



Let's talk about

CHILDHOOD

CANCER

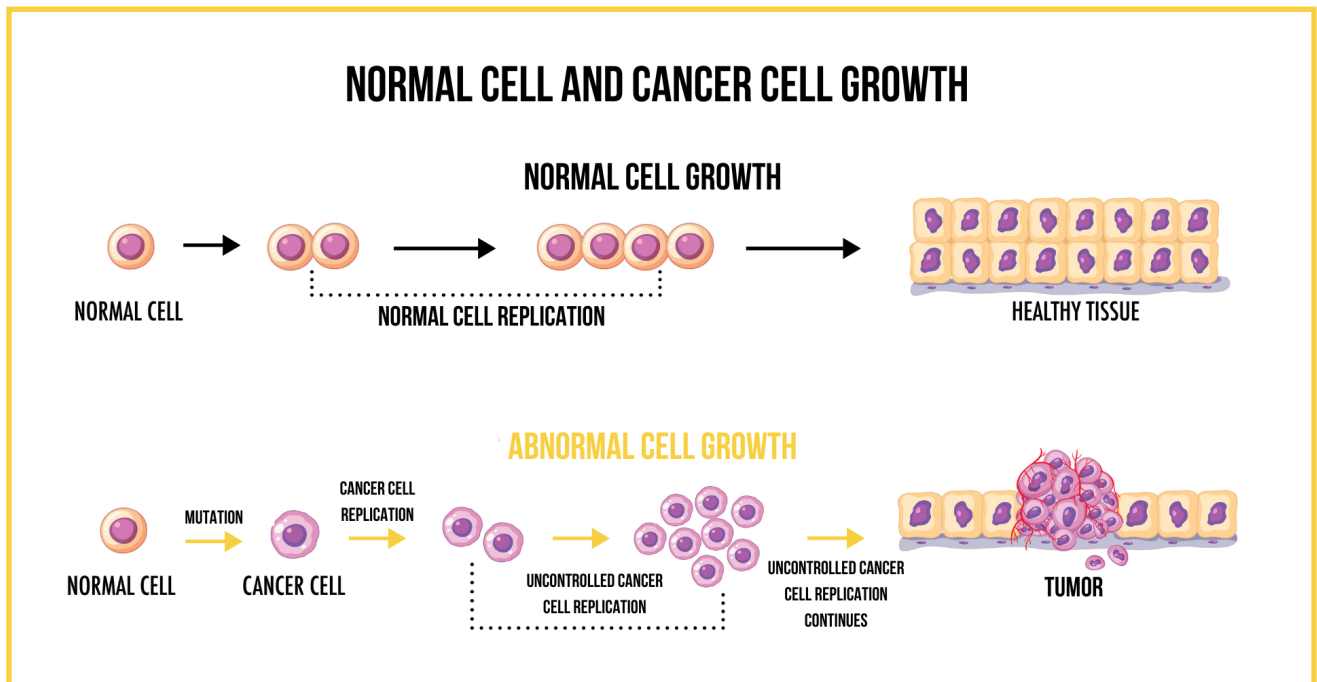
LEARN. FIGHT. HOPE.

A Guide for Patients and Families

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WHAT IS CANCER?

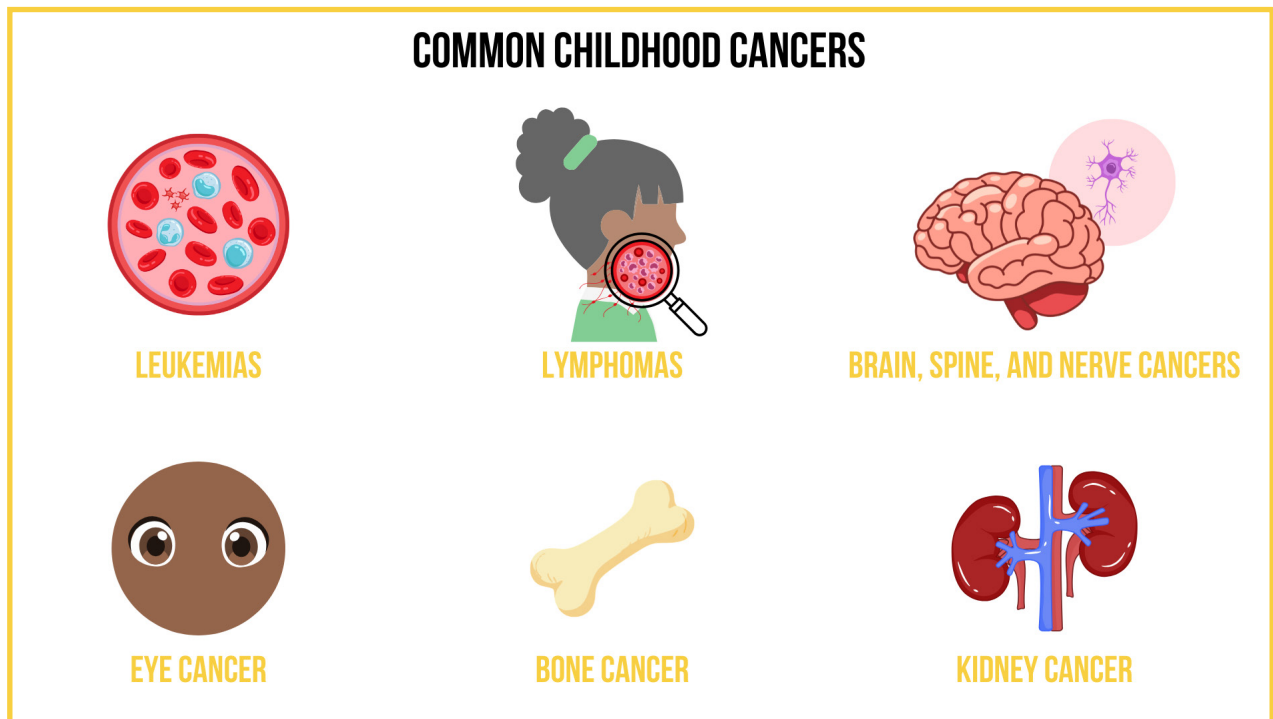


Cells are the building blocks of the human body. Each cell contains instructions that determine what the cell will become (for example, bone cells, skin cells, or muscle cells) and how fast the cell can grow.

Cancer is caused by errors (also called **gene mutations**) in the cell's instructions that cause the cell to grow and reproduce uncontrollably. This out-of-control cell growth can form tumors (abnormal growths). Cancer may spread to other parts of the body – called metastasis – but does not spread from person to person and is not contagious.

Cancer is the **second most common cause of death worldwide**, behind heart disease. Despite that, more people than ever are surviving cancer, thanks to new treatments, better prevention and awareness efforts, and early diagnosis.

WHAT IS CHILDHOOD CANCER?



All cancer begins when abnormal cells grow uncontrollably. Depending on where those cells are in the body, they either form masses (tumors) or circulate in the blood.

While any cancer affecting a child or young adult (aged 0-19 years) is considered a childhood cancer, the types of cancer that affect children are typically different from those that affect adults.

Many childhood cancers are blood cancers, including leukemias and lymphomas. They form in the blood, bone marrow, or lymph nodes.

Childhood cancers can also develop in other parts of the body, including the brain and spinal cord, muscles and soft tissues, bones, kidneys, eyes, and nerves. Different types of cancer behave differently, including how they grow, how they are diagnosed, and the treatment options available.

WHAT CAUSES CHILDHOOD CANCER?

Doctors do not know why some children get cancer and others do not. The causes of childhood cancer are not fully understood; however, some common childhood cancers are caused by gene mutations that can happen even before birth. Only a few factors are known to increase a child's risk of developing cancer, including radiation exposure, and some inherited syndromes.

RISK FACTORS FOR CHILDHOOD CANCER

A risk factor is any condition or behavior that increases the chance of developing cancer at some point in your lifetime. Some children with risk factors may never develop cancer, while others with no risk factors do get cancer.

RADIATION EXPOSURE: Children are more sensitive to radiation, so it is critical to limit a child's radiation exposure as much as possible. Radiation exposure can cause cancer both early and later in life. Children can be exposed to radiation through environmental sources, medical imaging tests, and radiation therapy during cancer treatment.

CHRONIC INFECTIONS: Certain infections can be a risk factor for childhood cancer, such as HIV, Epstein-Barr virus, and malaria.

INHERITED SYNDROMES: Certain genetic syndromes, such as Down syndrome, can increase a child's risk of developing specific types of cancer.

TYPES OF CHILDHOOD CANCER

Childhood cancer is classified based on the characteristics of the cancer cells (such as cell shape, size, and arrangement) and where they are located in the body. The three main categories of childhood cancers are (1) leukemias and lymphomas, (2) central nervous system (CNS) tumors, and (3) other solid tumors.

LEUKEMIAS AND LYMPHOMAS: These cancers begin with the growth of abnormal blood cells in the body. Common types include acute myeloid leukemia (AML), acute lymphocytic leukemia (ALL), Hodgkin lymphoma, and non-Hodgkin lymphoma.

CENTRAL NERVOUS SYSTEM (CNS) TUMORS: These cancers originate in the brain or spinal cord and are classified based on the type of cells involved, tumor location, and growth rate. Common types include gliomas, medulloblastomas, and ependymomas.

OTHER SOLID TUMORS: This category includes cancers that are not blood cancers and are not CNS tumors, such as neuroblastoma, Wilms tumor, retinoblastoma, germ cell tumors, and sarcomas.

CHILDHOOD CANCER CLASSIFICATION

When your child's cancer is diagnosed, the doctor may assign the cancer a "stage" or "grade". These are ways to describe the cancer based on the size of the tumor, how far it has spread, and how the cancer cells appear under a microscope.

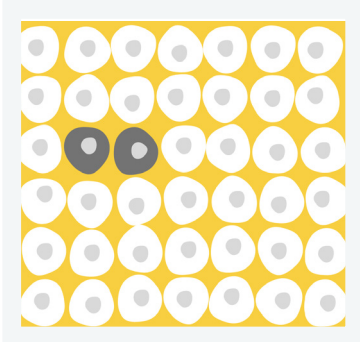
Many childhood **solid tumors** are classified using a Stage 1 through 4 system, which describes the cancer's size and spread (see illustration below). In general, lower-stage cancers are more localized to one area of the body, and higher-stage cancers have spread beyond their original site.

Leukemias and lymphomas often use a different classification system based on factors such as the type of cancer and the extent of its involvement in the blood, bone marrow, lymph nodes, and other parts of the body.

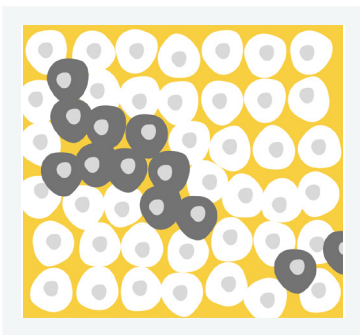
CNS tumors are not classified using a traditional staging system because these tumors rarely spread outside of their original area. Doctors typically assign a grade based on how the tumor appears under a microscope and how quickly it grows.

The stage and grade of your child's cancer at diagnosis will help determine which treatments are recommended. The exact treatment used depends on the type of cancer.

BASIC CANCER STAGING

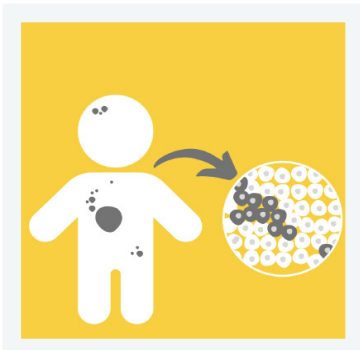


STAGE 1: Cancerous cells have been detected in one area or region of the body.



STAGE 2: The cancer has spread to neighboring tissues but has not spread to more distant areas of the body.

STAGE 3: Stage 3 indicates that the cancer has spread even more into neighboring tissues as well as the lymph nodes.



STAGE 4: Stage 4 is characterized by cancer that has spread to parts of the body that are distant from the original cancer site. Stage 4 cancers are also called **metastatic cancer**.

PROGNOSIS

Once your child is diagnosed with cancer, one of the first questions you might ask the doctor is “**What should we expect next?**” That largely depends on your child’s **prognosis**. A prognosis describes what doctors expect may happen with the cancer, including how it may respond to treatment. The prognosis can be used to help families and health care providers make informed decisions about treatment and care.

Prognosis is influenced by the cancer’s type and stage, your child’s age, and how well the cancer responds to treatment. Prognosis is sometimes expressed as a survival rate. The overall survival rate for a certain type of cancer reflects the percentage of people diagnosed with the same type and stage of cancer who have completed treatment and are still alive after a set amount of time, usually five years. For example, an overall 5-year survival rate of 68% means that 68 out of 100 people diagnosed with that type and stage of cancer are still alive five years after diagnosis.

Many factors can impact prognosis and survival rate, including:

- The type of cancer present
- Classification or extent of the cancer at diagnosis (see Page 7 for more info on childhood cancer classification)
- A child’s age at diagnosis
- A child’s response to cancer treatment

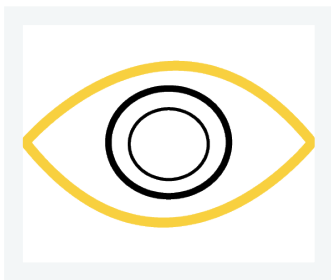
Different treatment options can impact survival rates for your child’s type and stage of cancer. Reviewing these statistics can help your doctor determine which treatment is best. It is okay to ask your child’s doctor not to share the cancer’s typical survival rate if you do not want to know. Some caregivers and families find that information helpful, while others do not.

Once you and your child’s doctor decide on a treatment plan, it is important for your child to **continue treatment** unless you discuss switching or stopping with the care team first. Cancer treatments are carefully calculated, and delaying or stopping before a treatment is completed can give the cancer a chance to progress, which can negatively impact your child’s prognosis.

CHILDHOOD CANCER SURVEILLANCE AND TREATMENT OPTIONS

Childhood cancer can be treated in many ways depending on the type of cancer, the prognosis, and other factors. It is important to talk to your child's doctor to determine the treatment plan that is best for your child.

SURVEILLANCE



Surveillance is most commonly used for children at higher risk for developing cancer. For example, children diagnosed with certain syndromes may be more likely to develop specific types of cancer. Syndromes that can increase a child's cancer risk include Down syndrome, Turner syndrome, Beckwith-Wiedemann syndrome, and Li-Fraumeni syndrome. During the surveillance stage, no active cancer treatment is provided.



ACTIVE SURVEILLANCE: Active surveillance typically involves imaging tests, blood and urine tests, and other clinical exams that can detect cancer early. The frequency of tests will vary depending on each situation and the recommendations of your child's doctor.

SURGERY



Surgery is a common form of treatment for many solid tumors. The type of surgery and whether surgery is helpful depends on the stage and location of the cancer.

RADIATION THERAPY



Radiation therapy is a treatment that uses rays of energy to destroy cancer cells. It is commonly used to treat solid tumors, quite often in combination with surgery or chemotherapy. If used before surgery, it is called neoadjuvant therapy, and the goal is to shrink the tumor's size. If used after surgery, it is called adjuvant therapy, and the goal is to kill any remaining cancer cells. Radiation therapy can also be used as part of palliative treatment regimens, which are treatments that address symptoms

rather than the cancer itself. The most common type of radiation therapy for childhood cancer is **external beam radiation therapy (EBRT)**, in which radiation beams outside the body are directed at the tumor.

TARGETED DRUG THERAPY



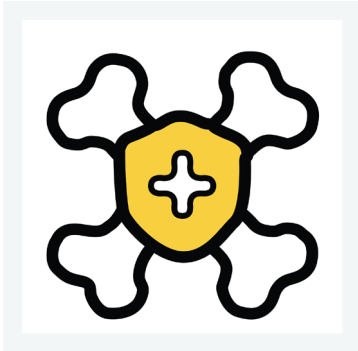
Targeted therapy works by targeting specific parts of cancer cells that control how the cancerous cells grow and spread. Targeted therapies damage the cells, with the goal of slowing or stopping the growth of the tumor.

CHEMOTHERAPY



Chemotherapy is a treatment that uses special drugs to destroy the cells in the body that are reproducing the fastest. Because cancer cells grow and divide much more rapidly than most other normal cells in the body, chemotherapy is often an effective way to kill cancer cells. Chemotherapy drugs are usually given through a tube into the vein, known as an IV, but some forms of chemotherapy are given in pill form. As with radiotherapy, childhood cancer patients often receive chemotherapy before or after surgery.

IMMUNOTHERAPY



Immunotherapy is a treatment that uses the immune system to fight cancer. Immunotherapy cancer treatments include: monoclonal antibody drugs (biological therapy), immune checkpoint inhibitor drugs, and more complex therapies such as T-cell transfer therapy. Your child's doctor may perform special tests to determine whether immunotherapy is right for your child.

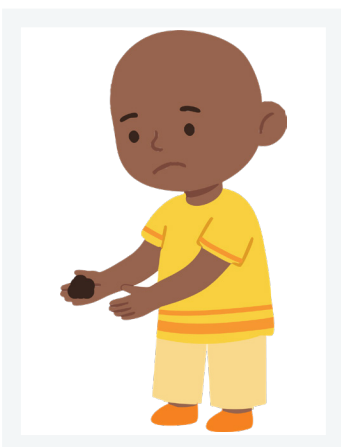
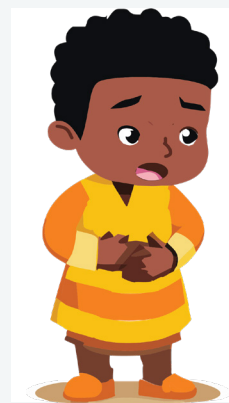
CHILDHOOD CANCER TREATMENT SIDE EFFECTS

Childhood cancer patients can experience side effects that develop because of the treatments received. If your child is undergoing treatment and starts experiencing a new side effect, it is important to let your child's doctor know right away. Your child's care team will be able to give you recommendations on how to manage your child's side effects. This may even include pausing or switching treatments to give your child's body a break.

Potential side effects of childhood cancer treatment fall into two categories: short-term and long-term side effects.

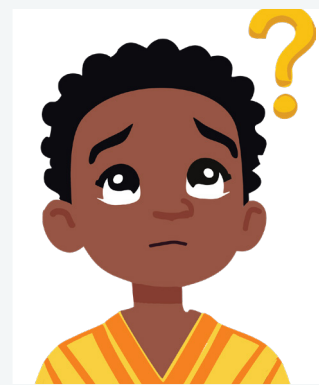
SHORT-TERM SIDE EFFECTS

GASTROINTESTINAL DISTRESS: Vomiting, nausea, constipation, and diarrhea are common side effects of chemotherapy. Nausea is when your stomach feels like you might throw up. Certain chemotherapy medications, foods, and smells can make nausea worse. Some signs of constipation include painful bowel movements or having fewer than three bowel movements per week. Frequent, loose, or watery bowel movements may be a sign of diarrhea.



HAIR LOSS: This is a side effect of chemotherapy. Chemotherapy targets the cells in the body that are growing the fastest. Hair cells are some of the fastest-growing noncancerous cells in the body, so chemotherapy will often affect these cells, causing hair loss. Your child's hair will typically grow back after chemotherapy treatments are complete.

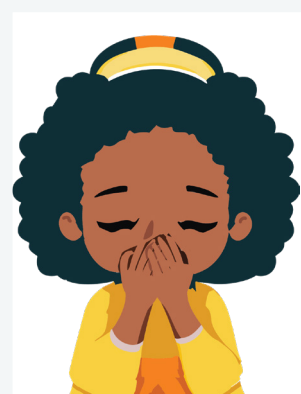
TIREDNESS: Your child may experience tiredness from the cancer treatment they receive, or they may feel tired from the cancer itself.



DIFFICULTY WITH LEARNING AND MEMORY:

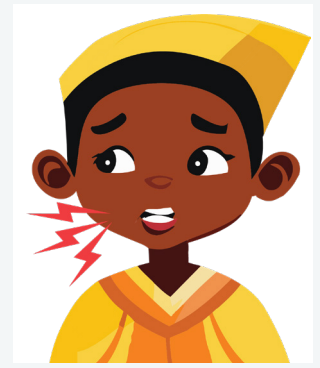
Chemotherapy and other treatments can negatively impact your child’s memory, concentration, and your child’s ability to learn new skills or problem solve. This is commonly referred to as “chemo brain”. These changes typically resolve once treatment ends, but in rare cases they can become long-term issues. Your child’s care team and school can help identify additional support and resources, if needed.

NERVE DAMAGE: Nerve damage, also referred to as neuropathy, is a side effect of certain chemotherapy drugs. Nerve damage most commonly occurs in the hands and feet and can cause weakness, loss of feeling (numbness), tingling sensations, sensitivity to cold, or pain. It may be temporary and resolve on its own, or it may be permanent.



LOSS OF APPETITE: Cancer treatment or the cancer itself can impact your child’s appetite. This is a short-term side effect, and your child’s appetite will return to normal eventually. Not consuming sufficient calories will contribute to increased feelings of tiredness.

MOUTH AND THROAT SORES: During treatment, you may notice little sores or scratches, swelling, white or yellow patches, or bleeding in your child's mouth, gums, or throat. They may cause discomfort when your child eats and swallows, as a sore throat would. If your child is experiencing this, it is important to talk to your child's doctor so their symptoms can be addressed.



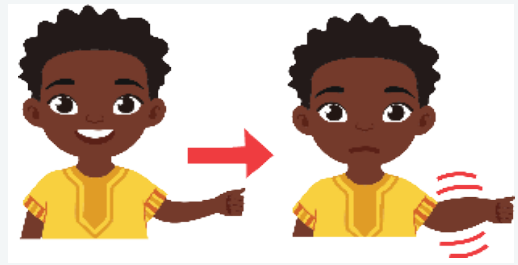
REDUCED IMMUNE FUNCTION: Children receiving cancer treatment often are at a higher risk of getting sick from infections. The cancer itself, as well as many treatment options, can weaken your child's immune system and make them more susceptible to infections. Your child's immune system should return to normal within a year of treatment ending.

HAND AND FOOT SYNDROME: Hand and foot syndrome causes redness, peeling skin, and pain in the hands and feet, particularly on the palms and soles.



SKIN AND NAIL CHANGES: Your child's skin may become drier than normal, more susceptible to sunburns, more prone to rashes, and itchy. Your child's nails may become more brittle, darken, or develop ridges due to the type of treatment they receive. These changes should all subside after treatment is finished.

LYMPHEDEMA: Lymphedema is a type of swelling that results from a buildup of fluid in the space between the skin and muscles. The most common areas to be affected by swelling are the legs, arms, head, and neck. Lymphedema often occurs after surgery or radiotherapy, either immediately or in the months and years that follow. If not managed properly, lymphedema can become a long-term condition.



LOW RED BLOOD CELL COUNT: Some cancer treatments can cause a decrease in the amount of red blood cells in the body, leading to a low red blood cell count (anemia). This may make your child feel dizzy, weak, short of breath, or more tired than usual.

BRUISING AND BLEEDING: Platelets are small blood components that help the body form clots and stop bleeding. Chemotherapy can lower the number of platelets in the body, which may lead to easy bruising, small red or purple spots on the skin, bleeding gums, or prolonged bleeding.



LONG-TERM AND LATE SIDE EFFECTS

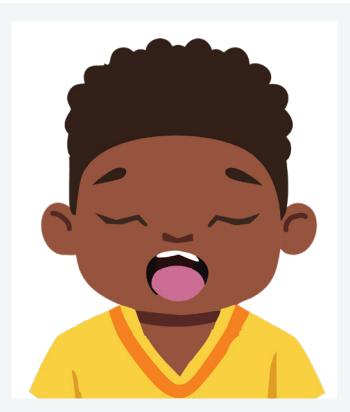
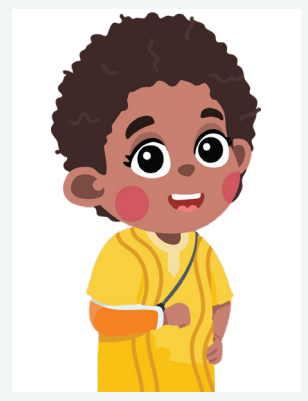
Many survivors of childhood cancers do not experience lasting health problems from their cancer treatment. However, some survivors may develop **long-term side effects** (those that begin during treatment and continue afterward) or **late effects** (those that develop months or years after treatment).

These may include:



LOSS OF FERTILITY: Cancer treatment can impact your child's ability to have children later in life. You should talk to your child's doctor before they begin treatment to learn how treatment may impact your child's fertility. Some cancer treatments only cause temporary infertility while other treatments may result in permanent infertility.

LOSS OF BONE DENSITY: Certain types of cancer treatment can sometimes reduce blood supply to nearby bone cells. This can make your child's bones more susceptible to breaks and fractures in the long term.



DENTAL CONDITIONS: Chemotherapy and radiation treatment can impact your child's teeth and gum health, leading to a higher risk of cavities, missing or small teeth, gum disease, delayed tooth development, and dry mouth.

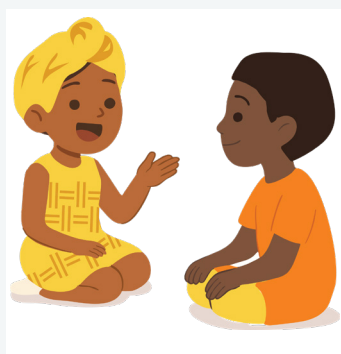
SIDE EFFECTS MANAGEMENT

Before beginning treatment, it is important to talk to your child's doctor about what side effects they may experience. This will allow you to plan ahead and know what is considered normal, what to watch out for, and how to manage any side effects your child experiences. Additionally, you may be able to take action to prevent or reduce the severity of some of your child's side effects.

MANAGING TIREDNESS

Extreme tiredness, which your child's doctor may refer to as fatigue, is the most common symptom for cancer patients. Fatigue can affect your child both physically and mentally, including their ability to be social and complete normal activities.

Behavioral strategies can help your child cope and make the most of the energy that they have. Strategies that you can use to help your child include:



ENCOURAGING SOCIAL CONNECTIONS

Your child may feel isolated from their friends and other children when they have to spend time in the hospital. This can contribute to feelings of sadness and disconnection. Encourage your child to stay in touch with friends through phone calls, or if your child's doctor deems it safe, by inviting friends to visit. You

can also encourage them to make friends with other children in the hospital who are undergoing treatment.

KEEP PLAYING

Play is an important part of childhood and can help your child cope with the stress of cancer treatment. It provides your child with an opportunity to express how they're feeling while also helping them to maintain a sense of normalcy during a challenging time. Simple activities like drawing, coloring, singing songs, reading books, playing games, and spending time with siblings and other children can help to improve your child's mood, reduce stress, and provide a sense of hope during cancer treatment.





PRIORITIZING PHYSICAL ACTIVITY: Engaging in physical activity is an effective way to prevent muscle loss and give your child more physical energy. Exercise can be as simple as walking, dancing, or playing a ball game. Talk to your doctor about how your child can safely exercise while undergoing treatment.

EMBRACING NATURAL LIGHT: Open window coverings to let natural light into your home and try to encourage your child to spend time outside every day. Spending time outside does not mean that your child needs to be active. Your child can just sit outside on a bench or relax under a tree to expose their body to natural light.



PLANNING YOUR CHILD'S DAYS: It might be helpful to record your child's symptoms and note what helps their tiredness, what makes it worse, and if there are certain times of day when they feel their best. With this knowledge, you can plan your child's days and try to line up activities requiring stamina with your child's windows

of energy. Focus on activities that are essential or that make your child happy and ensure that you also plan regular breaks for your child to rest.

EATING WELL

Diet is important because the food your child eats is responsible for providing their body with energy to fight cancer. Eating well can also help fight tiredness. Focus on offering your child lots of vegetables, protein, and prioritizing extra calories. Cancer treatments such as chemotherapy may alter your child's sense of taste and smell, which can impact their appetite. It is important to be aware of this so that they can continue eating well.

Many treatments for childhood cancer, especially surgery or certain types of radiation treatment, may temporarily alter your child's ability to digest food. Be sure to discuss this with your child's doctor to see if they recommend food guidelines for their specific treatment type. If your child is struggling with eating, try to incorporate the following:



TRYING NEW FOODS: Foods that your child has never liked in the past may appeal to them while they are undergoing treatment.

BALANCED DIET: Getting enough protein, complex carbohydrates, fruits, and vegetables in your child's body is important for them to stay strong. Good sources of complex carbohydrates include oat porridge, sweet potatoes, lentils, and beans. For high-protein foods, try adding eggs, meat, and fish into your child's meals.



EATING SNACKS: Eating throughout the day can help your child take in more calories than eating only at mealtimes and can be helpful in controlling nausea. It is good to eat every few hours.

TIMING FLUIDS: Drinking while you eat a meal can make you feel too full to continue eating, so try and encourage your child to drink their fluids after finishing their meals or between meals instead.

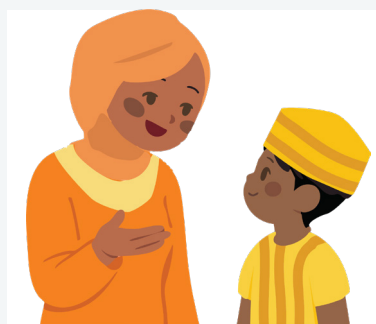


Talk to the doctor if your child is having trouble with their appetite. They can provide you with additional resources and advice that are specific to your child's situation.

PAIN MANAGEMENT

Pain is a common side effect of cancer that can be caused by the cancer itself or the treatment your child is undergoing. The pain your child experiences may be dull, tingly, achy, or sharp. It can be a constant presence, or it may come and go. It may change in intensity as well.

Some tools to help manage your child's pain are listed below:



EXPLAINING TREATMENT: Fear and anxiety can make pain feel worse. Before a procedure or treatment, explain to your child what will happen using simple and honest explanations that they can understand. You can show them with a toy or demonstrate what will happen, if appropriate. Knowing what to expect and having a trusted caregiver nearby during the procedure can help children feel calmer and may reduce their pain and distress.

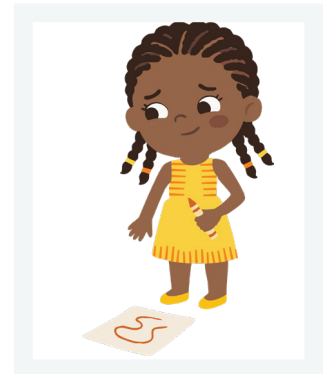
TALKING TO YOUR CHILD'S DOCTOR: It is important to talk to your child's doctor if their pain level changes, or if you want to alter the amount of pain medicine they are taking. There are options available to treat pain that your child's doctor can prescribe. Sometimes multiple medications are necessary to get the pain under control.





MOVEMENT: Various non-pharmaceutical therapies, like massage, can also be used to help manage your child's pain. Physical therapy exercises can also be used for pain that goes away with increased muscle strength.

DISTRACTION: It can help to distract your child to keep their mind off any pain they might be experiencing. Try using toys, games, songs, stories, or funny videos to keep your child focused on something enjoyable. You can also practice guided imagery by encouraging your child to imagine a favorite place or pleasant scene and focus on what they might see, hear, smell, and feel instead of the pain.



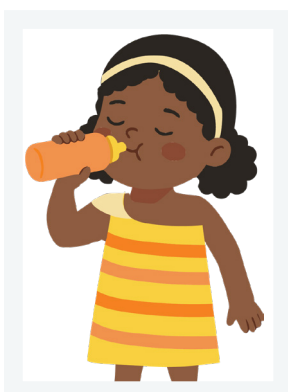
CONTROLLING NAUSEA & VOMITING



Many cancer treatments can cause nausea and/or vomiting. It is important to talk to your child's doctor if they are experiencing nausea or vomiting because your doctor can help find a medicine to control symptoms. Many patients are prescribed an anti-nausea medication to take daily.

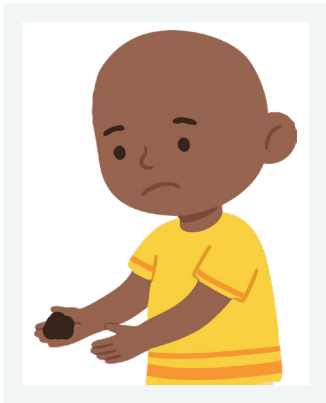
Similar to other side effects, tracking when your child's nausea and/or vomiting are worse can help your care team determine the best course of treatment. Pay attention to what foods or types of food (for example, sugary, greasy, fried, or spicy) impact your child's nausea.

STAYING HYDRATED



If your child experiences severe nausea or vomiting, it will impact their ability to stay hydrated. Dehydration is a state in which the body does not have enough fluids, which may lead to headaches and tiredness. To avoid dehydration, make sure your child drinks water or other clear liquids throughout the day. Talk to your doctor if nausea or vomiting are making it hard for your child to consume enough water. If ice is available, you may find that eating ice chips or sucking on an ice cube is a good way to get water into your child's system without aggravating nausea.

PREPARING FOR HAIR LOSS

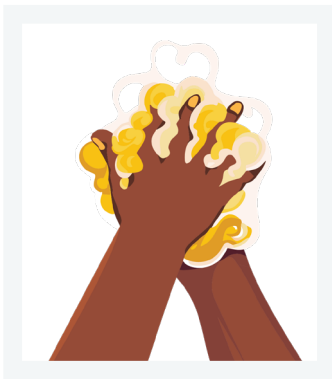


Hair loss is a common side effect of cancer treatment. Before your child starts treatment, it is recommended that you talk to your child's doctor or nurse so your child can prepare for the possibility of losing their hair.

Some people prefer to shave their head before hair loss begins, so they feel more in control of the process. Once hair loss begins, some people decide to get a wig, others choose to wear head scarves or hats, and some do neither. Remember that if your child had hair before

treatment, their scalp will not be used to sunlight, so it is important to protect your child's scalp from the sun using hats, scarves, or sunscreen.

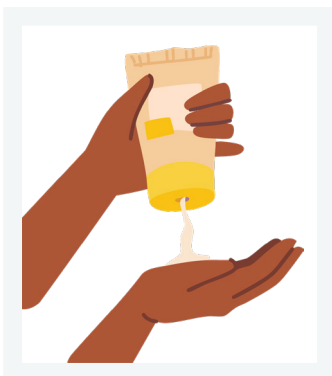
REDUCED IMMUNE FUNCTION



In addition to killing cancer cells, many cancer treatments also kill healthy cells, including those that fight off infections. This makes your child more vulnerable to other illnesses, like colds, the flu, or COVID-19. Try and boost your child's immune system in other ways while they are receiving cancer treatment by eating well, exercising, and lowering their stress levels. Other ways to protect your child from getting sick include having them wash their hands frequently, wear

a mask when they are in a crowded area, and avoiding people who are coughing or sneezing.

HAND AND FOOT SYNDROME



Some types of chemotherapy can cause the skin on hands and feet to redden, swell, peel, and undergo other changes. Depending on the severity, your child's doctor may address this by changing the chemotherapy drugs. Less severe versions of this syndrome can be managed by using natural moisturizers on the affected areas, taking pain relievers if needed, and protecting skin from heat (for example, from sun exposure or hot water). Your child's doctor may also give you special skin care instructions.

You can also apply cold compresses to your child's wrists and ankles to slow the swelling, elevate their hands and feet, and avoid rubbing the skin by wearing loose-fitting clothing and avoiding itching.

MUCOSITIS



Mucositis is when the mucus membranes swell as a result of cancer treatment. This can cause mouth sores, pain, and stomach discomfort. To manage mouth sores, take special care with your child's mouth. Have them brush their teeth more often but be gentle to avoid worsening the sores. You can also rinse your child's mouth several times a day with salt water. Ensure your child's diet is gentle by avoiding excessive sugar, spicy or acidic foods, and anything crunchy that could damage sores or swollen tissue. Also make sure your child is getting plenty of water to help their body heal.

REMISSION & MONITORING

“**Remission**” is a term that means the cancerous cells in the body have greatly decreased in number or disappeared entirely. Depending on the type of cancer your child has, the term “response” might be used rather than “**remission**.”

COMPLETE RESPONSE: No evidence of disease remains; all detectable cancer is gone.

PARTIAL RESPONSE: The size of the primary tumor has shrunk by at least 30%, or the number of cancerous cells in the body has decreased.

A complete response may continue for months, years, or the rest of your child’s life. There is a chance that some cancer cells may survive the original treatment and will grow back, though this chance decreases over time. Because of this, it is important to ask your child’s doctor how often they should visit for follow-up appointments once their treatment ends.

As with the initial cancer diagnosis, doctors cannot say why some patients see their cancer return, while others do not. Some risk factors for cancer recurrence include the cancer type, treatment method, and amount of time since diagnosis. In rare cases, childhood cancer survivors may develop a second, unrelated cancer rather than having the original cancer return.

Some risk factors of developing a second cancer include:

- Age during initial cancer diagnosis
- Chemotherapy and radiation treatment
- Certain inherited syndromes

At follow-up visits, the doctor may screen your child for cancer recurrence or when appropriate, for signs of a second cancer. When your child’s doctor checks for cancer after treatment is complete, it is called “**surveillance**” and is done to help detect any signs of cancer as early as possible.

Recurrences are classified as “local” (in the same exact spot or organ where it started), “regional” (in nearby lymph nodes or tissues), or “distant” (elsewhere in the body, also known as metastatic cancer). Symptoms of cancer recurrence are often the same as the original signs of cancer, including:

- Pain or discomfort
- A lump or mass
- Enlarged abdomen
- Dizziness
- Headaches
- Fatigue or weakness
- Easy bruising or bleeding
- Persistent fevers
- Bone and joint pain
- Loss of appetite and/or unexplained weight loss

If your child is experiencing any of these symptoms, it is a good idea to check in with their doctor.

Surveillance cannot prevent cancer recurrence. The goal of surveillance is to detect cancer recurrence *before* your child experiences symptoms, while the cancer is still easier to treat. Ask your child’s doctor about available screening options for their type of cancer.

QUESTIONS TO ASK YOUR DOCTOR

- What kind of cancer does my child have?
- What stage is the cancer, and can you explain what that means?
- What does this diagnosis mean for my child's treatment options?
- What are the side effects of this treatment option?
- Will my child be able to have children in the future?
- What do I need to do next?
- How quickly do I need to decide about my child's course of treatment?
- If your child had the same diagnosis as mine, what would you recommend to them?
- What resources (websites, books) do you recommend for me to learn more about my child's diagnosis?
- What are good resources for me and my child to use if either of us start to feel depressed or anxious during the course of their treatment?
- What are good resources for my other children to use if they start to feel depressed, worried, or anxious during their sibling's cancer treatment?
- Should my other children get screened for cancer?
- How often should my child have follow-up appointments when their treatment is finished?

Hospital visits are often stressful situations. If you ask a question but do not understand the answer, ask for clarification.

It might be helpful to bring something to take notes on during your child's appointment. You will have a lot of information presented to you, and taking notes can help you review what the doctor told you later.

TALKING TO CHILDREN ABOUT CANCER

The way you talk to your child about their cancer diagnosis will depend on their age and level of understanding. Younger children may need simpler explanations while older children may want more details. It is important to explain things calmly and honestly in a way your child can understand. Children often have fears about cancer, so it's important to encourage your child to share their thoughts and feelings, and address any misconceptions.

Some common fears and misconceptions your child might have about cancer are:

- **Cancer means you did something bad:** It's important to let your child know that nothing they did or said caused them to develop cancer. You can explain that doctors do not always know why some children get cancer and others do not.
- **Cancer can spread to others:** Some children may think that they can give cancer to someone else, or that they got cancer from another person. Let them know that cancer is not like other illnesses that can spread from person to person, and nobody can "catch" cancer from them.
- **Cancer means death:** Children may think that cancer always leads to death, especially if they know someone who has died from cancer. Reassure them that this is not true and that they are going to receive treatment that has helped many other children who have cancer.

Encourage your child to ask questions and let them know they can come to you whenever they want to talk about their diagnosis, treatment, or feelings. If appropriate, it can also be helpful to include siblings in these conversations, so they feel informed and supported as well. If you do not know the answer to a question, it is okay to say that and ask someone from your child's care team for help.

It may be easier to talk to your child about their cancer diagnosis over many small conversations instead of one large discussion. As your child grows, learns, and begins treatment, continue to check in with them and provide additional information that is appropriate for their age and needs.

MY CHILD'S DIAGNOSIS

Official diagnosis: _____

Where did my child's cancer originate?

Blood	Brain
Kidneys	Bone
Bone Marrow	Nerve Cells
Spinal Cord	Immune/Lymphatic System
Eyes	Soft Tissues

What is the stage of my child's cancer?

Stage 1	Stage 2	Stage 3	Stage 4
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Other staging or grading information about my child's cancer:

What is my child's expected treatment plan?

Surgery ☐ No ☐ Yes, my child's surgery will take place on _____ at _____. ☐ The surgery my child will receive is: _____.
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Chemotherapy

- ☐ No
- ☐ Yes, my child's chemotherapy will start on _____ at _____ . They will have _____ cycles of chemotherapy.

Drugs that will be required for each chemotherapy cycle:

_____ mg of _____

_____ mg of _____

_____ mg of _____

_____ mg of _____

_____ mg of _____

Radiation Therapy

- ☐ No
- ☐ Yes, my child's radiation therapy will start on _____ at _____ . They will receive radiation _____ days per week for _____ weeks.

Targeted Therapy

- ☐ No
- ☐ Yes, my child's course of targeted therapy will start on _____ . Targeted therapy will last _____ .

Drugs that will be required for each dose of targeted therapy:

_____ mg of _____

_____ mg of _____

Immunotherapy

- ☐ No
- ☐ Yes, my child's course of immunotherapy will start on _____ . Immunotherapy will last _____ .

Drugs that will be required for immunotherapy:

_____ mg of _____

PATIENT APPOINTMENT TRACKER

DATE	DOCTOR	NOTES	FOLLOW UP SCHEDULE

DATE	DOCTOR	NOTES	FOLLOW UP SCHEDULE

NOTES

[illegible]

[illegible]

[illegible]

DON'T FEAR GOING TO THE HOSPITAL, WE ARE HERE TO HELP YOU!

If you have any questions, please contact:

Developed by:



BVGH gratefully acknowledges Dr. Aimable KANYAMUHUNGA of the University of Rwanda and the University Teaching Hospital of Kigali for his medical review of this childhood cancer patient booklet. His expert recommendations have strengthened the accuracy, clarity, and practical value of this resource for patients and caregivers.