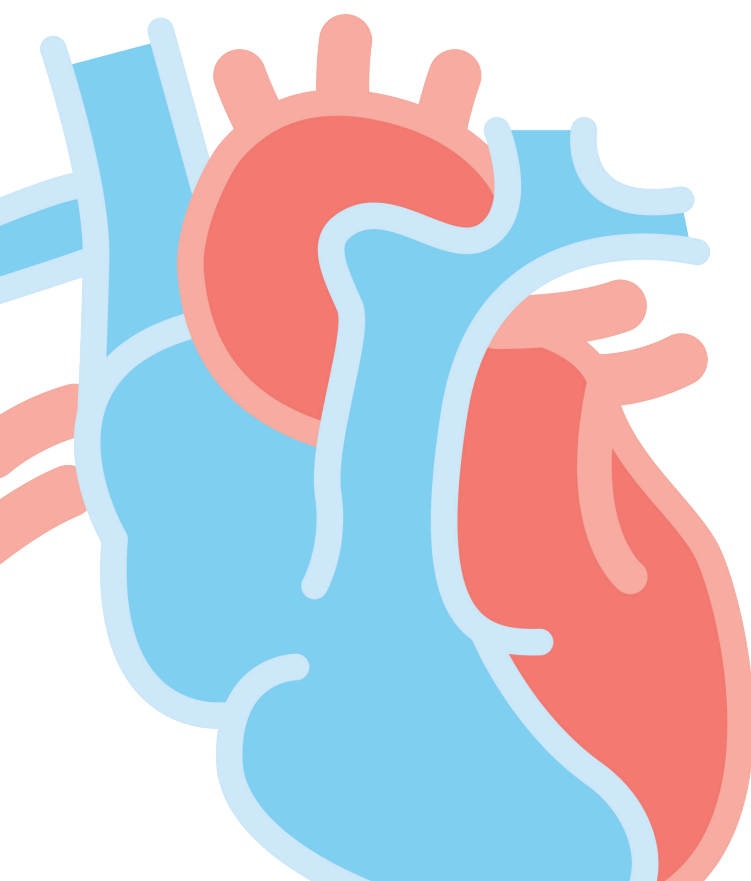




Boston Children's Hospital
Cardiology

BOSTON CHILDREN'S HOSPITAL
CARDIAC ANTITHROMBOSIS MONITORING PROGRAM (CAMP)

Direct Oral Anticoagulant Home Guide



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Hospital Department of
Cardiology

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Your information

THIS BOOK BELONGS TO

MY CHILD'S ANTICOAGULATION (BLOOD THINNER) MEDICATION

WHY MY CHILD NEEDS THIS MEDICATION

HOW LONG TO GIVE THIS MEDICATION

Our information

8:00 a.m. - 5:00 p.m., Monday - Friday, except Massachusetts state holidays

CAMP OFFICE HOURS

857-218-4974

PHONE

617-730-4636

FAX

CAMP@cardio.chboston.org

E-MAIL

24/7 On-call service

Call us at 857-218-4974 and press 1 to be connected to the page operator.
Ask them to page CAMP team and leave your name and callback number.

CAMP team

Amy Hellinger, PharmD

CAMP PHARMACIST

Molly Morrison, NP

CAMP NURSE PRACTITIONER

Natalia Miranda

CAMP ADMINISTRATIVE ASSISTANT

Courtney O'Shea, RN

CAMP NURSE

Paul Estes, MD; Christina VanderPluym, MD and Ryan Williams, MD

CAMP PHYSICIANS

Cardiology team

CARDIOLOGIST

CARDIOVASCULAR SURGEON

1 Contact us

How to contact the CAMP team

You can reach the CAMP office Monday–Friday, 8:00 a.m. – 5:00 p.m., to schedule appointments, get blood test results, request prescription refills and for all other non-emergency issues. You may call or email us as long as it is not urgent.

- **Phone:** 857-218-4974
- **Fax:** 617-730-4636
- **Email:** CAMP@cardio.chboston.org

For urgent or emergency matters

Monday–Friday, 8:00 a.m. – 5:00 p.m.

Call the CAMP office at 857-218-4974 and ask to speak to a coordinator. If you cannot get through to the office quickly, follow the after-hours steps below.

After hours, weekends and holidays

Call the office 857-218-4974 and press 1 to be connected to the page operator. Ask to page the CAMP team, leave your name and best callback number.

When to get in touch with the CAMP team

Non-urgent, but let us know as soon as possible:

- Missed a dose of any anticoagulant medications
- Starting a new medication
- Refill requests
- Blood test orders
- Upcoming surgical or dental procedures
- Concern for bleeding, increased bruising
- Any questions or concerns

Urgent:

- Severe headache
- Abdominal pain or swelling
- Severe back pain
- Head injury
- Bleeding that you cannot stop (lasting more than 10 minutes)
- Coughing up/vomiting blood (bright red or coffee colored)
- Blood in stool (black or red stool) or urine (tea colored or red pee)
- Bloody nose that lasts longer than 20 minutes
- Severe joint pain/swelling of joint
- Any other serious injury or trauma
- Any urgent concerns
- Any hospitalization

2 Introduction

This guide is intended to help our patients and families understand and manage a group of medications that prevent or treat abnormal blood clots from forming in the body.

The CAMP team is part of Cardiology at Boston Children's Hospital. Our team is made up of physicians, coordinators (nurses/nurse practitioners/pharmacist), a nutritionist and administrators. Our goal is to help your family manage antithrombosis therapy.

Antithrombosis is the process of slowing down the body's blood clotting process to prevent abnormal blood clots from forming or worsening. There are many different types of antithrombosis medications—some called anticoagulants (blood thinners) and some called antiplatelet agents. Each medication works differently to slow down the body's clotting system. Your child may take both an anticoagulant and an antiplatelet agent at the same time.

What is direct oral anticoagulant therapy?

Direct oral anticoagulants (DOACs)

- Newer kind of oral anticoagulant medications taken 1 or 2 times a day
- Many different types, most commonly used include:
 - » Apixaban (Eliquis®)
 - » Rivaroxaban (Xarelto®)
- Fewer blood tests needed than other anticoagulant medications (tests needed at the beginning of therapy, in 3-6 months and then yearly)
- Reversal agent (antidote) available

The most commonly used antiplatelet agents at home are:

- Acetylsalicylic acid (aspirin)
- Clopidogrel (Plavix®)
- Dipyridamole (Persantine®)

What you need to know



Why your child is on this medication



Why it is important to give medication exactly the way you are told to



Who to call for prescription refills, medication changes or with questions

3 Apixaban

Apixaban (Eliquis®): give twice a day

What is apixaban?

Apixaban is a blood thinner that helps to prevent strokes and blood clots and to treat blood clots. **Twice daily - as close to 12 hours apart as possible.**

How do I give apixaban?

In order for apixaban to work well, it must be taken as prescribed: 2 times a day, every day.

- Apixaban can be taken with or without food. If apixaban gives your child an upset stomach, give it with food.

What blood tests will my child need?

- **First blood test:** Your child will need a test called an apixaban peak level which is a time sensitive test. The level should be drawn 3-4 hours after a morning dose after the 4th dose of apixaban. They will have to test to check their liver and kidneys and complete blood count if they haven't had this done within 3 months of starting apixaban.
- We will help you schedule these blood tests.
- **Annual blood tests:** Each year, your child will have their blood tested to measure the apixaban level, a complete blood count and liver and kidney tests.

What are side effects of apixaban?

The major side effect is *increased risk* of bleeding and bleeding for longer amount of time, so your child needs to be careful to avoid getting hurt.

- A change in how the liver works
- Upset stomach
- Apixaban may not be safe during pregnancy.
Call your provider and CAMP team if there is a chance of pregnancy.

What if I miss a dose of apixaban?

If it is less than 6 hours from the time of the missed dose, give it right away. If it is close to the time for the next dose, skip the missed dose and go back to your normal time.

What medications should my child not have while taking apixaban?

Don't give your child ibuprofen (Advil®, Motrin®, Midol®, Aleve®). These medications can increase the risk of bleeding. Call the CAMP team before giving these medications. Tylenol® is safe to take to treat pain and a fever.

SIGNS OF MINOR (SLIGHT) BLEEDING

Nose bleeds and gum bleeds

Menstrual bleeding that is heavier than normal

Easy bruising

Bleeding after cuts that takes longer to stop

Do not stop giving apixaban if your child has minor bleeding. Instead, call the CAMP team and we'll help you come up with a safe plan.

SIGNS OF MAJOR BLEEDING

Red, dark, tea/coffee colored urine

Red or black stool (bowel movement)

Coughing up or vomiting bright red blood or "coffee ground" colored

A cut that doesn't stop bleeding after 10 minutes of pressure

A serious fall or hit to the head

Anything that brings your child to an emergency department or hospital

4 Rivaroxaban

Rivaroxaban (Xarelto®): can be given once a day, twice a day, or some patients need 3 times a day.

What is rivaroxaban?

Rivaroxaban is a blood thinner that helps prevent and treat strokes and blood clots.

How do I give rivaroxaban?

- Give the medication as prescribed by your doctor at the same time each day.
- Rivaroxaban should be taken with food.
- You may crush the tablets and mix with food, such as applesauce, if needed. Your child should take it right after mixing.

What are side effects of rivaroxaban?

Side effects may include:

- Increased bleeding: While taking this medication your child may bleed more easily, so they should be careful to avoid getting hurt.
- Dizziness
- Fainting (passing out)
- Headache
- Numbness or tingling in hands and/or feet
- Increased bruising or bleeding

What if I miss a dose of rivaroxaban?

If your child takes 1 dose a day: Give a missed dose as soon as you remember it. If it's close to the time for your next dose, skip the missed dose and go back to your normal time.

If your child takes 2 doses a day: Give the missed dose as soon as you remember it. If it's close to the time for your next dose, skip the missed dose and go back to your normal time. Contact the CAMP team.

If your child takes 3 doses a day: Skip the missed dose and take the next dose at your normal time.



5 Blood clots

What is a blood clot?

A blood clot is a clump of blood that has changed from a liquid to a gel-like state. You may see them called thrombus or an embolism.

Blood clots can form in any blood vessels in the body, either the arteries or the veins. They are risky because if they cause complete blockage of the vessel, they can result in decreased blood flow to that area or decreased blood return from that area. If the clot breaks free, it can also move to other organs in the body such as the lungs (pulmonary embolism) or the brain (stroke).

What causes a blood clot?

Most people don't develop blood clots spontaneously. They are usually provoked by something inserted into a blood vessel or by artificial material in the heart. Some people have genetic reasons for developing blood clots, and it may "run in the family," so let your doctor know if other people in your family have had blood clots.

We can do special tests to confirm if your child has these conditions.

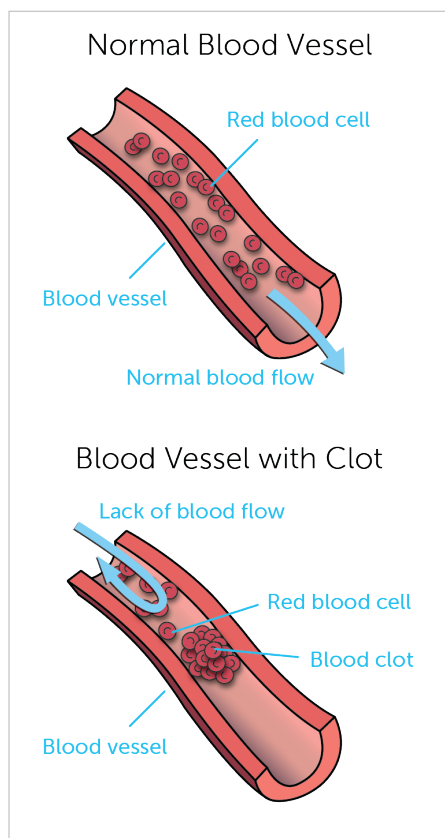
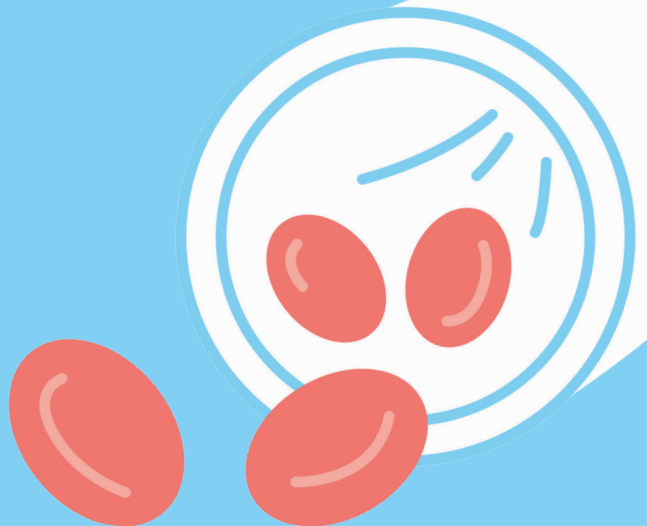


Figure 1

Who is at risk of getting a blood clot?

Children with these conditions may be at increased risk of clots:

- Artificial (mechanical or prosthetic) heart valves
- Certain types of heart arrhythmias (abnormal heart rhythms)
- Congenital heart disease (Fontan, Glenn, shunts)
- Cardiomyopathy
- Heart failure
- Kawasaki disease with/without coronary aneurysms
- Pulmonary hypertension
- History of blood clots
- Family history of blood clots (strokes, pulmonary embolism, deep vein thrombosis)
- Ventricular assist devices



6 Side effects of anticoagulant therapy

What should I do about my child's bloody noses?

A common side effect of anticoagulant and antiplatelet therapy is nosebleeds. These medications don't cause nosebleeds, but they make any minor trauma to the nose more likely to bleed and for longer amounts of time. The goal is prevention, or keeping nosebleeds from happening. We will teach your family ways to prevent nosebleeds, as well as ways of treating a nosebleed.

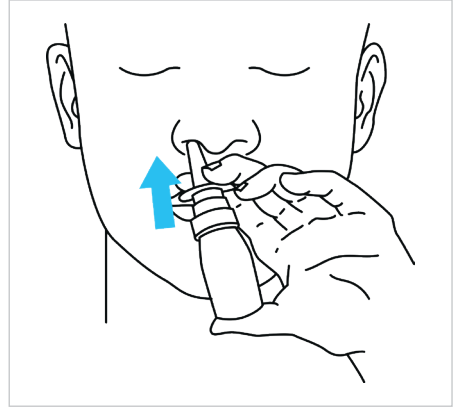


Figure 2

Prevention

- Keep fingers and other objects out of the nose!
- Spray saline nasal spray 2 times in each nostril once in the morning and once at night (see figure 2).
- Apply a pea-size amount of Vaseline to each side of the septum (inside middle divider of the nose) after saline spray once in the morning and once at night.
- Use a cool-mist humidifier in your child's bedroom.

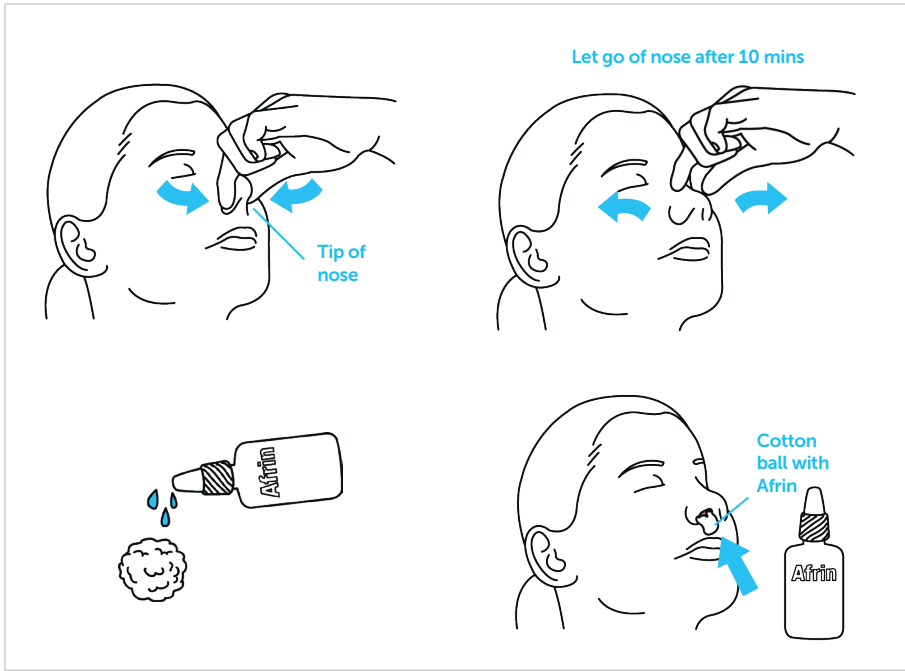


Figure 3

Treatment (see figure 3)

- Pinch the tip of the nose at the bottom (soft part of the nose) tightly for at least 10 minutes while keeping the head upright.
- Do not let go of the nose to check for blood during this time because it might irritate the broken vessels and cause more bleeding.
- After 10 minutes, gently let go of the nose. If it keeps bleeding, hold the nose for 10 minutes again.
- If bleeding continues, soak $\frac{1}{2}$ a cotton ball with Afrin (available over the counter) and then stuff it gently into the bleeding nostril. Continue to pinch the nose firmly afterward for 10 minutes.
- Don't put anything inside the nose to stop the bleeding except cotton balls soaked with Afrin.
- If this doesn't work and the nose is still bleeding a lot, call the CAMP team. You might need to go to an Emergency Room if it lasts longer than 1 hour.

7 Activity recommendations

Are there activities my child can't do while taking antithrombosis medications?

We want your child to stay active and exercise. If you don't see an activity on this list that your child likes to do, please ask us about it. As you can imagine, serious falls or injuries can be very dangerous for someone on antithrombosis therapy. We want to make your child's life as full and fun as possible, so let us know what activities are important and we will discuss a safe plan with all your providers.

SAFE ACTIVITIES		
Running Swimming Frisbee	Golf Tennis	Walking Playing

THESE ACTIVITIES ARE SAFE, BUT YOUR CHILD NEEDS TO WEAR SAFETY EQUIPMENT		
Baseball (not catcher) Basketball Bike riding Cheerleading (not above the ground) Gymnastics (not above the ground)	Horseback riding Ice skating Karate/Tai chi Mountain biking Roller skating Skateboarding	Skiing Snowboarding Soccer Track and field Volleyball Weight lifting

NOT SAFE		
ATV riding Competitive driving Field hockey Tackle football	Ice hockey Motorcycle riding Rock climbing	Rugby Tae kwon do Wrestling

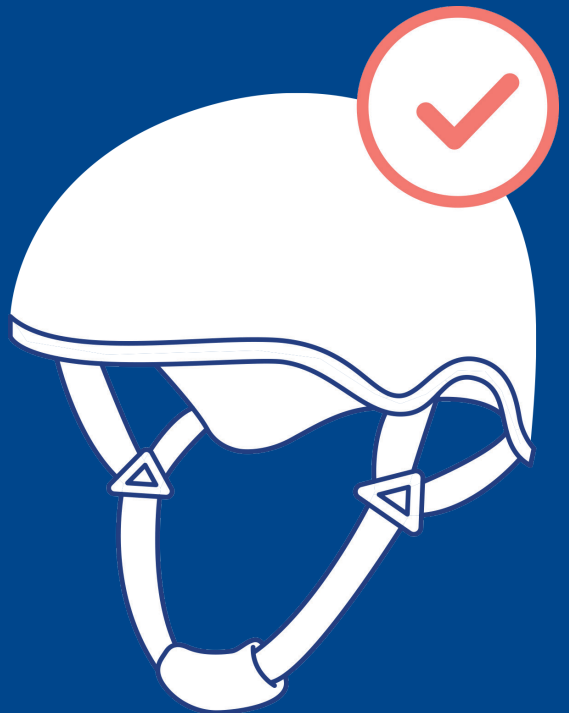
Safety guidelines

Please use safety equipment whenever possible and always use a helmet! Use knee pads and wrist guards. Try to prevent falls and remove things that could cause falls at home. This is especially important for younger children.

Please use either the medical alert bracelet we gave you or have one made. Always tell school nurses and teachers about bleeding risks and about being on an anticoagulant.

Use a soft bristle toothbrush and an electric razor (if that is needed).

Direct oral anticoagulant therapies can potentially increase menstrual bleeding or impact the frequency of periods. Please contact the CAMP team if there are concerns about increased bleeding.



8 Procedure



What do I do before a surgical or dental procedure?

Anticoagulant or antiplatelet medications may need to be stopped before a procedure. Please get in touch with us as soon as you know about a procedure so we can talk about a safe plan. Please do not stop medication until you speak with us. We will also form a safe plan to restart the medication.

9 Notes

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