope this booklet answered many of your questions. The following information comes to you from teens and young adults who have been in your shoes. We put together some tips we have learned along the way to help guide you through treatment. We hope you find them helpful.

Tips for processing your diagnosis

- » Take it day by day or even moment by moment. It's not a sprint, but a marathon. Take it one step at a time.
- » It's ok not to be ok. Cancer sucks.
- » Don't isolate yourself. Allow people to help you. It's not weak to ask for help.
- » Remember, your diagnosis is not your fault. Don't feel guilty about it (if you do, talk with someone on your care team).
- » The journey is a rollercoaster—you'll have your ups and downs. Making it through the bad days make the good days that much better.
- » A lot of things are going to change from the way you look to your day to day schedule. Try to keep up with your normal activities as much as you can, but know it will be different for a while.



Your Inner Circle

Friends: Your diagnosis will also affect your friends and other close relationships. When you are ready, don't be afraid to ask for what you need from them—they may want to help, but often don't know how. Try to be patient with your friends...they may not understand what you are going through. It's ok to tell people you need your space, too.

Parents/Caregivers: They are just trying to help (even if it's annoying). They may be very nervous—this is hard on them, as well. Tell them how they can help, and tell them what is not as helpful. Let them be the “bad guy” for you if you don't want to do something or see someone. Reassure them when you are feeling ok, and don't be afraid to tell them when you're not. When you can, show your appreciation.

Siblings: Ask your siblings what they want to know about your journey. They may feel very out of the loop. Your parents may need to be more focused on you right now, so ask your siblings how they are doing.

School or Work: Your peers may be wondering what you are going through and where you have been. Tell those closest to you what you would like them to pass along to the larger community.



How to deal with appointments and hospital stays

Come to the hospital expecting that you are going to wait. There are spaces for teens and young adults—check them out. The activities in there can help pass the time or bring things from home to do.

Write down any questions you may have prior to your clinic visits.

Find something good to watch.

Pack a bag and leave it in the car for every clinic visit, just in case you have to stay.

Bring snacks. There are snacks in clinic, but you can bring your own food, too.

Don't be afraid to ask for something you really want—there may be a way to make it happen.

Nothing is set in stone. Be prepared to stay longer than expected. Your care team just wants to make sure you are ok before you go home. Better safe than sorry.

The hospital is very different from home, but it gets easier with time. Transitions in and out can be tough. The team knows you want to be home and do their best to make it happen.

Makes sure you have all the information you need before discharge. Ask questions when you have them.

There is always a doctor on call 24/7 if urgent questions or concerns come up. You are never alone or without help.



The Reid R. Sacco Adolescent and Young Adult (AYA) Cancer Program at Connecticut Children's provides comprehensive cancer care for adolescents and young adults. We offer state-of-the-art medical care and support for the unique emotional and social needs of patients in this age group.

www.connecticutchildrens.org/aya