Handbook for Patients and Families

Aflac Cancer & Blood Disorders Center
Children's Healthcare of Atlanta

General information sheet

Child’s name ____

Medical condition(s) ____

Address and phone numbers

Arthur M. Blank Hospital

2220 North Druid Hills Rd NE, Atlanta, GA 30329

Aflac Cancer and Blood Disorders Center
Outpatient Clinics: Floors 7, 8 and 9 South Tower
Inpatient Units: Floors 9 and 10 North and West Towers

• Clinics (Monday to Friday, 8 a.m. to 5 p.m.)	404-785-1200
• After hours (including nights, weekends and holidays)	404-785-1200
• Billing and finance	404-785-1222
• Patient representative	404-785-6163
• Emergencies	911

Your child’s primary healthcare team

Your child’s clinic team ___________________________________

Your child’s attending doctor _______________________________

Your child’s fellow doctor __________________________________

Your child’s advanced practice providers _____________________

Your child’s outpatient nurses ______________________________

Your child’s primary inpatient nurses ________________________

Your child’s social worker __________________________________

Your child’s child life specialists ___________________________

Your child’s patient teaching coordinators ____________________

Your child’s nurse coordinator ______________________________

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Welcome

The Aflac Cancer and Blood Disorders Center:

- Is one of the largest childhood cancer and blood disorders programs in the country.
- Serves babies, children, teens and young adults with cancer and blood disorders.
- Includes a multidisciplinary team of specialists.
- Provides advanced testing, clinical care and research options.

Our mission

To provide the best care to children and teens with cancer and blood disorders. We strive to do this by:

- Caring for your child's physical and emotional needs.
- Educating patients and families about their disease.
- Doing research to help find the best way to treat and cure these diseases.
- Improving the quality of life for children in our care.

About the handbook

This handbook explains the medical care your child will get at our center. It should not replace any instructions from your child's healthcare team. It is not meant to be medical advice or a complete resource for all information on this subject. Your Aflac Cancer and Blood Disorders Center provider is the best source of information about what is right for your child's treatment.

- Your healthcare team may give you more information specific to your child's diagnosis and treatment. That information will go into more detail about cancer diagnoses, treatments, side effects and caring for your child.
- You can find an electronic version of the Children's Oncology Group Family Handbook (in English, Spanish and French) at childrensoncologygroup.org under the patients and families section.
- The information in this handbook is for you and your family. The content is the result of the work of many authors and editors. Their experience and current research, literature and practice are the basis of this manual.

Our promise to you

Our first priority is to provide you and your child with the best family-centered care. Our whole team will provide the support you need through your treatment journey. We try to give you a nurturing and caring experience and environment during each admission and visit.

It is our mission to give you and your family the finest complete treatment. We are honored and humbled that you have placed your child in our care. We will work every day to live up to that trust.

We want to hear from you

We work to improve our programs to provide the best care possible for your child. We want to hear from you if you have concerns about the care you or your child received.

In the hospital

For immediate issues or concerns	**Ask to speak with the family experience liaison or the nurse in charge.**
For matters that need more attention	**Ask for the manager, then the clinical director of the Aflac Cancer and Blood Disorders Center if needed.**

In the clinic

For immediate issues or concerns	**Speak with your primary nurse. If the matter cannot be resolved by your nurse, ask to speak with the nurse in charge.**
For matters that need more attention	**Ask for the manager, then the clinical director of the Aflac Cancer and Blood Disorders Center if needed.**

If you have concerns after speaking to Aflac leadership or want to file a formal complaint please contact the patient representative. The phone number is on the first page of this handbook.

Who helps care for your child?

Children's Healthcare of Atlanta is a teaching and research hospital. You will meet clinical staff who are in learning programs or are part of a research team. Ask for more information about roles of the people who care for your child in the hospital.

Your child's healthcare team may include:

- Advanced practice providers (nurse practitioner or physician's assistant)
- Attending physicians (supervising doctor)
- Case managers
- Chaplains
- Child life specialists
- Clinical research associates
- Family experience liaisons
- Fellow physicians (doctor in training for cancer and blood disorders)
- House officer or residents (doctor in training)
- Medical students
- Music therapists
- Nurses
- Nutritionists
- Patient care specialist or techs
- Physical, occupational or speech therapists
- Psychiatrist or psychologists
- School teachers
- Social workers

School program

The Children's school program is a school program for children at the Aflac Cancer and Blood Disorders Center. The goal of this program is to help students with cancer or blood disorders make a smooth transition back to school after their diagnosis.

Ask to speak to your child's Aflac school teacher if you have questions or need help with school concerns. Your child's teacher can meet with you during your hospital stay or clinic visit. The teachers will work with your child's school so they get the support they need. The teacher will also help when they are ready to go back to school.

Fertility preservation team

Some treatments for cancer or blood disorders may damage your child's reproductive organs. This may cause infertility or make it difficult to have children biologically later in life. We have a fertility preservation team that can meet with you and your child to discuss this.

Ask your healthcare team for more information about your child's risk for fertility and whether you should meet with the fertility team. You can also visit the Fertility Preservation Program website at **choa.org/fertilitypreservation**.

Cancer Survivor Program

We believe survivors of childhood cancer should have long-term care in a specialized program. This follow up starts when your child has been off treatment for 2 years. Blood marrow transplant (BMT) survivors treated for non-cancer conditions are included. Your primary cancer or BMT team will refer your child to the program. This program includes a team of people who specialize in childhood cancer and BMT survivor issues. The team may include:

- Oncologist
- Endocrinologist
- Nurses
- Advanced practice providers
- Social worker
- School teacher
- Psychologist or neuropsychologist
- Other specialists your child might need.

Goals of the program

- Every person in Georgia who has been treated for childhood cancer is checked for long term side effects.
- Raise awareness of the need for lifelong follow-up care for cancer survivors.
- Teach you and your family about the risks of long term cancer treatment and BMT.
- Teach you and your family how you can improve your child’s health and quality of life.
- Research how to help cancer survivors prevent late effects.

Caring for your child in the hospital

Tips for staying in the hospital

There are times when your child will be admitted, or stay overnight, at the hospital. We know that being in the hospital is not like being at home. Try to take everything 1 day at a time. Here are some things that may help your say at the hospital:

- Comfort items like a favorite pillow, blanket or stuffed animal.
- Your child's own clothes or pajamas.
- A journal or a notebook to write down notes and questions.
- A list of your child's medicines and doses.
- Things to entertain you and your child like activities, movies and books.
- You and your child's favorite snacks.
- Layers of clothes. The room temperatures may change often.
- Laundry detergent and dish soap if needed.
- Music, white noise, ear plugs or noise canceling headphones to drown out hospital sounds so you and your child can rest.

Ask questions when you have them. Everyone on our team is here for you.

Family-centered rounds

Each day your child's healthcare team meets with you to talk about the plan of care for your child. This most often happens between 9:30 a.m. and 12:30 p.m. but may be later on the weekends. Times may differ depending on the needs of your child. Let a team member know if you would like rounds to happen outside of the room.

- Please wake up and be ready before the team comes to the room. Always check with your child's nurse before leaving the unit to see when the team may be rounding on your child.
- We value your input in decision-making. We will ask for your suggestions and if you have questions. Write them down before rounds so we can talk about them with you.
- The team will talk with you about your child's:
    - Current symptoms.
    - Blood tests and imaging results.
    - Fluid intake and output.
    - Response to treatment.
    - Plan of care.

Patient and family responsibilities in the hospital

Hand hygiene (handwashing)

- When entering and exiting your child's room
- Before and after eating
- After cleaning up body fluids (when you change a diaper or empty a urinal)
- Before touching your child
- After using the restroom

Patient hygiene

- Your child should take a soap and water bath every day when they are in the hospital. Talk with your child's nurse if your child has a central line or you need help bathing your child.
- Patients with a high risk of infection must wear a mask when they are outside of their hospital room. The nurse will explain this to you if it applies to your child.

If your child has a central line (port, PICC or chest line):

- Daily chlorhexidine (CHG) baths if they are older than 2 months. Your nurse or tech will give you this special soap (as a liquid or wipes). Talk with your child's nurse about how the CHG bath will help protect your child from germs on their skin.
- Brush their teeth 2 times each day with a soft toothbrush and the hospital provided toothpaste.
- Rinse their mouth with the hospital provided mouthwash 3 times each day.
- Apply lanolin-based lip moisturizer 2 times each day.

Room hygiene

- Your child should have their bed linens changed every day and more often if dirty. Bed linens include sheets, blankets, pillowcases and personal bedding or comfort item. The hospital staff will help you change linens. Personal items should be washed daily in the family laundry room.
- Keep the bedside table and countertops clean. Please limit extra food and stuff.
- Throw away food and drinks in a timely manner. Talk with your care team about this.
- Our Environmental Services (EVS) team will clean your child's room every day. Please allow them to do this during the day when they are staffed appropriately.
- Speak up if linens are not changed, your room needs extra cleaning or staff are not washing their hands.

Visitor guidelines in the hospital

All visitors must wash their hand when they enter and leave your child's room.

- It is best for your child to have a parent or caregiver spend the night.
- Visitors who have a fever, rash, diarrhea, vomiting (throwing up) or other illness cannot visit.
- Visitors exposed to chickenpox or shingles cannot visit the hospital.
- Visitors younger than 18 years old can only visit your child when an adult is with them. This includes siblings.
- The number of visitors may be limited at times due to respiratory illnesses in the community. Ask your child's healthcare team about the current rules.

Discharge

The team will send your child home (discharge) when they have met their goals of treatment. These are the things the team talks with you about during family centered rounds. Time of discharge depends on your child's medicines, treatments, deliveries and ability to meet their goals. You will get paper instructions including a home medicine schedule.

- Your child's nurse will review medicines with you. Make sure you have them for home and know how to give them. This is a very important part of discharge.
- Please talk with your nurse or case manager if you have any questions about how to get home medicines.
- Ask your nurse what time your child might be discharged. Plan transportation for that time. Please tell your nurse as soon as possible if you need help with transportation.
- Remember to check the room for all belongings including phone chargers and electronics before leaving.

Caring for your child at home

Preventing infection at home

Your child may be exposed to people with infections. This can happen at home, school or in the community. Your child should wash their hands often. Handwashing is the best way to prevent infection. Other tips to lower the chance of infection include:

- Do not share drinks, food or toothbrushes. Throw away food and drinks in a timely manner.
- Do not allow sick visitors. Anyone who has had symptoms in the last 2 days should not visit or play with your child. Symptoms include:
  - Cough
  - Fever
  - Diarrhea or vomiting
  - Runny nose
  - Rash
- Keep your child's skin as clean as possible. If they wear diapers, keep the area very clean and dry. Change their diaper every 2 to 4 hours if they have redness or rash.
- Bathe your child with soap and water every day. Brush your child's teeth 2 times each day.
- Clean personal items often when in the community or when someone is sick at home. This includes things like
  - Cell phones
  - Remotes
  - Tablets
  - Toys
  - Game controllers
- Many of our families have pets at home. Is it okay to keep your pets and for your child to interact with their pets.
  - Talk with your child's Aflac team about the pets you have at home. Check with your child's team if your family is planning to get a new pet.
  - Your child should not clean up after animals (cat litter, bird cages, turtle or fish aquariums or similar spaces).
  - Stool and urine from animals may carry infections that can spread to your child.

Taking your child's temperature

- Make sure that you have a thermometer that works and that you know how to use it.
- You do not need to take your child's temperature every day. Take your child's temperature if your child feels warm to the touch or does not feel or look well.
- Take their temperature in the mouth, under their arm or in the ear (using a special thermometer). **Do not take a rectal temperature. This can cause bleeding or an infection.**

When to call your child’s Aflac doctor

The following is a list of signs and symptoms that require you to call.

Call 911 or go to the nearest emergency department right away if your child has:

- Trouble breathing.
- Skin, lips or nails that look blue.
- A new seizure or a seizure that is not normal for your child.
- You cannot wake your child up (change in level of consciousness).

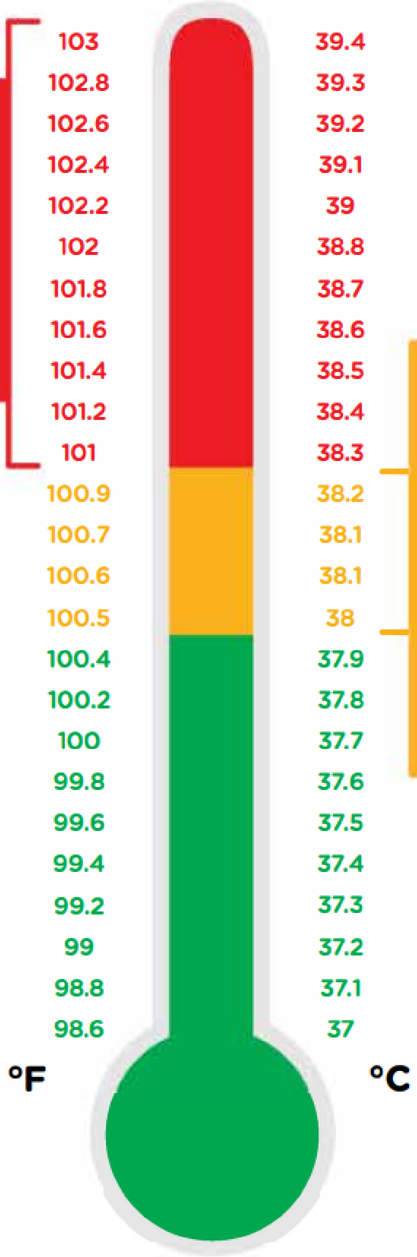
Call your child’s Aflac doctor right away if your child has:

- A fever of 101°F (38.3°C) or higher at any time.
- A fever of 100.5°F (38.0°C) to 100.9 (38.2°C) twice in 1 hour.
- Any signs of infection like a new rash, cough, runny nose, diarrhea or vomiting.
- Redness, swelling or drainage around your child’s port or central line.
- Bleeding that does not stop within 5 minutes.
- Stopped responding to your questions (your child may be awake but not acting themselves).
- Blurry vision (trouble seeing) or a change in vision.
- A severe headache that does not go away with your child’s normal pain medicine.
- Dehydration, not able to drink fluids.
- Been around someone with chickenpox or shingles.
- Questions about medicines.
- Concerns about symptoms and how to treat them.

Do not wait for the clinic to open. Always call right away if you have concerns about your child.

Fever with low blood counts

This is a fever. Call your doctor immediately. Do not give your child any fever-reducing medicine, such as Tylenol (acetaminophen) or Motrin (ibuprofen).



Do not give your child any fever-reducing medicine, such as Tylenol (acetaminophen) or Motrin (ibuprofen). Recheck their fever in 30 minutes to an hour. If their temperature is still 100.5°F or higher, call your doctor.

Contact your Aflac Cancer and Blood Disorders Center doctor:
Arthur M. Blank Hospital, 404-785-1200

Aflac
Cancer & Blood Disorders Center
Children's
Healthcare of Atlanta

Visiting the emergency department

Most children will visit the emergency department (ED) during their treatment. Our goal is that you and your child have a quick and smooth visit. **It is important that you call your Aflac team before you get to the ED so we can prepare for your child**.

A fever is an emergency for your child if they are immunosuppressed or have a central line.

Our doctors or nurses may tell you to go to the ED if your child has

- A fever, bleeding, pain or dehydration
- An issue with their central line
- Other emergencies that cannot be treated at home

Give the ED staff the following information about your child:

- Their diagnosis and important treatment information (medicines, chemotherapy, radiation or bone marrow transplant).
- Their emergency card. You should have received this card when your child was diagnosed. This helps the ED team decide the best care for your child.

It is very important that you get care right away for a fever.

Remember these important tips for quick, safe care in the ED:

- Always call your child's Aflac doctor before going to the ED. There is a pre-registration process that will register your child before they get to the ED. This will shorten the wait time.
- Give a working cell phone number. This allows the Aflac team and the ED to call you. It may delay your child's care if you go to the ED without calling the doctor first or give the wrong phone number.
- If possible, it is best to go to the Arthur M. Blank Hospital. Tell the Aflac team if you **live more than 1 hour** away. The doctor may plan for care at another ED. Please call your child's doctor as soon as possible to help coordinate safe care for your child.
- Do not give your child anything to treat a fever, like Tylenol (acetaminophen) or Motrin (ibuprofen), unless instructed by your doctor.
- It is very important for the ED get blood tests (labs) and I.V. antibiotics quickly if your child has a fever. The ED staff will poke your child for labs and antibiotics if they are unable to use your child's port, central line or PICC. This is the safest way to get your child treatment quickly.
- If your child has a port, put numbing cream on their port site before getting to the ED. You can choose 2 other spots for numbing cream if needed for pokes. Do not place numbing cream on more than 3 sites at a time.
- Pack a bag in case your child needs to spend the night in the hospital. Bring personal items and a list of your child's medicines.

Outpatient clinics

Clinic appointments

Making an appointment

Clinic hours: Monday to Friday, 8 a.m. to 5 p.m.

- Call during clinic hours to make an appointment. You should know the name of your child's doctor.
- Please be on time for your clinic appointment. The appointment may be rescheduled if you are more than 20 minutes late.
- Arrive 30 minutes before your appointment to allow time to park and get through security.

Visitor and sibling guidelines

- Siblings and other family members may come to the clinic with you and your child.
- Please do not bring siblings or visitors who are sick. This includes fever, runny nose, cough, sore throat, diarrhea and vomiting.

Before the appointment

- Put numbing cream on your child's port or poke sites, 30 minutes to 1 hour before the appointment.

What to bring to the clinic

- A list of your child's current medicines and doses. Bring medicine bottles and your pharmacy details.
- Your child's insurance information.
- A lunch or snack if you are going to be at the clinic for many hours.
- Activities for your child to do.

If your child has a fever with a cough or rash, please call the clinic before you arrive or tell the clinic staff as soon as you arrive. Tell the staff if there are any exposures to or cases of chickenpox in your child's school or daycare.

Clinic check-in

- You may be asked to fill out some forms and confirm your address and phone number. You will sit in the waiting room until your child's name is called.
- All children younger than 18 years old must have a parent or guardian with them. A parent or guardian must come to every visit and stay with the child for the whole visit.
- A staff member will take you to a triage room. They will check your child's vital signs, height and weight.
- Then the staff member will then take you to a clinic room to wait for your child's nurse or doctor.

Numbing cream

What is numbing cream?

Numbing cream is used to help prevent pain with a needle stick. You may be given a prescription for numbing cream, also called EMLA or LMX. There are also over the counter brands of numbing cream you can buy at your local pharmacy, like 4% lidocaine cream.

Who uses numbing cream?

Any child getting a needle stick for:

- Blood draw or IV placement
- Port Access
- Lumbar puncture
- Medication injection

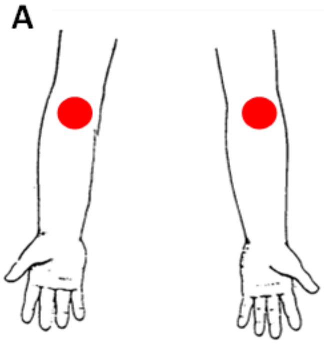
How to use numbing cream:

- Follow instructions on the packing to open the tube.
- Put on the skin **30 minutes before needle stick**.
- Put a quarter-sized amount on areas that may get a needle stick. **Do not rub cream into the skin.**
- Put clear plastic wrap (like Press ‘N’ Seal® Glad® product) with the sticky side down on top of the cream so it does not rub off.
- **Only put cream on a maximum of 3 areas of the skin at a time** (ex: both elbows and port site).
- **Do not leave it your child’s skin for more than 2 hours.**

Where to put numbing cream:

For blood draws and IVs: Apply cream to the inside of the elbows where the arm bends (site A) and/or tops of hands (site B).

A



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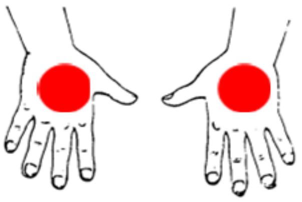
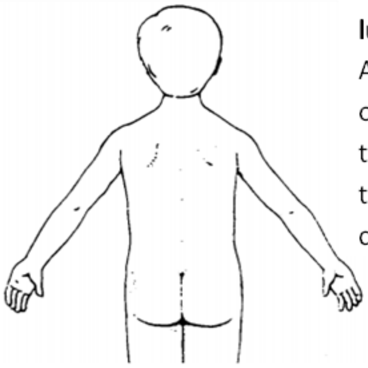
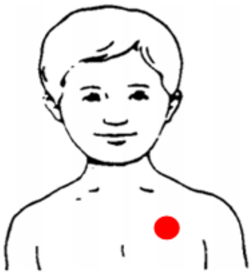


For spinal taps or lumbar punctures: Apply cream to center of lower back. Find the tops of hipbones and trace your finger to the center of lower back.



For port access: Ports can be placed in several areas of the chest. Apply the cream to the port site appropriate for your child.



Labs before clinic appointments

Why does my child need labs before their visit?

Some procedures and treatments are not safe if your child's blood counts are too low.

Your child's Aflac team may check labs before:

- Sedation
- Chemotherapy
- Blood transfusions
- Admissions
- Surgeries

If your child gets labs checked before their visit, it could:

- Prevent delays in care and avoid wait times.
- Reduce unnecessary trips to the clinic or hospital.

Where can we get labs checked?

When your child gets labs before a clinic visit for chemotherapy or transfusions the following is important:

- Only nurses at a children's hospital or Aflac clinic should use your child's central line to draw these labs.
- Your child should be poked for labs at an outpatient site or other medical site.
- Labs are drawn at:
    - Arthur M. Blank Hospital main lab.
    - Children's outpatient locations.
    - Local sites such as Quest, LabCorp and medical centers as instructed by your team.

NOTE: If your child needs a type and screen drawn for blood products, this must be done at the Aflac clinic where the transfusion will occur or in the main lab at the hospital the transfusion will be done.

What do I need before my child gets labs?

- Lab orders
    - The Aflac team sends the order if you go to a Children's location.
    - We will give you a paper order for a non-Children's location.
- Lab locations and contact information.
- Numbing cream, refer to the numbing cream teaching sheet.

When should I contact the Aflac team?

- If you have trouble with lab orders at the lab location.
- If you want to know lab results before the visit.
- To let us know when the labs have been drawn.

Sedation and procedures

Your child will go to the sedation suite if they need a bone marrow aspirate or lumbar puncture. Sedation staff will call you 1 to 2 days before your sedation appointment to give you an arrival time. They will also give instructions about eating and drinking before the appointment. Review your child's medicines with the nurse when they call. You can expect that your child can:

- Eat solid foods (including hard candy) or chew gum until 6 hours before the appointment.
- Drink clear liquids until 2 hours before the appointment.
- Have breast milk until 4 hours before the appointment.

NOTE: Some children have their procedures done in other locations like the operating room or interventional radiology. The instructions for eating, drinking and arrival times may be different. You should expect a phone call from that department before your scheduled procedure with specific instructions.

Marcus Infusion Center

The Marcus Infusion Center is an outpatient space in the Aflac Cancer and Blood Disorders Center on the 9th floor of the south tower. It provides extended clinic hours (8:00 am to 8:00 pm) for:

- Infusions, chemotherapy and IV fluids.
- Blood and platelet transfusions.
- Sick visits.

What to expect

- There are private and semi-private rooms. Each space has a TV and a chair for a parent or guardian.
- You can bring food with you. You can also buy food in the cafeteria or coffee shop.
- A parent or guardian can go into the infusion room with their child.
- A child life specialist can help support your child.

How do I schedule an appointment?

The Marcus Infusion Center is open Monday to Friday from 8 a.m. to 8 p.m. Infusion appointments can be made with a scheduler. **Walk-in visits are not accepted.**

Communicating with the clinic

Calling the clinic

What options will I hear?

- Transfer to Spanish
- Sick, fever or urgent concern
- Scheduling or canceling appointments
- To speak with your nurses for medicine refills or routine questions
- For other doctors, hospital or pharmacies to speak with our team
- Contact information, address and directions
- Medical Records
- Running late for an appointment

Call for urgent needs during office hours: Monday to Friday, 8 a.m. to 5 p.m.

Sick or urgent calls include:

- A fever at or above 101°F (38.3°C)
- A fever of 100.5°F (38.0°C) to 100.9 (38.2°C) twice in 1 hour.
- Any other signs of illness, dehydration, severe headache, uncontrolled pain or bleeding.

Call your child's Aflac clinic. Choose the option for sick or urgent call. **Leave a voicemail. Call again if you do not get a call back in 15 minutes. Come to the emergency department if you called 2 times and no one called you back.**

Call for urgent needs after hours, on weekends or holidays

Call the Aflac clinic. Your call will go to an **call center**. The on call doctor will call you back within 15 minutes. Call again if you do not get a call back in 15 minutes. Come to the ED if you called 2 times and no one called you back.

In case of an urgent concern or emergency, call 911 or go to the nearest emergency department right away.

If you have a routine question or need a prescription medicine refill:
Call your child's Aflac clinic during office hours and press the option to speak with a nurse. Then choose your child's team. A nurse will call you back.

- Please call 2 to 3 days before your child is out of medicine. This allows time to refill your prescription.
- On call doctors can not refill narcotic pain medicines after hours.

MYchart

Mychart is another way to communicate with your Aflac team about your child’s care. Mychart can be used for:

- Routine questions
- Prescription refills
- Limited lab results and medical information

You can sign up for a Mychart account during your clinic appointment or from home. Please visit **choa.org/Mychart** to learn more. If you have urgent issues, please contact your child’s doctor **by phone** right away. Do not use Mychart for urgent issues or concerns.

Other resources

Children’s Oncology Group

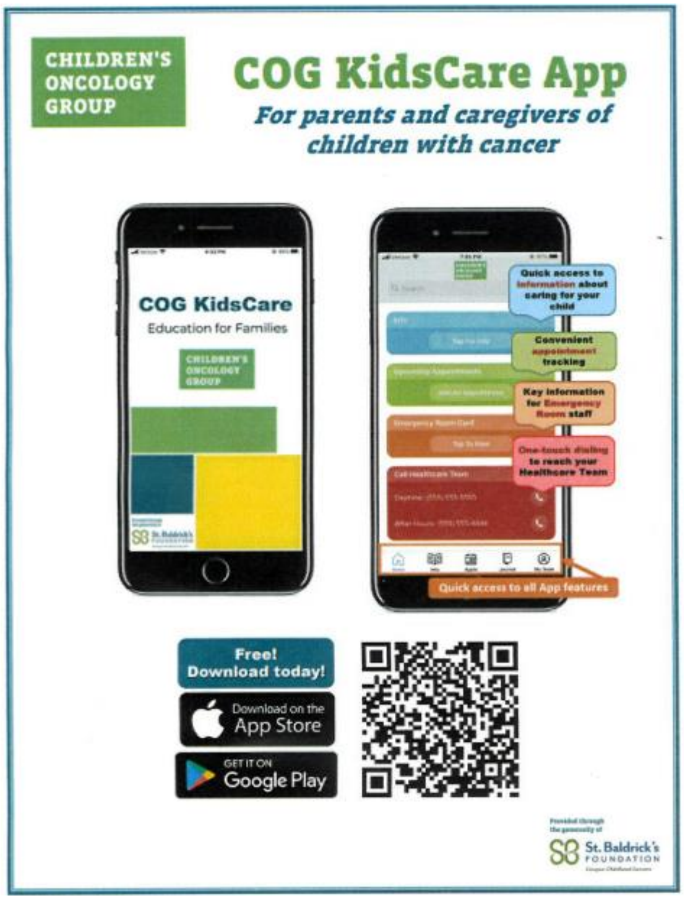
Video with Aflac information:

New Diagnosis Guide: Caring for Your Child at Home – Video (password = CHOA-COG1):

English Video Time Stamps:

- Welcome – 00:00
- What is cancer? (00:26)
- How is cancer treated? (00:53)
- What is a PICC? (1:58)
- What is an external CVL? (2:13)
- What is a port? (2:45)
- Numbing cream (3:00)
- Talking with your child about cancer (3:28)
- Clinical trials (4:06)
- How to call the Aflac cancer center (5:04)
- When to call 9-1-1 (6:10)
- Fever guidelines (6:33)
- How to check temperature (8:03)
- When to call for immediate help (8:17)
- POP process (9:04)
- Oncology wallet card (9:58)
- Cancer center locations (10:23)
- Managing symptoms (10:36)
- Infection prevention (13:56)
- Other precautions (15:31)
- Giving medicines (17:05)
- Brain tumor and shunt precautions (18:05)
- Review (18:49)

Family handbook:


CHILDREN'S ONCOLOGY GROUP

COG KidsCare App

For parents and caregivers of children with cancer

Free! Download today!

Download on the App Store

GET IT ON Google Play

Provided through the generosity of St. Baldrick's Foundation

APHON

Diagnosis specific handbooks:

https://www.aphon.org/education/patient-family-resources/

This handbook should not replace instructions given to you by your child's doctor and healthcare team. It is not meant to be medical advice or a complete source of all information about this subject. Your child's doctor is the best source of information about what is best for your child's treatment and care.

Health-related information changes frequently, and therefore information contained in this handbook may be outdated, incomplete or incorrect. This handbook may contain printed material that has been updated by Children's Healthcare of Atlanta. Please talk with a member of your child's healthcare team if you need an up-to-date copy.

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Call 911 or go to the nearest emergency department right away in case of an urgent concern or emergency.

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