

**CHILDREN'S  
ONCOLOGY  
GROUP**

A New  
Diagnosis  
Guide *for*  
*Teens and*  
*Young Adults*



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## **Download Online**

In addition to printed copies, the *Children's Oncology Group Family Handbook* and *New Diagnosis Guide for Teens and Young Adults* can be found at [childrensoncologygroup.org/cog-family-handbook](http://childrensoncologygroup.org/cog-family-handbook).

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# Introduction

This guide was written for patients and families learning about a new cancer diagnosis. The diagnosis of cancer brings changes to your life and the lives of your whole family. Many adolescents and young adults have told us that their diagnosis brings feelings of fear, anger, and sadness. Having these feelings during this stressful time is normal. You are not alone. Having cancer is not your fault. There is nothing that you did, or did not do, that caused your cancer.

You are getting a lot of information right now. You are being asked to learn about medical topics and care when you are likely feeling overwhelmed. This New Diagnosis Guide was created to help you focus on the most important information that you need right now, in this time just after your diagnosis. By working with your health care team and taking one step at a time, you will learn what you need to know to care for yourself. This guide is an introduction to your learning. Your health care team will continue to review important information with you throughout your treatment.

## *Why am I at a Children's Hospital?*

You may be questioning why you are at a children's hospital as an adolescent or young adult with cancer. Pediatric cancer is treated differently than adult cancer, and your health care team has the expertise needed to treat your cancer. We know that it can be hard feeling older than everyone else. Talk with your health care team about groups and opportunities to connect with other patients your age.

As an adolescent or young adult, you should feel comfortable being a part of the discussions and decisions about your treatment. Share your feelings about how the decisions being made will affect you. We encourage you to ask questions! There are no bad questions. It is important to ask about your medical care and physical health, but it is also important to talk to your team about how you are feeling emotionally. Your mental health is just as important as your physical health! It can be helpful to talk to 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 cancers and treatments. See the “Resources” section at the end of this guide. You can share confidential (private) information with your health care team, and this information will not be shared with your family without your permission. But, for your safety, the team is required to tell your parents/guardian/spouse about any child abuse or homicidal (harm to others) or suicidal (harm to self) thoughts. Ask a trusted health care team member if you have a specific concern about your privacy.

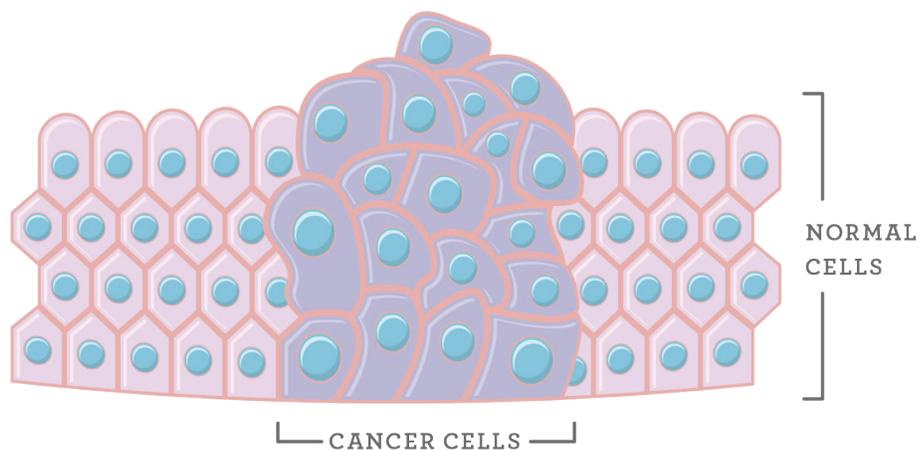
Again, always feel free to ask questions of any member of your health care team. There are members of your health care team who are available to talk with you about your cancer and can help you and your family cope through counseling, financial assistance, and access to resources. Talk with your health care team about your needs so that you get the right support.

## About Cancer and Its Treatment

### *What is Cancer?*

Cancer is one name for a group of diseases. Each type of cancer has its own name, treatment, and prognosis (chance of responding to treatment). Cancer in adolescents and young adults can generally be divided into three groups:

- Leukemias (cancers of the blood-forming cells)
- Lymphomas (cancers of the immune system)
- Solid tumors (cancers of the brain, bones, muscles, organs, or other tissues in the body)



## How is Cancer Treated?

Each type of cancer will be treated differently, depending on what doctors have found to be the best treatment for that type of cancer. You may receive one or a combination of the following treatments at different times in their therapy.

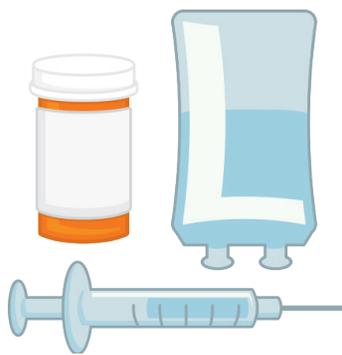
### SURGERY

Different types of surgery are used to treat cancer. Sometimes, taking out the tumor may be the only treatment needed. Usually chemotherapy, immunotherapy, or radiation is also used to kill any cancer cells still in the body.



### CHEMOTHERAPY

Chemotherapy is medicine that treats cancer by stopping cells from growing, or by destroying cells. Chemotherapy can be given in a number of ways including:

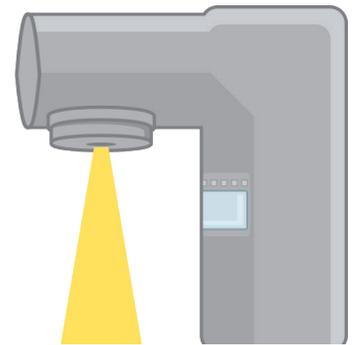


- by mouth
- into a vein
- as an injection (shot)
- into the spinal fluid

Talk to your health care team about the ways your chemotherapy will be given.

### RADIATION THERAPY

Radiation therapy delivers high energy x-rays that damage and destroy rapidly growing cells, such as cancer cells.



## IMMUNOTHERAPY

Immunotherapy uses the immune system or medicines made in the laboratory from immune cells to fight cancer. Immunotherapy can be given:



- By mouth
- Into a vein

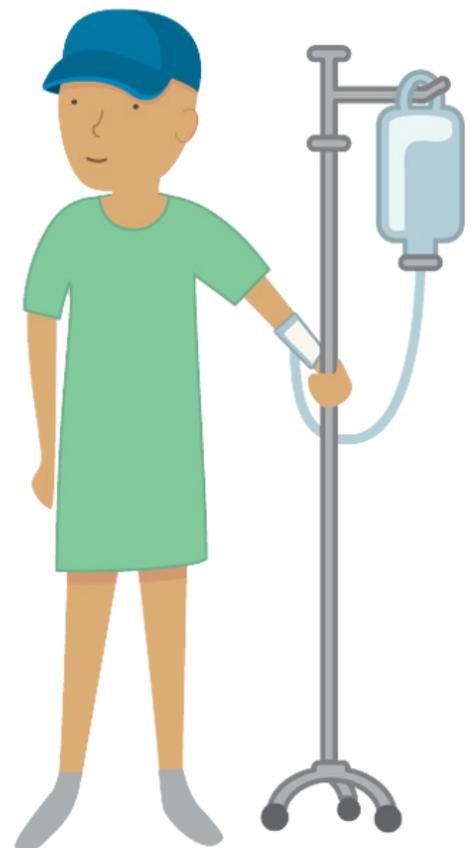
Talk to your health care team about how your immunotherapy will be given.

## TARGETED THERAPY

Targeted cancer therapies block the growth and spread of cancer, while limiting or avoiding damage to normal cells and tissues. Targeted therapy can be given:

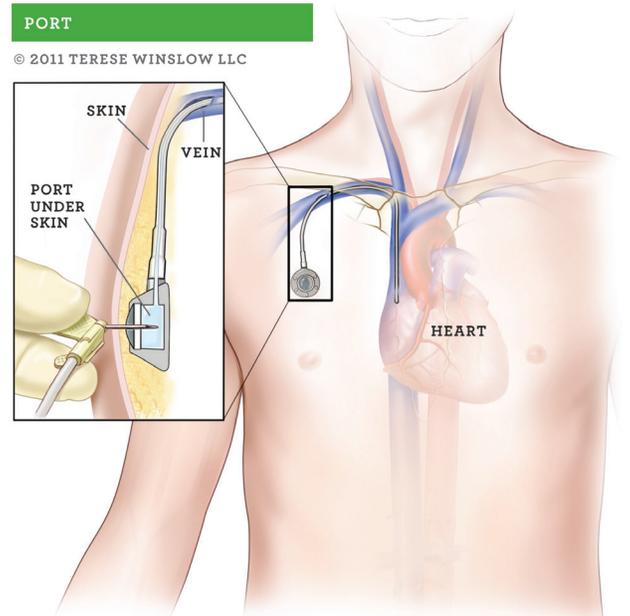
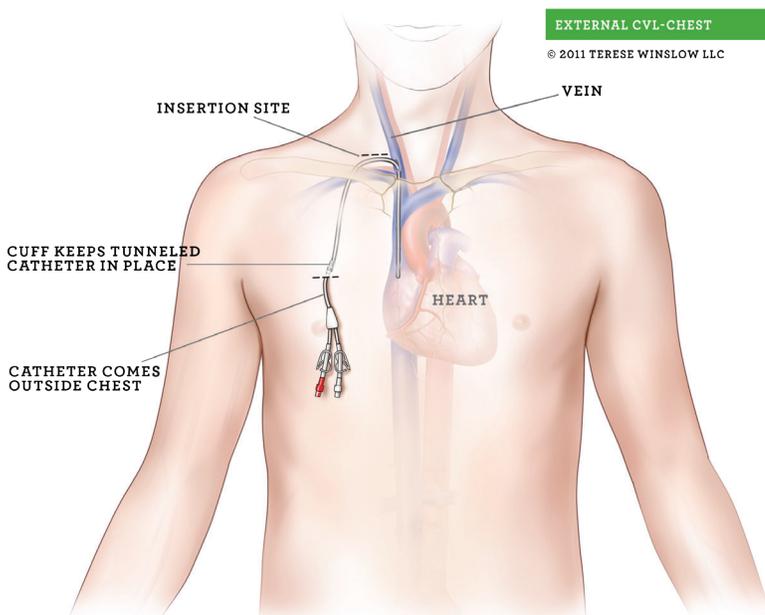
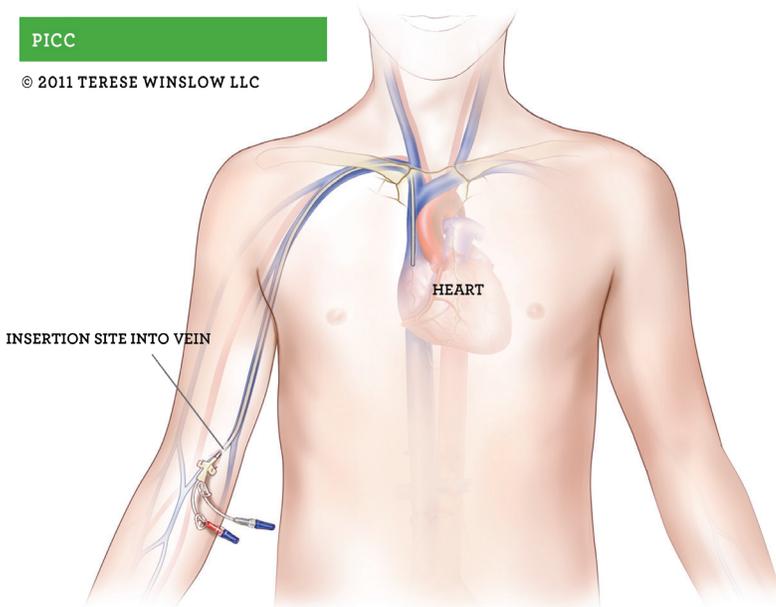
- By mouth
- Into a vein

Talk to your health care team about how your targeted therapy will be given.



## CENTRAL VENOUS LINES (CVLs)

A central venous line provides a safe way to give medicines, including chemotherapy, through a vein. The different types of central venous lines are pictured here. If you have a PICC (peripherally inserted central catheter), or external CVL, your nurse will teach you how to care for this line at home. If you have a port, you may be asked to apply a numbing cream on the skin over the port before you come to the clinic or Emergency Room. The cream can help make putting the needle in the port easier for you by numbing your skin. Check with your nurse to see if this is something you will need.



## ***What is a Clinical Trial?***

Clinical trials are research studies done to help the health care team understand more about diseases, like cancer, and how best to treat them. The progress that has taken place in treating cancer has been made possible through clinical trials and the adolescents and young adults who participate in them.

The Children's Oncology Group (COG) is the largest pediatric clinical trials group in the world. The COG has treated more young people with cancer than any other organization. Doctors, nurses, and other experts around the world are working to continually improve treatments for cancer. Your doctor and health care team will let you know if there are clinical trials available for you. Some clinical trials are about treatment and some are about ways to try and better support you through treatment. If a clinical trial is available you will have the chance to talk about the trial and ask as many questions as you want with your health care team. This will help you to learn about the trial and what it will mean for you if you are a patient on the trial.

You may always choose, or give your permission to be part of a clinical trial. Participation in a clinical trial is completely voluntary. If you are 18 years or older, this is called informed consent. If you are under 18 years old, this is called informed assent and you and your parent or legal guardian will be asked to give informed consent. A member of your health care team will explain this to you and your family. After permission is given, you will get a copy of the signed consent form explaining the clinical trial.



# When to Call for Help

Sometimes adolescents and young adults with cancer will have symptoms that are warning signs of a serious condition. Your health care team considers these symptoms a sign of an emergency. In an emergency, you need to take action right away.

**You, or your friends or family, should call Emergency Services (“911” in the U.S. and Canada) immediately if you:**

- are having severe difficulty breathing
- have skin and/or lips that look blue
- are having a seizure (and you have NOT been told that a seizure can be managed at home)
- do not wake up after someone has tried to wake you (loss of consciousness)



**Call your health care team immediately (do not wait until the clinic or office opens) if you have:**

- fever (temperature of \_\_\_\_ or higher)
- chills (shivering)
- trouble with breathing
- bleeding that does not stop within 5 to 10 minutes
- change in behavior or level of consciousness (such as being very sleepy, very irritable, or not making sense when talking)
- sudden change in vision
- severe or repeated headache
- new weakness of the face, arm, or leg
- uncontrolled pain
- a break or leak in the central venous line (CVL)
- repeated vomiting or diarrhea
- not been able to drink fluids
- exposure to chickenpox or shingles



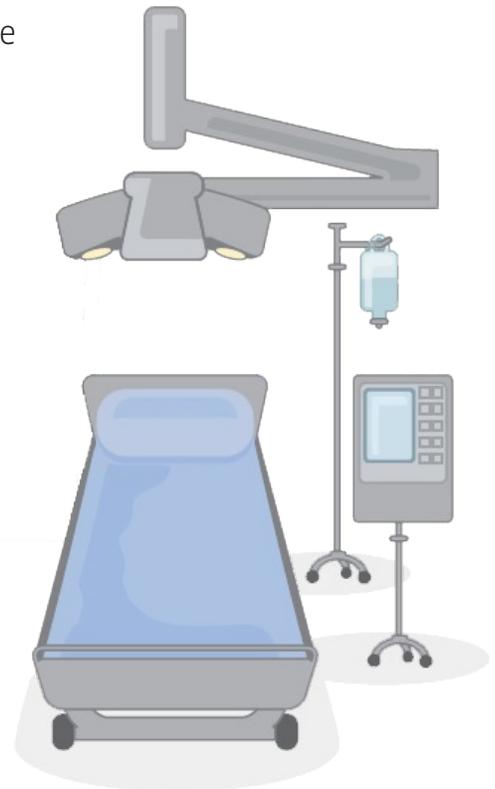
# Visiting the Emergency Room (ER)

If you have a fever or other emergency, your health care team may tell you to go to the Emergency Room. When you arrive in the Emergency Room, you or your parent should tell them:

- your type of cancer
- date of your most recent cancer treatment
- results of recent blood tests
- you must be seen right away for a fever and given antibiotics promptly
- you cannot wait in an area with other people who may be sick
- you cannot have an enema, suppository, or rectal temperature

Ask your health care team for a letter that explains your diagnosis and possible needs in the Emergency Room. You or a family member should bring this letter with you any time you go to any Emergency Room.

A Treatment Overview page is included in the beginning of this guide. You or a family member can use it to record your diagnosis and important treatment information, as well as who to call for help. Take the Treatment Overview page with you when you visit the Emergency Room.



# Fever

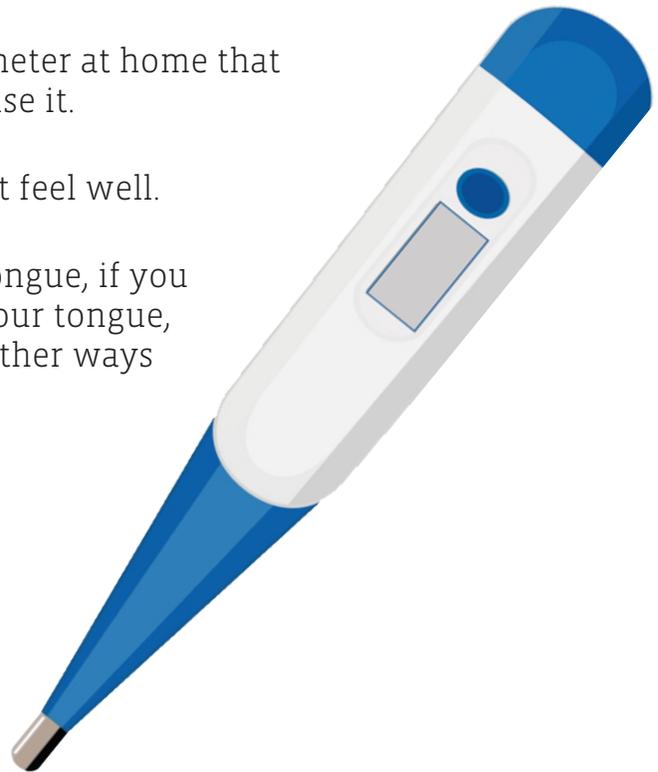
**A fever may be a sign of a serious infection.** People who receive cancer treatment are at high risk for getting serious infections. If you have a fever and do not get medical care right away, you could get very sick and this could be life-threatening.

- ◇ **Call your health care team immediately if you have a fever. Do not wait for the clinic to open.**
- ◇ **Do NOT take aspirin (salicylate), acetaminophen (Tylenol®), or ibuprofen (Motrin and Advil®) unless you are told to do so by your health care team.** Sometimes an infection can occur without fever. Any time you have chills or you are concerned that you do not feel well, even if there is no fever, call your health care team immediately. Do not wait for the clinic to open.

If you become ill or have a fever, there is a chance you will need to be admitted to the hospital for antibiotics and care.

## *Taking your Temperature*

- Make sure that you have a thermometer at home that works, and that you know how to use it.
- Take your temperature if you do not feel well.
- Take the temperature under your tongue, if you cannot take a temperature under your tongue, your health care team can review other ways to take your temperature.



# Managing Symptoms

Our goal is to keep you safe and feeling as well as possible during treatment. By understanding the side effects of treatment, you will know when to call the health care team for help. It is always OK to ask for help if you are not feeling well or are uncomfortable, whether you are in the hospital or at home.

## *Bleeding and Feeling Very Tired*

Chemotherapy can lower your blood counts. This can cause bleeding or make you feel very tired. Call your health care team if you:

- are very tired, pale, or have a headache or feel dizzy
- are bruising more easily than usual
- have small red dots on the skin
- have bleeding from the nose, gums, or around the central venous line. **Call your health care team immediately if you have bleeding that does not stop within 5 to 10 minutes.**
- if you are female and have changes in your menstrual period, such as heavier bleeding or bleeding that lasts longer than normal for you

To prevent bleeding, you may need to:

- avoid rough activities such as contact sports
- use a soft toothbrush
- avoid taking aspirin or ibuprofen during times when the blood counts are low
- use a clean electric razor when shaving your face, legs or underarms
- If you are female, your team may talk to you about taking medicine to stop menstrual bleeding

## *Pain*

Pain in people with cancer can be from many causes. Cancer cells in the body can cause bone or tissue pain. Some side effects of cancer treatment, such as mouth or skin sores, can be painful. Recovering from some surgery can also be painful. Call your health care team if you have:

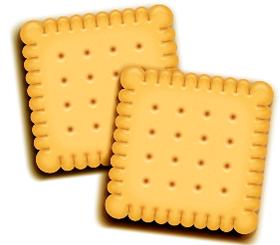
- new or increasing pain
- pain that is not getting better with the pain medicines you have been given to use at home

# Nausea, Vomiting, and Diarrhea

Cancer therapy can cause nausea and vomiting. You may be sent home with medicines to take at home to help with nausea and vomiting. There are many types of medications that can treat nausea and vomiting.

Many adolescents and young adults are curious about the benefits of marijuana (or medical cannabis) for treating nausea. Some medications that your health care team prescribes may include the main ingredient in marijuana/cannabis. These medicines may help to control nausea and increase your appetite. Follow the instructions on all medicines carefully. If you are using marijuana on your own, in any format (edible, oils, inhaled or others), you should let your health care team know. If marijuana is helping your nausea, it is important for your team to know so they can better treat your symptoms.

If you have nausea or vomiting, you can also try sips of cool, clear liquids or small bites of foods that are easy to digest, such as crackers or rice.



Diarrhea (frequent, watery bowel movements) can sometimes happen as a result of cancer therapy.

Vomiting and diarrhea can place you at risk for dehydration (not enough liquid in the body). **Call your health care team immediately if you have signs of dehydration, which may include:**

- dry mouth or lips
- no tears when crying
- urinating (peeing) less than normal
- dark urine (pee)
- having repeated vomiting or diarrhea
- not being able to drink fluids

## Constipation

Constipation is when you have hard stools (bowel movements) that happen less often than usual. Chemotherapy (such as vincristine) and other medicines (such as pain medicines) can cause constipation.

Follow the instructions for any medicines you are given to help with constipation at home. Call your health care team if you have:

- a change in your regular bowel movement pattern (not as often, not as much)
- pain when having a bowel movement
- hard bowel movement l even after giving medicine for constipation
- notice blood or bleeding when cleaning yourself after a bowel movement

## **Fertility**

Fertility is the natural ability to produce offspring (children). Some chemotherapy, surgery, radiation, and cancers may affect your ability to have your own biologic children someday. When possible, it is best to have a conversation with your healthcare team about fertility preservation before starting treatment. If no one on your healthcare team has discussed this with you yet, feel free to ask questions. For some adolescents and young adults, there are options to preserve fertility. These may include:

- Sperm banking (males)
- Egg preservation or ovarian tissue preservation (females)

## **Hair Loss**

Some kinds of cancer therapy may cause hair loss or thinning of the hair. Hair loss may begin 7 to 10 days after the treatment has started. Hair on the scalp and other parts of the body may also be affected. Some adolescents and young adults prefer to cut their hair as short as possible when the hair starts to fall out. Hair will usually grow back when the cancer treatments become milder, or when treatment is finished.

Coping with hair loss can be difficult. Talk to your health care team members about your feelings. Many people choose to wear wigs (which are available at little to no cost), hats, scarves and other head coverings. Though some choose to cover their heads during times of hair loss, others have shared that with the support they receive from staff, friends, and family, they feel empowered to be bald.

# Fatigue

Many young adults with cancer have fatigue (feeling tired or weak, not wanting to do things, not being able to focus, tiredness that affects your work, social life or daily routine) during and following treatment. Many things can cause fatigue, such as:

- Cancer treatment (surgery, chemotherapy, or radiation)
- Low blood counts
- Poor nutrition
- Fever
- Pain
- Not getting enough sleep
- Poor quality of sleep
- Worry or depression
- Trying to do too much
- Lack of physical activity
- Medications



## *Managing Fatigue*

Tell your health care provider if you are experiencing fatigue. It is helpful to be specific when you describe fatigue to your provider. For example, saying “I was so tired I could not go to school or work for two days” is more helpful than saying “I was really tired.” You can do many things to help fatigue.

- When possible, be physically active daily
  - ◊ This includes light exercise, like walking or riding a bike
- A physical therapist can help with an exercise program to increase your strength and endurance.
- If your appetite is poor, try to eat healthy foods every two to three hours while awake
- Try to make each snack as nutritious as possible. Talk to your dietician for ideas.

- Avoid caffeine
  - ◊ This includes tea, coffee, soda and energy drinks
- Have a regular bedtime routine
  - ◊ Try to avoid screens for at least 30 minutes prior to bedtime
- Get plenty of sleep each night
  - ◊ Recommended sleep for a healthy young adult is 7 or more hours/night
- A psychologist or counselor can help you with managing your worry or depressed feelings that may be affecting your sleep.
- If you are having pain that interferes with sleep, talk to your health care team.

It is important to know that it is normal to feel tired or weak after chemotherapy or radiation and that treatment can also change how you feel about your body, or can lower your sex drive. Some people also have trouble with erections or vaginal dryness, which can include pain. If you feel this way, you are not alone and can talk to your health care team about this.

## ***Physical Activity***

It is important to stay physically active while receiving cancer treatment. Being active not only helps your physical recovery, but can also improve your mood, lessen fatigue, and is a great way to connect with friends. Some activities may be limited or restricted depending on your type of cancer, treatment, or any medical devices that you may have (such as a port of G-tube). Talk to your health care team about what physical activity is best for you. Walking is generally helpful, with the goal of increasing steps and decreasing sedentary time (time spent sitting or lying down).



# Preventing Infection

Whether at school, work, home, or in your community, you will be exposed to germs. We all have germs on our skin and in our mouth and intestines (gut). Germs can also be found in the environment and in people with infections. People being treated for cancer cannot fight germs as well as healthy people. It is very important to take steps to prevent infection.

## Hygiene

The best way to prevent infection is to keep your hands clean. To prevent the spread of germs from one person to another, you should:

- wash your hands often with soap and water and/or use a hand sanitizer
- encourage family members, friends and visitors to wash their hands with soap and water and/or use a hand sanitizer when they are around you
- not share cups, water bottles, or eating utensils with other people
- not share a toothbrush with anyone
- bathe or shower regularly, daily if possible, as instructed by your health care team

It is especially important to wash hands after using the toilet and before:

- caring for your central line
- preparing your medicines
- preparing/eating your food

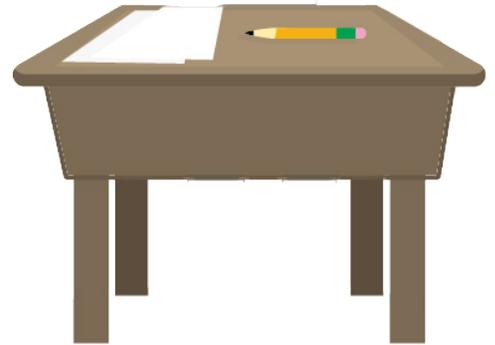


## ***Screen Friends for Infections***

We encourage you to continue to have visitors, including your friends. Be sure to ask ahead of time if the visitor or friend is sick or has been exposed to an infection. Anyone who has a fever, runny nose, cough, diarrhea, or rash should not visit you.

## ***School and Work***

Your health care team will talk to you about whether attending school and/or work are safe for you while receiving cancer treatment. If you are able to go to school, it is not “all or nothing”. You may be able to go some days but not all days, depending on how you are feeling. If you are in college, connect with the office of disabilities and chronic illness to find out what school accommodations are possible. Talk to your social worker about the best school plan for you.



If you are working, your social worker can work with you and your employer to see what options may exist for you to remain employed, as well as other options available to you. You may qualify for government or disability benefits to help support you when you cannot work.

It is important to remember, whether at school, work or in the community, if you are around people that have a rash, are coughing/sneezing, have a runny nose or have had vomiting or diarrhea, you should keep your distance. If you are not able to keep your distance, you may need to consider going home.

## ***Caring for Animals***

If you have a pet, you should not clean animal cages (such as a bird cage or turtle aquarium), empty cat litter boxes, or deal with animal waste. Animal waste may carry germs that can spread to you. If you live on a farm, talk with your health care team about any additional safety measures that may be needed when working with animals.

# Precautions During Treatment

## *Sexual Intimacy*

Having cancer does not mean that you cannot have sex. Cancer is not contagious – your partner cannot catch it from close contact such as touching, hugging, kissing or sex. As an adolescent or young adult, sexuality is a very important and normal part of your life. Having sex or being intimate is possible even with central lines, feeding tubes, or other devices, but there are important things to think about. It is important to talk to your healthcare team about your questions, concerns, and behaviors. Your health care team knows the treatment that you are getting and can talk to you about any risks related to your treatment plan.

Chemotherapy can remain in bodily fluids for up to 48 hours after the last dose, so it is safest for your partner to avoid exposure to body fluids until this time.

When your blood counts are low, you are at increased risk for infection and bleeding. Having sex during this time further increases your risk for infection, including sexually transmitted Infections (STIs). To protect yourself from infection, always use a condom or dental dam. Because your risk of infection is higher at times, it's important to treat any infection as soon as possible, and to be tested for STIs regularly. If you are interested in getting tested for STIs while undergoing cancer therapy, talk to your healthcare team.

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

If you use sex toys, wash them with hot soapy water every time you use them.

While some cancer treatment can affect fertility, pregnancy is possible. Women can get pregnant during and after treatment, and men receiving cancer treatment can get a female partner pregnant, whether he is on or off therapy.

Pregnancy when you have cancer can be very dangerous for both the pregnant woman and the developing baby because chemotherapy can cause birth defects. **It is very important to use protection with birth control medicine, devices and condoms. Talk to your healthcare team for more information on how to prevent pregnancy.**

It is important to know that it is normal to feel tired or weak after chemotherapy or radiation and that treatment can also change how you feel about your body, or can lower your sex drive. Some people also have trouble with erections or vaginal dryness, which can include pain. If you feel this way, you are not alone and can talk to your health care team about this.

## **Substance Use**

### **SMOKING**

Cancer treatment can have effects on the heart or lungs, and surgery and radiation can affect the way your lungs function. Tobacco (in all forms, including traditional cigarettes, e-cigarettes/vaping, chew, and hookah pipes) can also affect the heart and lungs. To protect your heart and your lungs and to decrease your risk of getting other cancers you should never use any tobacco products.

### **DRINKING ALCOHOL**

Chemotherapy and other medicines that you take for cancer treatment may react with alcohol. Alcohol can also put an extra strain on your liver. If you drink alcohol during your cancer treatment, you may need extra blood tests and monitoring to make sure your liver is healthy. You could have delays in your cancer treatment if your liver is hurt by the combination of alcohol and cancer treatment.

### **DRUG USE**

During your cancer treatment you may be given prescription medications to help with side effects. It is important that you only use these medications for the purpose they were prescribed, and only when needed. Taking street drugs or drinking alcohol while on chemotherapy or while taking medication

for your cancer treatment can cause dangerous side effects. Interactions between your chemotherapy and street drugs can seriously affect your organs and can even lead to death. If you are using or thinking about using street drugs, please talk to your health care team. You may be thinking of using drugs or alcohol to help with nausea, vomiting, decreased appetite, anxiety, pain, or to get away from your problems. There are many ways to help deal with the side effects and stress of undergoing cancer treatment and it is important that your health care team can help you through this tough time.



## Safety

### DRIVING

Ask your health care team if you should avoid driving at any time during treatment (after procedures, if you have seizures, and for other reasons). If you have been told that it is okay to drive during treatment, make sure to avoid driving after taking any medicines that may make you tired or feel loopy (such as ativan, benadryl, marinol, pain medications). Always wear your seatbelt when getting in a car, whether you are the driver or a passenger. Never text or talk on the phone while driving! Wear a helmet when biking, riding an ATV, motorcycle or snowmobile.

### TATTOOS AND BODY PIERCINGS

It may be okay for you to get a tattoo or body piercing, but it is important to plan this for a time when you are not at risk for infection or bleeding and your body can heal properly. Talk to your health care team about the best time to plan to get a tattoo/piercing. They may suggest that you wait until you finish treatment. If you choose to get a tattoo or body piercing, go to a

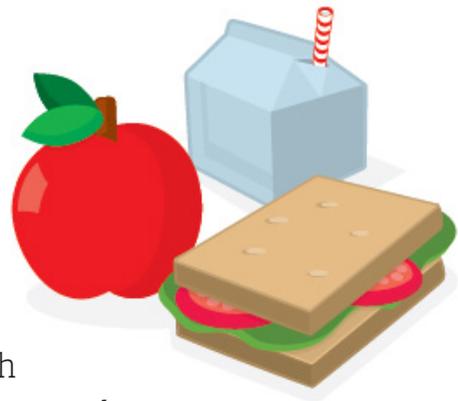
licensed tattoo/piercing parlor. Going to an unlicensed shop or having a friend give you a tattoo/piercing increases your risk for infection, including HIV or Hepatitis B which can be deadly. If you already have piercings, you must watch them closely during your cancer treatment for any redness, swelling, pus, or increase in pain. If you notice any of these signs of infection, talk to your healthcare team.

## **SUN SAFETY**

Chemotherapy and other medicines make your skin extra sensitive to the sun, and you can get sunburned more easily. Medications you may be taking can also make your skin more sensitive to the sun. If you are in the sun, even for a short period of time, use sunscreen and reapply as needed. Wear a hat when out in the sun, and if it is not possible to keep your head covered, use sunscreen on your head. Avoid using tanning beds and lamps. You will need to follow your treatment teams' direction if receiving radiation or any other treatment that might affect your skin.

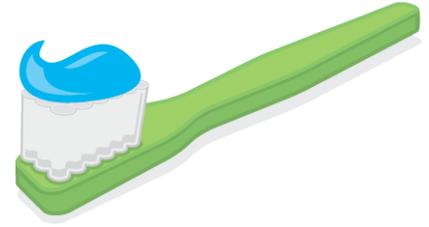
## **Nutrition**

Try to eat healthy foods when possible, including foods which contain vitamins and minerals. Protein is also important for cell repair and development and building and maintaining muscle mass. Good sources of protein include eggs, meat, milk, cheese, yogurt, and peanut butter. Include foods high in fiber such as fruits, vegetables and whole grains. These foods can also help you deal with issues like constipation. Drinking water is good for hydration and in general helps keep everything moving. Your healthcare team can talk to you about a nutrition plan that meets your body's specific needs, as your needs may change throughout treatment. Nutritional supplements, vitamins, and herbs can prevent some cancer drugs from working. Please talk with your health care team if you are interested or currently taking nutritional supplements.



## Dental Care

Keep your teeth, mouth, and gums clean. You should brush your teeth after each meal and before bed with a soft toothbrush and toothpaste. Mouth rinsing (swishing and spitting) with water after eating is also very helpful to keep your mouth clean. Check with your health care team before seeing the dentist.



## Vaccinations

Some vaccines should not be given while you are receiving treatment. Flu shots are usually recommended for you and all family members. Talk to your health care team before you receive any vaccines.

## Varicella (Chickenpox or Shingles) Exposure

If you have been in contact with anyone who has the chickenpox or shingles, call your health care team immediately. It is possible you will need to get a medicine to protect against chickenpox. For this medicine to work, you must get it as soon as possible after contact.

## Chemotherapy Safety

Chemotherapy leaves the body through urine, stool, and vomit. Because of this, while you are receiving chemotherapy and for 48 hours after the last dose, it is important to take the following precautions:

- ◇ Close the lid and flush twice after each time you use the toilet
- ◇ Wash clothes or bed linens that have been soiled with body waste separately from other laundry using hot, soapy water. Then wash them again with your regular laundry.
- ◇ If soiled clothes or bed linens cannot be washed right away, keep them in a sealed plastic bag.
- ◇ Dirty items that are not soiled with body waste can be touched and washed as usual.
- ◇ Avoid sexual activity during this time so as not to expose your partner to bodily fluids
- ◇ When possible, women who are pregnant or breastfeeding should avoid touching your body waste during and for 48 hours after you have received chemotherapy. If it is necessary for a pregnant woman to handle soiled items during this time, they should wear disposable nitrile gloves.

## ***Central Venous Line Emergency Care***

If you have a PICC or external central venous line, never use scissors near the line or dressing. If you see a break or leak in the line, clamp the line above the break right away. Call your health care team and go to the hospital or clinic to have the line fixed.

## ***Precautions for Patients with Brain Tumors and/or Shunts***

If you have a brain tumor or a shunt, call your health care team immediately if you have:

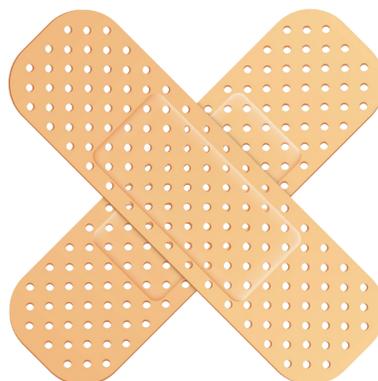
- ◇ Severe or repeated headaches
- ◇ Repeated vomiting
- ◇ Extreme sleepiness
- ◇ Irritability
- ◇ Confusion
- ◇ Swelling or redness along the shunt tract

You or your friends or family should call Emergency Services (“911” in the U.S. and Canada) immediately if you have:

- ◇ Seizure (and you have NOT been told that a seizure can be managed at home)

## ***Postoperative/Wound Care***

If you have had surgery, the nurse can show you how to care for the wound and to change the bandage if needed. Generally, it is important to keep the area clean and dry, and to protect the wound from stress (such as rough activities) until it is fully healed.



# School, Work, and Friendships

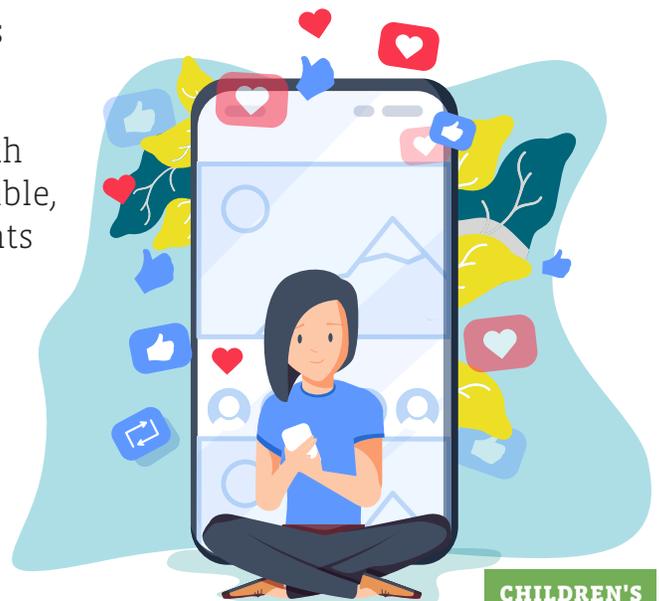
It can be challenging to figure out how to explain your cancer or treatment to your friends, classmates or co-workers. It's up to you to decide who you will tell about your cancer and how you tell them. Some people use social media as a way to keep friends and family informed, others keep things very quiet. There is no right or wrong way to share your story. You may find it helpful to keep close friends informed about what you are going through and to tell your friends what you need from them. Your health care team can help you figure out what feels best for you.

There may be times when you have to miss social events or gatherings with your friends because you aren't feeling well or because you are in the hospital. You can ask to be included in some way via video calling, or by inviting your friends to spend time with you at home or in the hospital. Many young people feel that having at least one close friend to talk to is helpful. Talk to your health care team about having friends visit in the hospital and/or coming with you to clinic visits.

It is very normal during cancer treatment to sometimes feel too tired to think and concentrate, especially on school work. This might mean that you will need to take a break from school, or do less course work. Thinking about missing school and getting "off track" at school can be very upsetting. It is very important to talk about your school plans with your health care team, and in particular your social worker.

It is normal to feel like you don't have control of your life when you are receiving cancer treatment. There are things you can do to take back some control.

- Maintain routines and activities as much as possible.
- Ask your health care team for flexibility with timing of treatment and testing when possible, so you can participate in social/school events that are important to you.
- Keep up with school and/or work to the best of your ability.
- Accept help from friends and family but be honest when you need time alone.



# Taking Medicines

It is important to understand the reason for each of your medicines, and how to take each of them correctly. The main types of medicines are for:

- Treatment of cancer (some young people will take these medicines at home)
- Prevention of complications (such as infection)
- Management of symptoms (such as pain and nausea)

Before you go home, you will receive a list of your medicines. Be sure that you know:

- The name of each medicine
- What each medicine is for
- How much medicine to give
- When to give the medicine
- How to give the medicine



It is best to pick up your medicines from the pharmacy before you go home so that you can review them with your health care team. If you are not able to pick up the medicines before you go home, be sure you know where to get the medicine, and what to do if the pharmacy is unable to get any of your medicines for you.

If you have trouble taking medicines or cannot swallow pills, tell your nurse or doctor. Your nurse or child life specialist may also be able to help you learn and practice how to swallow pills. Talk to your health care team about what to do if you vomit a dose of medicine at home.

After you go home:

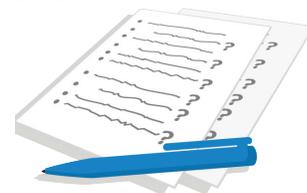
- Bring your medicines and medicine list with you each time you come to the clinic, hospital, or Emergency Room.
- Let your health care team know right away when your supply of any medicine is running low.
- Keep your medicines locked in a safe place, out of reach of children and pets.

# Resources for AYA with Cancer

## **American Cancer Society**

Resource to get answers to your questions about cancer, find links to a great deal of related information, and search specific types of cancer in order to make informed treatment decisions.

<https://www.cancer.org/treatment/understandingyour-diagnosis.html>



## **AYA Advocacy/Education Portal**

- 15 to 40 Connection: a growing national organization dedicated to improving cancer survival rate through the power of early detection.  
<https://www.15-40.org/>
- Seventy K: Utilize programs that offer patients unique experiences using technology, education and imagination to improve your journey from diagnosis to wellbeing.  
<https://reimaginewell.com/>
- Ulman Foundation: Offer a community of support for young adults and their loved ones impacted by cancer.  
<https://ulmanfoundation.org/>
- NIH: Offers links to resources for questions about cancer, treatment, clinical trials, and issues that may be faced after treatment. It also contains links to research studies and reports.  
<https://www.cancer.gov/types/aya>

## **Q&A for Young Adults with Cancer**

Learn more about the challenges and issues AYA patients face in this booklet from MD Anderson's Young Adult Advisory Council.

[www.mdanderson.org/aya](http://www.mdanderson.org/aya)

## **National Comprehensive Cancer Network (NCCN)**

- AYA Care Guidelines  
<https://www.nccn.org/patients/guidelines/content/PDF/aya-patient.pdf>
- AYA Guidelines for Patients  
<https://www.nccn.org/patients/guidelines/aya/index.html#71/z>

## **Teen Cancer America**

Aims to educate and support medical institutions and health care professionals in the development of specialized AYA cancer care units.

<https://teencanceramerica.org>