

hematology/oncology family guide



dayton
children's



dear parents and caregivers

It is our privilege to care for your child throughout their cancer journey. We understand this process is overwhelming to you and your family. We encourage you to read this binder and use it to store information and as a reference. Please write down any questions about your child's treatment plan to discuss with your care team at each visit. Please bring this binder to each hospital visit. If you believe your child can understand this information, please share it with them.

At Dayton Children's, we not only care for your child, but also your family. We understand that you know your child better than anyone else does, so it is important that parents and caregivers feel they are part of the care team. It is our goal to always go above and beyond to ensure you have a positive experience. We recognize that each child has unique needs. Please let us know if there is anything our team can do throughout treatment to help meet the needs of your child and family.

Dayton Children's maintains accreditation by the American College of Surgeons. In order to provide the best and most state-of-the-art care for your child, we are also members of the international Children's Oncology Group (COG), a group dedicated to improving the outcome for all children with cancer.

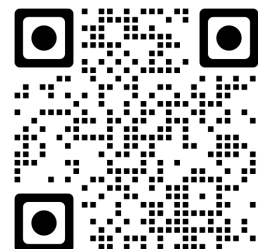
We hope the material in this binder will provide helpful information and resources to assist you along the way. Please scan this QR code to complete a brief survey about this binder so we can improve it for future patients.

Sincerely,

Comprehensive Center for Blood
and Cancer Disorders



Jordan M. Wright, MD
Division chief



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introduction to Dayton Children's Hospital

important information about your child's care

patient name: _____

diagnosis: _____

date of diagnosis: _____

primary oncologist: _____

nurse practitioner: _____

nurse navigator: _____

chemotherapy protocol: _____

central line type & size: _____

port needle size: _____

central line access tips: _____

pneumocystis prophylaxis: _____

home care company & phone number: _____

radiation center & phone number: _____

your team members

Chief, division of hematology/ oncology and Attending	Dr. Jordan Wright	
Attending	Dr. Lionel Chow	
Attending	Dr. Mukund Dole	
Attending	Dr. Lubna Mehyar	
Attending	Dr. Rachael Courtney	
Director	Kate Barrett, MS, BSN, RN, CPON	
Nurse manager	Heather Cantrell, BSN, RN, CPHON	
Assistant nurse manager	Jenifer Selmon, BSN, RN	
COG study nurse	Ashley Ross, BSN, RN, CPN	937-641-5314
Nurse navigator	Cassidy Ortlieb, BSN, RN	937-641-3653
Social work	Whitney Taverna, MSW, LISW	937-641-5300
Child life specialists	Rita Falkenbach, BS, CCLS Laura Busher, MS, CCLS	937-641-3303
Dietitian	Sara Lacy, MS, RDN, LD	937-641-5133
Chaplain	Darryl Fairchild	937-641-8980
Psychologist	Laura Meyers, PsyD	937-641-8905
Family support specialist	Susan Fletcher, MSW, LISW-S	937-641-4190
Pharmacy	Main campus - Dayton	937-641-5500
Pharmacy	South campus - Springboro	937-641-5080
Pediatrician/Family doctor		

Jordan M. Wright, MD

Division chief
Associate Professor

of Pediatrics at Boonshoft School
of Medicine, Wright State
University

Hemophilia program
director



Dr. Wright focuses on blood disorders, including helping patients with conditions in which their blood doesn't clot enough or it clots too much. He also treats patients battling cancer.

Dr. Wright comes to Dayton Children's from Cincinnati Children's Hospital Medical Center. He completed a fellowship in pediatric hematology/oncology and earned a master's degree in clinical and translational research at the University of Cincinnati. Dr. Wright served his pediatric residency and internship in the University of Alabama at Birmingham's program at Children's of Alabama. He earned his doctorate at the Medical College of Georgia in Augusta.

I chose to work at Dayton Children's because: I appreciate the dedicated and experienced team of doctors, nurses and staff who are all focused on providing outstanding care for children.

Lionel Chow, MD. PhD

Attending Neuro-oncology

Dr. Chow focuses on childhood brain cancer. His expertise is to provide patients and families with the best care and treatment available for brain tumors that also meets the unique needs of each patient.



Dr. Chow received his medical training and research doctorate at McGill University in Montreal, Canada. He completed his pediatric residency and hematology/oncology training at The Hospital for Sick Children in Toronto. He then moved to St. Jude Children's Research Hospital in Memphis, Tennessee. Before coming to Dayton Children's, Dr. Chow established his own brain tumor lab at Cincinnati Children's Hospital Medical Center.

At Dayton Children's, Dr. Chow is continuing his brain tumor research with the goal of developing better treatment options for patients with aggressive forms of this disease.

I chose to work at Dayton Children's because: the hospital is going through exciting changes and growth that will make this an even better place for children to receive their care.

Lubna Mehyar, MD

Attending

Dr. Mehyar received her medical degree from Jordan University of Science and Technology in Irbid, Jordan. She has completed one residency, a pediatric hematology oncology fellowship and a pediatric bone marrow transplant fellowship. Dr. Lubna Mehyar is board-certified in pediatric hematology/oncology. Prior to coming to Dayton Children's, Dr. Mehyar spent several years at West Virginia University as a member of their pediatric hematology and oncology faculty.



At Dayton Children's, Dr. Mehyar is bringing her dedication to help kids and their families with hematological/oncological disorders as well as those who need bone marrow transplant.

I chose to work at Dayton Children's because: It is a state of the art when it comes to providing patient care.

Mukund G. Dole, MD

**Attending
Associate Professor
of Pediatrics** at Boonshoft
School of Medicine,
Wright State University
Program Director of the West
Central Ohio Comprehensive
Sickle Cell Center in Dayton



Dr. Dole obtained his medical degree from the University of Bombay and received his general pediatrics training at Children's Hospital of Louisiana and LSU Medical Center, New Orleans, Louisiana. He completed his fellowship in pediatric hematology/oncology at the University of Michigan, Ann Arbor, Michigan. He is board certified in general pediatrics and pediatric hematology/oncology.

Besides being a general hematologist/oncologist, Dr. Dole has a special interest and expertise in management of patients with sickle cell disease and other related hemoglobin disorders. Along with other members of his department, he remains an active participant in clinical trials conducted by Children's Oncology Group (COG) for managing children with cancer.

Rachael Courtney, DO

Hematology/oncology



Dr. Courtney comes to Dayton Children's with several years of experience from St. Jude Children's Research Hospital in Memphis, Tennessee. She obtained her medical degree from Lake Erie College of Osteopathic Medicine and served as a resident at the University of Florida at Jacksonville.

Dr. Courtney completed a fellowship at Children's Hospital of Pittsburgh of UPMC. She is board certified in general pediatrics and pediatric hematology/oncology.

Dr. Courtney is interested in the science behind hematology/oncology diseases and enjoys working on challenging medical cases. Whether it is an emergency case or a complex oncological condition, she feels lucky to be part of a medical team that can help kids and families find help and cures. Dr. Courtney loves working with kids because of their innocence and she feels lucky every day that she has a chance to make them better.

I chose to work at Dayton Children's because: It was abundantly clear that they care deeply about the children they care for and strive every day to make sure the care here is top notch.

comprehensive center for blood and cancer disorders

hematology/oncology clinic

Appointments are Monday – Friday

8:45 am to 4:00 pm

- Clinic appointments are usually made by the hematology/oncology receptionist. If you need an appointment or need to change or cancel an appointment, call 937-641-3111.
- Please make every effort to arrive on time for your appointment. If you cannot arrive on time, please call the receptionist.
- **NOTE: If you arrive over 15 minutes late for an appointment, we will make every effort to see you that day. We will attempt to work you into a later time slot, but know that you may have to reschedule.**
- If you need to cancel or change an appointment we have scheduled with another department, please call that department to reschedule. **Please notify our receptionist of the new date and time.**

outpatient infusion room

Monday – Friday 7:30 am to 4:30 pm

If your child is scheduled in the infusion room, please do not bring other family members with you. This helps us focus on your child and give your child the best care. Call 937-641-5559 if you have any questions.

A parent or legal guardian must accompany your child to each visit.

what to bring to your clinic visit:

- An up-to-date insurance card
- All of your child's medications so the nurse can review the medication and correct dosing
- Your medication calendar to report any missed doses or uses of "as needed" medications
- List any questions, concerns or events that occurred since the last visit
 - Examples: Illnesses, physical complaints, school problems

hematology/oncology inpatient unit

- Located on the fourth floor of the tower at the main campus. This is a 24-hour inpatient pediatric unit.
- Scheduled admissions should arrive at 9:00 am in the clinic.
- Remember that patients on this unit easily get sick. Do not visit if you are ill.
- It is recommended that an adult stay with the patient at all times. Visitors under 18 years of age will not be able to stay overnight in the unit.

**All family members and visitors to the hematology/
oncology floor will need to be on your visitor list
(see page 38 for details) and get a visitor ID badge
before coming to the floor. Visit the welcome center
in the atrium on the first floor to get a visitor badge.
Please bring your photo ID with you to get a badge.**

emergency phone numbers

Call 911 or emergency services immediately if your child experiences any of the following:

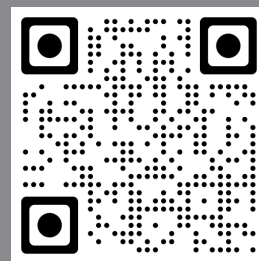
- Cannot breathe or having difficulty breathing
- Is not able to wake up
- Is having a seizure

for emergency evening calls

Call the hospital operator at night (after 5:00 pm) and on weekends and holidays. 937-641-3000

- Ask the operator to page the hematologist/ oncologist on-call

Please do not page the physician on-call for medication refills or questions that could wait until the next clinic day.



Scan this code to watch a video with instructions for coming to the emergency department.



education checklist

people you may see (consults)

*Please ask your nurse to check all of the specialties that will be seeing your child.

- Child Life/Beads of Courage: _____
- Psychology: _____
- Neuropsychology: _____
- Dentistry: _____
- Emergency department: _____
- Genetics: _____
- IV therapy: _____
- Nutrition: _____
- Ophthalmology (eye): _____
- Pharmacy: _____
- Radiation oncology: _____
- Social work: _____
- Family support specialist: _____
- Fertility preservation: _____
- Physical therapy: _____
- Occupational therapy: _____
- Speech therapy: _____
- Other(s): _____

consents

*Please ask your nurse which consents your child will need.

- Consent for blood (good for 2 years): _____
- Chemotherapy consent: _____
- Lumbar puncture consent: _____
- Bone marrow consent: _____
- Sedation consent: _____
- Surgery consent: _____

supplies to go home

*Please have your nurse check which supplies you need.

- Chemotherapy gloves
- EMLA & Tegaderm™ patch (numbing cream and tape for port)
- Central line emergency clamps (for Broviac® central venous catheters)
- Antiseptic skin cleanser (CHG/Theraworx®) for central line patients
- Thermometer
- Other: _____

what should you pack?

Storage is VERY limited. All clothes for you and your child must fit in your child's closet. All non-clothing items must fit in one small laundry basket. If you are admitted for an extended period of time, you are strongly encouraged to change out toys and clothing each week to avoid clutter and allow thorough room cleaning.

- Clothes: We encourage the patients to dress in their own clothes when possible and change those clothes daily. Hospital gowns are available if desired. A washer and dryer are available.
- Laundry soap and dryer sheets.
- Toiletries: shampoo, conditioner, body wash, toothbrush and toothpaste, etc.
- Bring photos, washable blankets or other comfort items that give the child a feeling of connection to their home and family.
- Bring books, music, movies, video games, tablets, cell phones (and chargers) or other activities to do while in their room or the playroom.
- If their visit is during the school year, bring their homework assignments with them. There is often plenty of time to do school work so they do not fall behind during treatment.
- Parent/caregiver home medications such as ibuprofen (Motrin®) and acetaminophen (Tylenol®), antacids and any prescriptions you need.

Please do not give home medications to your child while in the hospital. All patient medications will be supplied by the pharmacy.

things to leave at home

- Live plants and flowers. These are sources of infection for oncology patients.
- If possible, plush or stuffed toys should be avoided. Otherwise, they should be washed and dried in an automatic dryer each week.
- Large suitcases/duffel bags.
- Christmas lights, lamps, curling irons, hair dryers, boom box, fans, toasters, slow cookers, coffee makers
- We are promoting a healthy environment for healing and growth. Dayton Children's and associated property is 100 percent smoke-free. Please leave all associated items at home.

Please ask your nurse if you have any questions about items allowed in patient rooms.



your stay at Dayton Children's Hospital

what to expect during your hospital stay

a color for every caregiver

During your hospital stay you may come into contact with a number of caregivers. Many of them are dressed in scrubs. As shifts change, it may be difficult to determine the role of many of these caregivers. While identifying a doctor in a white lab coat is fairly easy, telling the difference between a nurse and a therapist can be a little more challenging. Dayton Children's is taking some of the guesswork out of recognizing the role and area of expertise of your caregivers with a color-coded dress policy. You can recognize any of our health care professionals by the following colored scrubs:



attending physicians
black



residents
pewter gray



registered nurses
navy blue



patient care assistant
turquoise



respiratory therapy
maroon



environmental services
light gray



child life
pink



lab
hunter green



medical imaging
grape



patient access
plum



volunteers
royal blue smocks



rehab/therapy
teal



pharmacy
light blue



surgery - operating rm.
pewter gray



EEG
eggplant



ortho
royal blue



technicians
red



telecommunications
white

daily routine:

- At 4:00 am your nurse will come to do an assessment. Labs are drawn so results are available during morning rounds.
- Each morning, you and your child will see your whole care team. We call these **family-centered rounds**. You can expect to meet with doctors, nurse practitioners, social workers, dietitians and nurses. This gives the team time to discuss any lab results or events that occurred overnight with you and your child. The whole team is present, so this is a great opportunity for the family or patient to ask questions. Discuss your concerns with us so that we can work with you to make a plan for the day.
- Your child will have an assessment from their nurse every 4 hours (8:00 am, noon, 4:00 pm, 8:00 pm, midnight and 4:00 am).
- We encourage age-appropriate activity when your child is able. This helps maintain muscle strength and stamina. Your child should be out of bed a minimum of 2-3 times a day.
- An activity center is located on the inpatient unit. Child life provides activities throughout the day.
- You and your child are also able to leave the unit for walks when approved by the medical staff.
- Please let your nurse know before you leave the hematology/ oncology unit.

family support member:

- We encourage a family member to stay with each child for their entire hospital stay to provide comfort and assist with daily activities (feeding, diaper change, etc.).
- We encourage family members to rotate, if possible, to provide each caregiver with a much-needed break and ensure they are caring for themselves.
- If you need to leave your child for a short period of time and another family member is not currently present, a child life volunteer may be able to sit with your child for 15-30 minutes. Let your nurse know if you need to step away for a bit and would like a volunteer to sit with your child.
- Remember our staff is unable to stay with your child for a prolonged period of time as they need to provide care to multiple patients.

safe sleep

While we encourage a family member to stay with the child overnight, we do not allow siblings to stay on the inpatient unit. Safe sleeping practices are very important at Dayton Children's. To keep your child safe, the following guidelines apply:

- If your child is under the age of 2 years, a crib will be provided. When your child is in the crib, we ask that the side rails be up and the crib top (clear plastic at the top) be pulled securely down to prevent your child from falling.
- Sleeper sofas are available in each patient room for a family member to stay. At no time may a parent sleep with a child under 1 year of age due to risk of accidental suffocation.
- Bed sharing for patients over 1 year is not recommended. You may sit or lie in bed with your child as long as you remain awake.
- Family members are not allowed to sleep in the patient's bed.



infection control

Infection prevention is a top priority at Dayton Children's. Since this is so important to your child's health, we will do the following things each day:

daily care

- Soap and water bathing and linen changes
- Patients with a central line (PICC, Broviac, infusaport) will also be asked to use Theraworx wipes daily.
- Mouth care is done 3 times a day (please see corresponding binder section for more information).
- Hand washing is the best way to prevent infection. Make sure everyone (you, your child, visitors or anyone else caring for your child) washes their hands upon entering your room, handling your child's central line, before and after playing or eating, after going to the restroom or diaper changes.
- Do not allow anyone sick to visit your child in the hospital. Your child will have a decreased immune system and even a common cold could make them very sick.
- No live plants are allowed in patient areas due to risk for infection.

room cleaning

- Please keep belongings in one small laundry basket so we can effectively clean the room each day.
- A member of our staff will use special wipes to clean all hard surfaces and mop the floor.
- If you are admitted longer than 7 days, your room will be sanitized with an ultraviolet light. This light will kill certain germs to help prevent infection. You will be asked to leave your room for up to one hour during this process.
- For longer admissions, deep cleaning of your room will occur every 30 days. You can expect to be moved to a different room if available so staff can complete the deep clean process.

care signs

Outside each room is an electronic alert screen that we call care signs. These screens share patient-specific safety precautions, like isolation status. They help our team, family and visitors know what to wear to help prevent the spread of germs. Alerts could also be things like fall risk, patient napping, mother breastfeeding and happy birthday! Take a look at these and tell any visitors to look at these screens before entering your child's room.

hand hygiene tips

- Safety is the number one concern for all of our patients. Hand washing is the most important way to stop the spread of infection.
- Before you enter your child's room, you should use alcohol-based cleaner, such as hand sanitizer. Or, you can use soap and water to wash your hands. Scrub your hands for 15 seconds, then rinse and dry them.
- Wash your hands after using the restroom or changing a diaper.
- Cough into a tissue or your shirt sleeve. Do not cover your mouth with your bare hands.

caring for your child

mouth care

Good mouth care can help prevent mouth sores (mucositis). Mucositis can allow bacteria into your child's blood and cause blood stream infections or sepsis.

routine oral hygiene for all patients

- 5 mL nystatin swish and swallow or swab for infants 3 times daily
- 5 mL Biotene® rinse or swab for infants 3-4 times daily

tooth/tongue brushing

- Brush 2-3 times per day with soft bristle brush and Biotene toothpaste
- No flossing unless your platelet count is over 20,000 and approved by your doctor
- Water or lanolin-based lip balm at least 2 times daily

cryotherapy (eating/drinking during certain chemotherapies)

- Use cold substance (ice water, popsicle, “freezies” or chew ice) for the duration of infusion. This decreases blood flow to cells in the mouth and reduces exposure of these cells to chemotherapy.
- Your nurse will tell you which chemotherapy medications are likely to cause mucositis.
- This treatment is only used for infusions lasting 60 minutes or less.

dental procedures

- A dental consultation will be performed at the time of your child's diagnosis for children with poor oral health and/or a need for extensive dental work.
- We may ask that your child have their braces removed prior to starting therapy. Braces may increase your child's risk of infection if their treatment causes mucositis (mouth sores).
- If your child has a central line (Broviac/port/PICC), they will need antibiotics before any dental visit. This is very important for preventing infection.
 - Amoxicillin is the antibiotic of choice. It should be taken 30 minutes **before** your dental appointment. If your child is allergic to amoxicillin, an alternative antibiotic can be used.
- Hold dental procedures, if possible, until your child is no longer neutropenic (has low counts of white blood cells). Talk with your doctor about the best time for dental work to be done.



chemotherapy

safe handling

Chemotherapy medicines are used to destroy rapidly dividing cells such as cancer cells. Chemotherapy comes in many forms such as pills, shots or intravenous (IV). The IV forms can be given for a short time or as a several-hour infusion.

what is an exposure to chemotherapy and why is this harmful?

Because chemotherapy affects the genetic makeup of cells, healthy individuals should avoid exposure to chemotherapy. Exposure to chemotherapy could cause unwanted changes to a healthy person's cells.

Exposure to chemotherapy can occur in many different ways.

1. Contact with the patient's vomit, urine or stool
2. Breathing in vapors from the medicine
3. Skin contact with liquid forms of chemotherapy from a spill or splash

Although the risk of danger from handling these small amounts of chemotherapy is slight, it is a good idea to avoid unnecessary exposure.

what do the nurses do to avoid exposure?

When the nurses give chemotherapy, they will put on a gown, gloves, mask and goggles. This is to protect themselves from any spills, splashes or vapors that may accidentally occur while they are giving the drug. If an accidental chemotherapy spill occurs, the nurses have been instructed to make sure that no one has contact with the spill and that it is kept from spreading until they can clean it up with a special chemotherapy spill kit.

what safety measures should be used while my child is receiving chemotherapy?

When your child is receiving IV chemotherapy, please ask the nurse how to handle the IV pole and bag as the child moves around. Please have your child remain on the unit while your child is receiving chemotherapy, unless your child's nurse or doctor tells you differently.

If the IV bag begins to leak or the tubing becomes disconnected, the following precautions should be observed:

- Contact a nurse immediately.
- Do not move the child or his chemotherapy so as not to spread the chemotherapy spill to other areas.
- Do not attempt to clean up the mess. The nurse will need to use special equipment to clean up the liquid.
- Should you come in contact with a chemotherapy spill, wash immediately with soap and water and change any soiled clothing.

what do parents need to do when they are home to avoid exposure?

After your child receives chemotherapy medicine, the following precautions should be used for 48 hours:

- Wear disposable gloves while helping your child when he or she is vomiting.
- Wear gloves when changing diapers or cleaning up vomit, stool or urine.
- Wear gloves when handling soiled linens, emesis basins, bedpans or urinals.
- After handling any bodily wastes, remove your gloves, dispose in trash and wash your hands thoroughly with soap and water.

(Chemotherapy content pulled from CHI#1249.)

caring for your child's central line

You will receive instructions from the nurses on the care of your child's port. Instructions for other central lines (PICCs and Broviac central venous catheters) will come from IV therapy. A daily bath with prescribed cleanser will be required for patients with indwelling central lines and for those with accessed ports.

Monitor your child's central line site each day for signs of infection (redness, swelling, yellow drainage, foul odor). If your child is at home or has a Broviac, check the dressing each day to ensure it is occlusive (keeping air out). If the dressing is peeling, place a piece of tape over the peeling edge and call your home care nurse to come to your home to change it.

- **Ports:** If the microclave (end of your child's port tubing) falls off, immediately clamp the tubing and call your physician for additional orders. Attach a new microclave if you have one. Do not flush the port with saline or heparin.
Call your doctor immediately.
- **Broviac central venous catheters:** If at any time you notice a hole in the Broviac tubing or there is a break in the tubing, clamp off the line between your child and the break using your emergency clamp.
Call your doctor immediately for further instructions.

fertility preservation

Fertility preservation is a part of cancer care, even during childhood. It is an essential part of the medical care at Dayton Children's. Exploring fertility preservation options in both males and females who have gone through puberty provides hope to the patients for starting a family one day. As more survivors are entering into adulthood, this is often a vital part to their quality of life. Your physician will talk to you about your/your child's fertility risk factors. We are here to work together and find the best option for you.

The Dayton Children's oncology team meets with patients whose medical condition or treatment may place them at risk for infertility (unable to have children) in the future. The effect on fertility may be temporary or permanent depending on your treatment. By educating patients and families early about the risks of their diagnosis and treatments, they can decide if fertility preservation is available and right for them. We have partnered to provide all available fertility preservation options to our patients.

SpringCreek Fertility offers our patients the following counseling:

- Side effects of their diagnosis on fertility
- Potential side effects of treatment
- Fertility sparing options
- The importance of using contraception during and immediately following treatment

options for females:

- **Oocyte harvesting:** This method requires 2 weeks of medication to "stimulate" the ovaries to make eggs. The eggs are then removed while the patient is sedated and saved for later use.
- **Lupron:** Lupron is an injection given every 3 months that is believed to help protect the ovaries from the effects of chemotherapy. This option can be discussed with your child's physician.

options for males:

- **Sperm banking:** Sperm is produced by masturbation. Samples are then frozen for future use.

nutrition tips for chemotherapy

When you have cancer, you need to eat to keep up strength. When you feel well, eating enough food is often not a problem. But when you are undergoing cancer treatment, eating can be challenging. Not everyone has eating problems during cancer treatment. If you do, tell your doctor or nurse right away and a dietitian can assist you. Eating well throughout treatment will help you feel better, keep up strength, tolerate treatments better and heal faster.

nutrition guideline

- **Keep hydrated:** Examples of fluids include water, juice, milk, broth, sport drinks, punch, popsicles, ginger ale, lemon-lime soda.

Fluid goal: _____

- **Get adequate protein:** Protein helps heal and repair cells and keeps muscle strength. Protein foods are meats, fish, eggs, cheese, milk, cottage cheese, yogurt, nuts/seeds, beans, nut butters and tofu.

Your recommended amount of protein is _____ grams/day.

food safety

- Wash all raw fruits and vegetables under running water.
- Check expiration dates.
- Avoid eating raw meat or eggs.
- Avoid salad bars, buffets and potluck dinners.
- Avoid raw eggs that are cracked.
- Avoid foods from bulk containers.
- Avoid foods from a delicatessen (purchase deli meat pre-packaged).
- Avoid tasting free samples.
- Use leftovers within 3 days.

common nutritional side effects due to chemotherapy

- Weight loss
- Loss of appetite
- Constipation

- Diarrhea
- Changes in taste and smell
- Mouth tenderness or sores
- Nausea
- Vomiting
- Fatigue/tired

tips to help manage nutritional side effects

If you encounter any of these side effects, please let us know so we can help.

1. Weight loss: Avoiding weight loss is important to maintain your strength, healing and tolerance of treatment.

- Eat on a schedule instead of waiting until you feel hungry.
- Eat 5 to 6 small frequent meals.
- Eat foods that are high in protein and high in calories.
 - **Good protein foods:** Cheese, cottage cheese, milk, yogurt, eggs, nuts, peanut butter, meat, fish, beans/legumes, and nutritional supplements such as Boost®, Ensure®, Pediasure®, and Carnation Breakfast Essentials®
 - **Good calorie sources:** Whole milk, cheese, granola, dried fruit, butter, gravy, sour cream, cream cheese, mayonnaise and salad dressing.

2. Loss of appetite

- Eat 5 to 6 small frequent meals.
- Keep snacks readily available.
- Eat foods that are high in protein and calories.
- Drink liquids between meals. Eat before drinking.
- Eat softer foods.
- Eat on a schedule instead of waiting until you feel hungry.
- Use nutritional supplements such as Boost, Ensure/Pediasure, or Carnation Breakfast Essentials when not able to eat a meal/snack.
- Keep active. Take walks, play outside, and limit quiet activities such as TV and video games to 2 hours/day or less. Being active will make you/your child feel hungry.

3. Constipation

- Drink plenty of liquids — at least 8 cups of liquids each day.
- Drink hot liquids such as tea, prune juice and soups.
- Eat high-fiber foods such as dried fruits, whole grains, dried beans, raw fruits and vegetables.
- Be active each day.

4. Diarrhea

- Eat small frequent meals/snacks.
- Eat yogurt.
- Eat more foods with soluble fiber such as oatmeal, bananas, applesauce, canned peaches and pears.
- Avoid foods that can make diarrhea worse:
 - Foods high in fiber such as raw fruits and vegetables, whole grains
 - Drinks that have a lot of sugar such as regular soda and punch
 - Very hot or very cold drinks
 - Greasy, fatty or fried foods
 - Dried beans, broccoli, cauliflower, cabbage
 - Milk products unless they are low lactose
 - Alcohol
 - Foods or drinks with caffeine
 - Sugar-free products sweetened with xylitol or sorbitol
 - Apple juice

5. Changes in taste and/or smell

- Choose foods that look and smell good.
- Marinate or season foods.
- Try tart foods/drinks such as orange or lemon (unless mouth is sore).
- Make foods sweeter if foods have a salty/bitter taste.
- Avoid foods with smells that bother you. Eat room-temperature foods, drink through a straw, cook outdoors and/or avoid smells of the kitchen.
- If you have a metal taste in your mouth, eat with plastic utensils and avoid foods from metal containers.
- For older children who are able to rinse and spit, use the following mouth rinse: Mix 1 teaspoon (tsp) salt, 1 tsp baking soda, 1 quart water. Rinse and spit 4 times daily.

6. Mouth tenderness or sores

- Avoid extreme hot or cold foods.
- Cook foods until they are soft and tender.
- Cut food into small pieces.
- Moisten foods with gravy, sauces or broth.
- Do not eat foods that can burn or scrape your mouth such as potato chips.
- Avoid acidic foods and spicy foods, like tomatoes, oranges and lemons.

7. Nausea

- Don't eat your favorite foods when nauseated.
- Avoid foods that are greasy, fried or high in fat.
- Avoid foods with strong odors.
- Eat 5 to 6 smaller meals.
- Sip on liquids throughout the day.
- Have foods/drinks that are not too hot or too cold.
- Eat dry toast or crackers before getting out of bed in the morning.
- Don't skip meals or snacks — eat foods that are easy on your stomach.

8. Vomiting

- Once the vomiting subsides, drink small amounts or clear liquids such as broth, ginger ale, juice, gelatin, sports drinks and popsicles.
- Try to keep hydrated. Sip on liquids throughout the day.
- Once able to eat clear liquids without vomiting, try foods such as yogurt, dry toast, pretzels, fruit, potatoes, rice, sherbet, pudding, crackers, applesauce and soup. Then advance to a regular diet as tolerated.

9. Fatigue/tired

- Prioritize your activities.
- Take short walks when you can.
- Drink plenty of fluids. Be sure to get at least 8 cups each day.
- Make sure you get plenty of rest.
- Try eating some protein, fat and fiber at each meal to help sustain energy level.
- Not eating/drinking enough can make you feel tired.

Reference: Eating Hints: Before, During and After Cancer Treatment.
National Cancer Institute.

understanding blood counts during treatment

type	function	values	possible symptoms for low values	treatment
Red blood cells (RBC)	Carry oxygen to the body	Measured by hemoglobin (Hb) Normal - more than 12	Tiredness Irritability Headache Paleness	Red cell transfusion
Platelets (PLT)	Prevent bleeding Help clotting	Normal - More than 150,000 Acceptable - More than 50,000 Caution - Less than 50,000	Petechia (small purple spots) Bruising Bleeding (nose, gums, urine, stool, vomit)	Platelet transfusion Call immediately for headache or head injury if platelets are low
White blood cells (WBC)	Fight infections Make antibodies	Normal - 5,000-10,000 Usual - Less than 5,000	Fever Other signs of infection	Acetaminophen (Tylenol) - Please call physician before giving Antibiotics - oral, IV
Neutrophils Absolute Neutrophil Count = ANC ANC=WBC x % neutrophils	Fight bacterial infections	Normal - More than 1,000 Caution - Between 500-1,000 Isolate - Less than 200	Same as white blood cells	Same as white blood cells Admission to hospital if fever and ANC < 200

your guide to Dayton Children's

our campus

where to park

For the convenience of families and visitors, the garage in front of the hospital is free and can be accessed from the main driveway off Valley Street. RTA bus tokens are available in the Altitude gift shop.

handicap parking

There are handicapped spaces by the lower level of the Cox building to the left of the main entrance, and in the parking garage.

smoke-free campus

For health and safety reasons, Dayton Children's is an entirely smoke-free campus. No one may smoke or use electronic cigarettes anywhere inside the building or outside on hospital property.

U.S. Bank ATM

The U.S. Bank ATM is located on the first floor by the purple elevators.

free wi-fi

Free wireless internet is available throughout the hospital. Please check your wireless setting and click on "Dayton Children's Guest Wireless." No passwords are required.

pharmacy

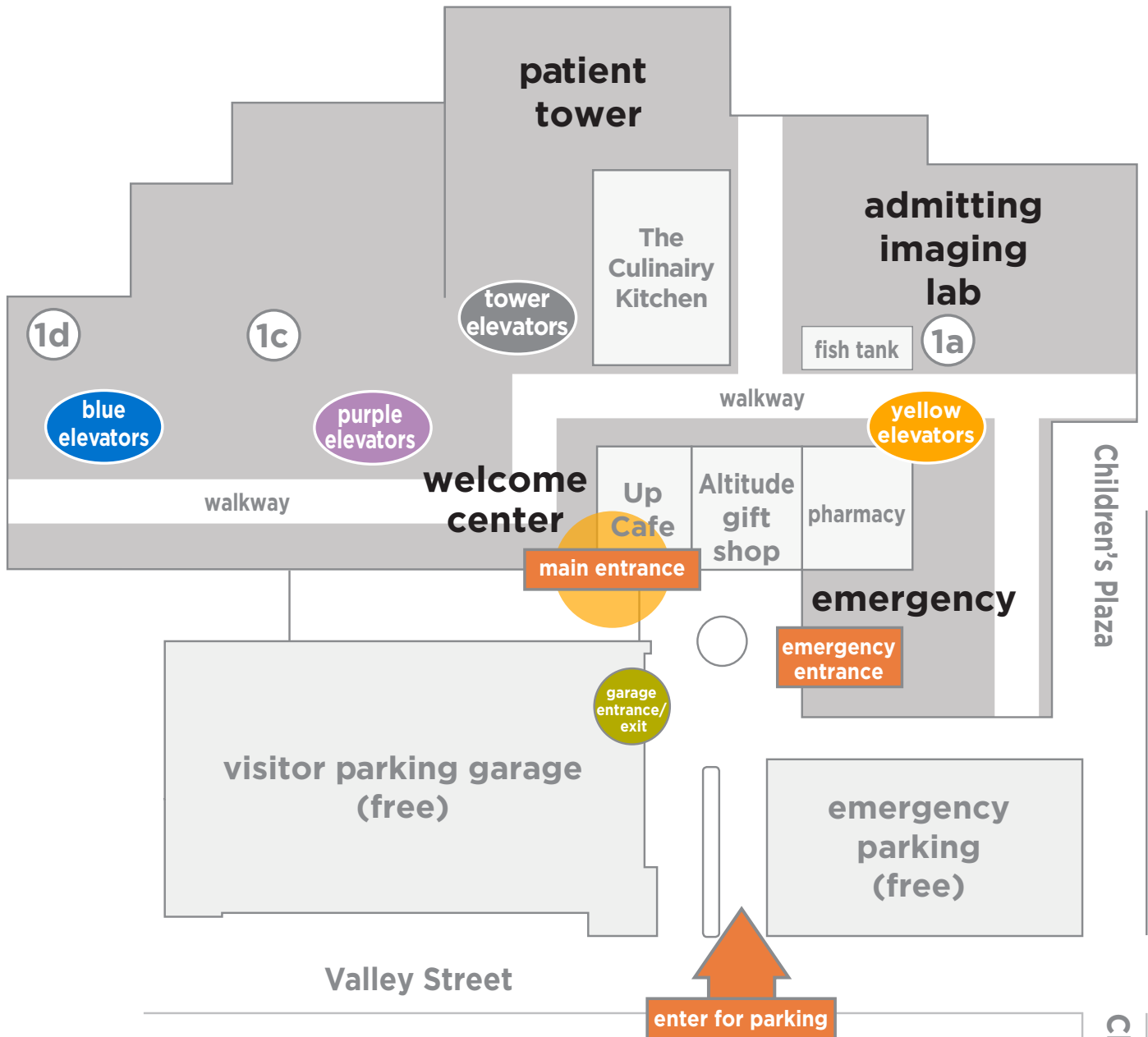
For your convenience, a pharmacy is available at our main and south campus. Our pediatric pharmacists have specialized training to help ensure the safe and effective use of medication in children from infants to young adults.

main campus:

- Located on the first floor by the yellow elevators across from the fish tank
- Hours: 24/7/365

south campus:

- Located on the first floor of the specialty care center building
- Hours: Monday-Friday 6:00 am to midnight
- Saturday and Sunday 12:00 pm (noon) to 10:00 pm



public safety 937-641-3636

Dayton Children’s goes to great lengths to ensure the safety of patients and families. Security cameras are located throughout the hospital and parking lots. Public safety officers are available 24 hours a day. All public safety staff wear identification badges. Upon request, public safety can escort you to your vehicle or provide a courtesy ride to the Ronald McDonald House. If you need public safety any time night or day, call 937-641-3636, or stop by the public safety office located straight off the yellow elevators.

visiting hours and spending the night

Visitation hours for family and friends

Parents and/or legal guardians of hospitalized patients are encouraged to stay with their child during their stay.

- All visitors must stop at the welcome center by the Up Cafe to get an ID badge. Bring your photo ID with you to get a badge.
- Hospital visitation hours for those other than parents are 8:00 am to 8:00 pm.
- Any visitors coming outside of normal visiting hours should come through the main entrance. Also, you will need to check in at the nurse's station.
- Family lounges and waiting areas are available for the comfort of families and visitors.
- For safety reasons, overnight sleeping in lobbies, waiting rooms or open public areas is not allowed.
- Visitation may be temporarily suspended any time there's a community-wide contagious disease outbreak. This will be communicated on our website.
- Please remember patients in this inpatient unit easily get sick.
Do not visit if you are sick.

Sleepovers for parents

To respect all patients, the hospital staff may limit the number of visitors in a patient's room to one parent overnight. Additionally, for safety reasons, siblings of patients are not allowed to spend the night.

Looking for a hotel?

Visit our website, childrensdayton.org.

Visitor ID and approved list

The safety of our patients is top priority. To help keep them safe, Dayton Children's limits visitors to 10 people. All family members and visitors will also need to be badged. Your care team will tell you more about the visitor list. To get an ID badge, please take your photo ID to the welcome center by the Up Cafe. Please wear your badge at all times while at Dayton Children's.

meals, snacks and coffee



Grab a bite to eat at The Culinary Kitchen, located on the first floor. Menu items include everything from a new stone-deck oven creating delicious pizzas, to rice bowls, to international favorites. Salads, sandwiches and other family favorites are also available. For hours, please go to GetWellNetwork.



The Up Cafe is on the first floor in the atrium. It offers coffees, teas, hot chocolate and fresh baked goods. Please go to GetWellNetwork for hours.

Other meal options

Dayton Children's offers several options for free and paid meals. Visit GetWellNetwork for all the details. You can also order from local restaurants for delivery to the welcome center.

spaces to relax and play

Skydeck

Children and families can enjoy sunshine and fresh air on the new Skydeck, an outdoor activity area. This space is separated from the public Skydeck to reduce infection risk. This space is closed in the winter and when the weather is bad. Signs will be posted if it is closed.

Activity center

New rooms and spaces for physical therapy and active play provide a safe place for children to play games and activities.

other key services



Altitude gift shop

Located in the Take Flight Gallery around the corner from the Up Cafe, Altitude gift shop has everything from unique gift items to things you may need during your stay here. The gift shop is open from 8:00 am to 8:00 pm every day. To call in an order to the gift shop, call 937-641-3890 between 10:00 am and 5:00 pm.

family resource connection

Could the right connection to a community resource help your family?

Dayton Children's Family Resource Connection can connect you to community resources such as food banks, utility programs, job training, adult education, parenting classes, household items, personal care and educational support for children. If you think you can benefit from these services, call the Family Resource Connection at 937-641-3716 Monday - Friday, 9:00 am to 6:00 pm.

social work

Our social workers are available 24 hours a day, 7 days a week to assist children and families with health care services, understanding financial issues and contacting community resources. If you wish to speak with a social worker, request these services.

child life

Dayton Children's has child life specialists as part of the care team. Child life specialists are pediatric health care professionals who work with children to help them cope with the challenges of hospitalization, illness and disability. They provide children with distraction techniques during select procedures, age-appropriate preparation for medical procedures, coping strategies and play activities.

Emily's Beads of Courage

As your child goes through their cancer journey, beads are provided to help document their journey. Different beads are provided for accomplishments and procedures such as surgery, scans, chemotherapy, blood transfusions, etc. Child life will provide you with information on this program when you meet with them.

volunteer resources

Volunteers are very special people who help us go above and beyond. They comfort and support our patients and their families through a variety of services. From greeting and guiding families and visitors when they enter the hospital, to helping child life in the activity rooms or patient rooms, to keeping kids company when they are inpatient, our volunteers are at the heart of what we do. Volunteers wear royal blue smocks. If you'd like a volunteer to sit with your child while you go grab a bite to eat or take a quick break, call volunteer resources at ext. 3333 Monday - Friday from 8:00 am to 5:00 pm, or let your nurse know that a volunteer is needed.

chaplain spiritual services

Chaplains, as members of the health care team, give emotional and spiritual care to patients, families and staff members. They offer acceptance and comfort during illness, injury and loss. Our chaplains have extensive training in working with children and their families in times of emotional crisis. Chaplains are either in the hospital or on-call around the clock.

If your child, you, or anyone in your family would like to speak to a chaplain of your own faith, or have your own clergy notified of your child's hospitalization, speak with your child's nurse or dial "0" for the hospital operator to have a chaplain paged.

Our interfaith chapel, open 24 hours a day, is located on the first floor across from the pharmacy (by the yellow elevators).

MyKidsChart

Through Dayton Children's MyKidsChart, you have a secure, online connection to your child's health information. You can review your child's health history, immunization records, test results and more, all online. You can also request an appointment or a prescription refill and send a medical advice question. Ask your nurse or a member of your care team for more information and how to sign up.

GetWellNetwork

GetWellNetwork is an education and entertainment system available on your TV. Your nurse can assign videos for you to watch specific to your child's care. You can also watch movies or TV, play games and learn more about Dayton Children's. Use the tiles at the bottom of the screen to find information about places to eat, play and take a break. Instructions on how to use the remote and keyboard are in your room.

Ronald McDonald House Charities programs



Ronald McDonald House – 937-224-0047

The Ronald McDonald House is located across the street from Dayton Children's. It offers families many of the comforts of home, such as hot meals, on-site laundry facilities, and private guest rooms at little or no cost to them while their child is receiving inpatient medical care. The Ronald McDonald House also offers transportation to and from the hospital. Ask your nurse for an application to stay, or visit the Ronald McDonald Family Room to pick one up.



Ronald McDonald Family Room – 937-641-5875

The Ronald McDonald Family Room offers parents, grandparents and siblings a quiet place to have a break, take a nap, shower or do laundry. The Family Room also has coffee, snacks and light meal options. For hours and location, visit [GetWellNetwork](http://GetWellNetwork.com).

going home

We understand that your family has had many big changes recently. We want to ensure we have answered all of your questions, and that you are comfortable caring for your child when you go home. You are not alone. The hematology/oncology clinic is available Monday-Friday 8:00 am to 5:00 pm. After 5:00 pm, a physician is on-call to answer your questions. Your child is important to us. No question is too small.

hand washing

Continue good hand washing even after you leave the hospital. Hand washing is the best method to prevent infection. Soap and water are best for killing germs. Wash your hands while you sing your ABCs. If you are traveling or not near soap and water, an alcohol-based hand sanitizer is the next best cleaner.

temperature

Take your child's temperature if you are concerned they may have a fever or they are not feeling well. We recommend oral (by mouth) thermometers if your child is able. Make sure your child has not had hot or cold beverages for 30 minutes before taking an oral temperature. This may affect the temperature result.

If your child is too young for oral temperatures, we recommend axillary (under the arm). Make sure your child's arm is tight against their body as you take their temperature. **Do not take rectal temperatures as this can be a risk for infection.**

If your child has a temperature of 101°F, call your physician immediately. If your child's temperature is 100.5°F, retake the temperature in one hour. If the temperature remains 100.5°F or higher, call your physician immediately.

If they have a low-grade fever, **do not give Tylenol (acetaminophen) or Motrin (ibuprofen)** as these may "hide" a fever. If you do not have a thermometer, or think you do not know how to use it correctly, please ask your nurse. We can provide you with a thermometer if needed.

procedures

If your child is scheduled to have a procedure such as a spinal tap or bone marrow, you will receive instructions from the surgery department. Please arrive at your scheduled time to the hematology/oncology clinic or surgery desk. To get to the surgery desk, come in the main entrance, then turn right and take the yellow elevators to the second floor. Please be sure to read the given instructions, particularly about what your child can eat or drink, and follow them closely. If your child eats the morning of the procedure, we will have to delay the surgery time.

school visits

When your child is discharged from the hospital, we want to help make their transition back to school as easy as possible. Members of our staff can visit your child's school. We do education for staff members caring for your child. We also provide age-appropriate education to your child's classmates to relieve any fear or misunderstanding.

school and church

Even when your child's blood counts are low, we encourage children to attend school and any church activities as much as possible while in treatment. This is important for psychological development and maintaining social interaction with their peers. If your child has frequent or extended admissions, we will work with their school to help establish tutoring.

activity

We encourage your child to exercise and play as much as they are able. This is important to keep up their strength. We do not encourage contact sports due to the risk of injury. Contact sports include football, dodge ball, wrestling, etc. If you have questions about what your child is able to do, please ask your physician. Your child may have additional restrictions if they have a low platelet count as this places them at increased risk for bleeding.

immunizations (vaccines)

The influenza vaccination is the only vaccine given during therapy.

No live intranasal flu vaccine may be given. Your physician can discuss this topic with you. Vaccinations can be given four weeks before starting chemotherapy and still be effective.

All immunizations should be started six months after finishing chemotherapy. Under rare circumstances, your doctor may begin inactivated vaccines at three months. Check with the clinic doctor or nurse for any questions.

Healthy family members in the household can safely get inactivated vaccines. **No live intranasal flu vaccine may be given.**

Immunization of children following a bone marrow transplant (stem cell transplant) are excluded from the above schedule. Timing and immunization schedule will depend on recovery of the immune system after the transplant. Recommendations will be customized.

sunscreen

Chemotherapy can make your child's skin even more sensitive to the sun. Certain medications (like Bactrim® and methotrexate) can make these sensitivities worse. When going outside, even for a short period, it is important to apply sunscreen. We recommend broad spectrum UVA/UVB sunscreen with 30 SPF or higher. Reapply every two hours or more as needed. Avoid all tanning beds during this time.

returning for clinic visits

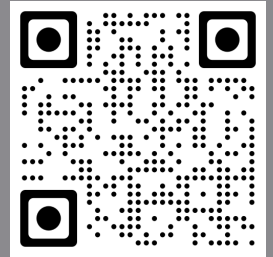
When you return for clinic visits, please bring the following:

- An up-to-date insurance card
- All of your child's medications so the nurse can review the medication and correct dosing
- Your medication calendar to report any missed doses or uses of "as needed" medications
- List of any questions, concerns or events that occurred since the last visit
 - Example: Illnesses, physical complaints, school problems

resources, tips and tools

when to call your doctor

- Fever of 101°F (38.3°C) or higher, **call immediately**
 - If a fever of 100.5°F, retake temperature in **one** hour. If fever still 100.5°F or higher, **call the doctor immediately.**
 - If your child's fever is not quite 101°F, do NOT give Tylenol (acetaminophen) as this will "mask" the fever. Retake the temperature as instructed.
 - If you do not have a thermometer at home, please let your nurse know.
- Chills
- Being exposed to chickenpox or shingles
 - Be prepared to tell the doctor when the exposure happened. You may be able to give medicine within 72 hours to prevent the disease or lessen side effects.
 - If you have concerns your child may have chicken pox or shingles, please call the hematology/oncology clinic **before** you bring your child in. They will be directed to an isolation area.
- Frequent diarrhea or vomiting (more than four times in eight hours)
- Seizures
- Change in mental status – being very sleepy, irritable or not making sense when talking
- Break in the central line, or port needle breaks/dislodges
- Pain not relieved with medication



Scan this code to watch a video with instructions for coming to the emergency department.

- Signs of bleeding
 - Red or black stools
 - Pink, red or brown urine
 - Red or coffee brown vomit
 - Bleeding gums or nosebleeds
 - Bruising or petechiae (small red or purple spots on the skin)
- Swollen or painful testicles
- Difficulty breathing
- Severe headache when he/she wakes up, especially if relieved by vomiting
- Let your physician know if your child stops drinking or begins to drool
- Call three days before your child needs dental work to get the right antibiotics
- Anything that you think is abnormal for your child



when to have your doctor paged after hours

(after 5:00 pm on weekdays, on weekends and holidays)

- Fever of 101°F (38.3°C) or higher, **call immediately**
 - o If a fever of 100.5°F, retake temperature in **one** hour.
If fever still 100.5°F or higher, **call the doctor immediately.**
 - If your child's fever is not quite 101°F, do NOT give Tylenol (acetaminophen) as this will "mask" the fever. Retake the temperature as instructed.
 - If you do not have a thermometer at home, please let your nurse know.
- Frequent diarrhea or vomiting (more than four times in eight hours)
- Seizures
- Change in mental status – being very sleepy, irritable, or not making sense when talking
- Chicken pox/shingles rash – itchy or painful, blister-like rash
- Uncontrollable bleeding
- Pain not relieved by prescription medication
- Break in the central line, or port needle breaks/dislodges
- Difficulty breathing

Please do not page the physician for medication refills or questions that can wait until the next clinic day.

call 911 or emergency services immediately if:

- Your child cannot breathe or is having difficulty breathing
- Is not able to wake up
- Is having a seizure

when to call your family doctor/pediatrician

For well-child visits and problems that are not directly related to your child's cancer treatment.

If you are unsure, always call and ask.

We are here to help you.

financial/insurance concerns

We understand that getting your child well is the top priority. We also understand that the medical care to help your child get better can cause financial worries and questions. Our social worker will meet with you during your hospital stay and can help you navigate these topics. We also have team members and resources to help you.

financial counselors

Our financial counselors meet with families who are in need of financial assistance or need help covering hospital expenses.

If you don't have insurance, have a large out-of-pocket co-pay, or have questions about insurance, call 937-641-3316.

patient accounts

For questions on medical bills you have already received, call our billing representatives who are available Monday - Friday from 8:00 am to 4:00 pm at 937-641-3555 or toll-free at 1-800-228-4594 (Ohio only).

children's financial assistance programs

For families that qualify, Dayton Children's offers:

- Financial aid for Dayton Children's health care bills
- Assistance by trained financial counselors, including help filing for Medicaid, HCAP and State Child Health Insurance Plans
- 100 percent financial aid, also known as charity care

other programs available for patients

- **Montgomery County Human Services Levy** – This is available for Montgomery County residents. It helps provide assistance for residents with overwhelming medical bills.
- **Ohio Medicaid and Healthy Start** – These programs provide assistance for families with income below 200 percent of the poverty level.
- **Ohio BCMH (Bureau for Children with Medical Handicaps)** – This program provides coverage for children with specific illnesses, such as cancer.
- **Ohio Care Assurance Program** – This program provides free care for any Ohio resident whose income falls below 100 percent of the federal poverty level.
- **Children’s Charity Care** – This program provides assistance to low-income families with large hospital bills.

3 tips to get started

get organized

Find one place in your home to keep all of your important information. This may include treatment plans, insurance information and/or upcoming bills.

Your child will also have many appointments with multiple departments. Use a calendar to keep track of all your child’s appointments.

read your medical plan

Take time to read your health plan information. Your human resources department may be able to provide you with additional information or answer any questions. In many instances, you may ask your insurance company to assign you a caseworker to help with questions and claims. Insurance information can be very complicated to understand. It may be helpful to talk directly with your employer’s benefit specialist.

talk to your employer

It is expected that you may need additional time away from work when your child is diagnosed with a serious medical condition. Talk with your human resources department to see if you qualify for the Family Medical Leave Act (FMLA). We are happy to fill out the necessary forms to help secure your job while you spend this time caring for your child.

other support resources

CaringBridge.org

Create an account to share health updates, photos and videos with people who care about you. You can customize your settings to make your updates private or public. The website is also designed to rally your family and friends together when you need support.

Special Wish of Dayton

A Special Wish grants wishes for children 0-20 years old diagnosed with life-threatening conditions. Visit their website (aspecialwishdayton.org) to refer a child. If the child meets the medical requirements, the Special Wish team works to create an unforgettable wish experience for the child and their family.

Flying Horse Farms - Located in Mt. Gilead, Ohio

Flying Horse Farms provides a delightful camp experience free of charge to families and children with serious illnesses. The camp is staffed 24/7 by a team of physicians, nurses and other health care professionals from across Ohio and Pennsylvania.



parent partners

Parents are the experts when it comes to their children. Your ideas and experiences are the key to helping us give children the best possible care. Parent partners are volunteers who share their stories, give us advice, and tell us what matters most to families.

Just like our children, parent partner opportunities come in all shapes and sizes. The following opportunities are currently available:

- Our E-Advisory council uses a private Facebook page called “Parent Partner Insider.” Caregivers are encouraged to answer polls, provide feedback on hot topics and tell us what is important.
- Our family action collaborative teams are made up of parents and staff members working together to improve care in a specific department or around a certain medical condition.
- Our patient family advisory council and The Center for Community Health and Advocacy meet monthly to offer input on issues that impact all children and the community.
- Our parents encouraging parents mentors have extensive experience with their own child and are trained to provide support through email and/or phone with a parent or caregiver facing a new diagnosis or on-going medical condition.

If you would like more information about how you can become part of our team, please contact our family partnership coordinator, Teresa Prouty, at parentpartners@childrensdayton.org or call 937-641-5904

notes and questions

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questions to ask					
instructions/recommendations					
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	surgery			tests	

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	surgery				tests



dayton
children's