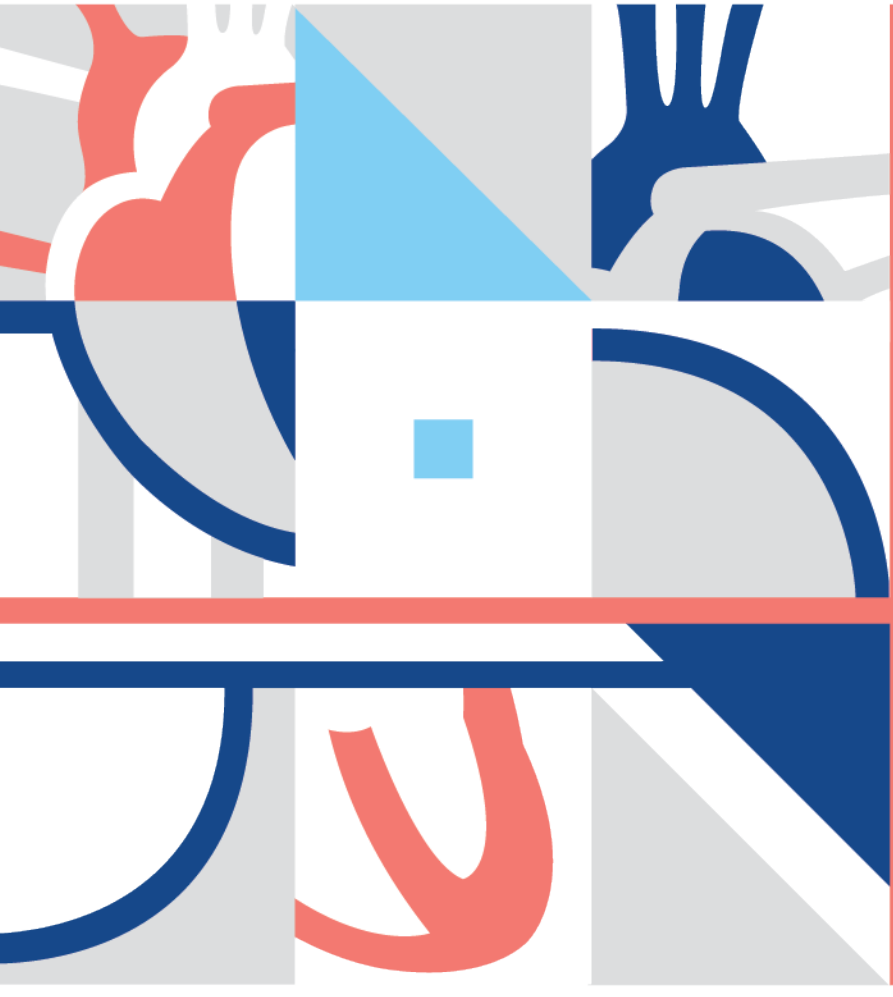
Boston Children's Hospital
Cardiology

BOSTON CHILDREN'S HOSPITAL
CARDIAC ANTITHROMBOSIS MONITORING PROGRAM

CAMP Home Guide



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My information

THIS BOOK BELONGS TO

ANTICOAGULATION (BLOOD THINNER) MEDICATION

REASON THIS MEDICATION IS NEEDED

TARGET RANGE IS _____ TO _____

CAMP team

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CAMP PHARMACIST

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CARDIOLOGIST

CARDIOVASCULAR SURGEON

Table of Contents

1 How to Contact the Team

Key point: Call the CAMP team at 857-218-4974 during regular business hours. For nights, weekends and holidays, call 617-355-6369 and ask to page CAMP (pager #5568).

The Cardiac Antithrombosis Monitoring Program (CAMP) is a division of Cardiology at Boston Children's Hospital that works to help you and your family manage antithrombosis therapy (AT). This means that we help you understand and manage medications that prevent and/or treat blood clots. The team is made up of a physician, coordinators (nurse practitioners/pharmacist), a nutritionist and office administrators.

- CAMP office phone 857-218-4974
- CAMP office fax 617-730-4636
- CAMP email CAMP@cardio.chboston.org

CAMP coordinators (nurse practitioners/pharmacist) are available by calling the office number or emailing the address above.

For urgent or emergency matters

Monday–Friday, 8 a.m.–5 p.m.
Contact 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 page operator at 617-355-6369 and ask to page CAMP or pager #5568. Please leave a call-back number.

When to contact the CAMP team

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

- ☐ Missed a dose of any anticoagulant medications
- ☐ Refill requests
- ☐ Lab (blood test) orders
- ☐ Starting or stopping a medication
- ☐ Illness (nausea, vomiting, diarrhea, severe flu-like symptoms, infection and any major illness)
- ☐ Upcoming surgical or dental procedures
- ☐ Concern for bleeding, increased bruising
- ☐ Any questions or concerns
- ☐ Admitted to outside hospital
- ☐ Any changes in DIME: Diet, Illness, Medications, Error (missed doses)

Urgent:

- ☐ Severe headache
- ☐ Abdominal pain or swelling
- ☐ Severe back pain
- ☐ Head injury
- ☐ Bleeding that you cannot stop (lasting more than 15 min)
- ☐ 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 15 minutes
- ☐ Severe joint pain/swelling of joint
- ☐ Any other serious injury or trauma
- ☐ Any urgent concerns
- ☐ Any hospitalization

2 Introduction

Key point: The CAMP team helps your family manage medications that help prevent and treat abnormal blood clots.

What is antithrombosis therapy (AT)?

Antithrombosis (AT) therapy is the process of preventing abnormal blood clots from forming or worsening. There are many different types of AT medications. Some are **anticoagulants** (AC) and some are **antiplatelet agents** (AP). Anticoagulants prevent blood clots by slowing down the time it takes your body to form a blood clot. Antiplatelets prevent the platelets (tiny blood cells that help your body form clots) in your blood from clumping and forming abnormal clots. Some patients may take both an anticoagulant and an antiplatelet agent at the same time.

What are examples of AT medications?

There are several commonly used AT medications. This guide will explain the two most common: warfarin **(page 8)** and enoxaparin **(page 13).** Warfarin is a tablet taken by mouth, and enoxaparin is a medication given by injection through a small needle.

A more complete list of AT medications commonly used at home is listed to the right.

Blood tests

Routine lab (blood) tests should be drawn **Monday–Thursday** unless a member of the CAMP team asks you to go on a Friday, Saturday or Sunday. Routine blood tests will be drawn at a frequency determined safe by the CAMP team. If you have blood drawn and do not hear from us within 24 hours, please contact us.

List of anticoagulants

DRUG NAME	BRAND NAME(S)	HOW IS IT GIVEN	HOW IS IT MONITORED
Warfarin	Coumadin®, Jantoven®, Marevan®, Waran®	By mouth (oral) once daily	Blood test called INR (International Normalized Ratio)
Enoxaparin	Lovenox®	Injection by small needle under the skin (subcutaneous) twice a day	"Lovenox level": low molecular weight heparin (LMWH) test; also called anti-Xa level ("anti ten-a level")
Fondaparinux	Arixtra®	Injection by small needle under the skin (subcutaneous) once a day	"Fondaparinux level": blood test called anti-Xa level ("anti ten-a level") with Fondaparinux assay
Apixaban	Eliquis®	By mouth (oral) once daily	No blood monitoring required
Rivaroxaban	Xarelto®	By mouth (oral) once daily	No blood monitoring required
Endoxaban	Lixiana®, Savaysa®	By mouth (oral)	No blood monitoring required

List of antiplatelets

DRUG NAME	BRAND NAME(S)
Acetylsalicylic acid (ASA)	Aspirin®
Clopidogrel	Plavix®
Dipridamole	Persantine®

What is a blood clot? Think of a blood clot like a traffic jam. Blood clots could prevent blood cells from reaching their destination. Antithrombosis therapy helps the blood flow freely through the blood vessels so that it can be used by the rest of the body.

3 Blood Clots

What is a blood clot?

A blood clot is a clump of blood that has changed from a liquid into a gel-like state. You may hear blood clots 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 completely block the vessel, it can cause less blood flow to and from that area **(see Figure 1).**

If the clot breaks free, it can also move to other organs in the body, like the lungs (causing a pulmonary embolism) or the brain (causing a stroke). Most people do not develop blood clots out of nowhere. Instead they are caused by something inserted into a blood vessel or by artificial material in the heart.

Some people have genetic reasons for being more likely to develop blood clots. Since it may "run in the family," let your doctor know if other people in your family had blood clots.

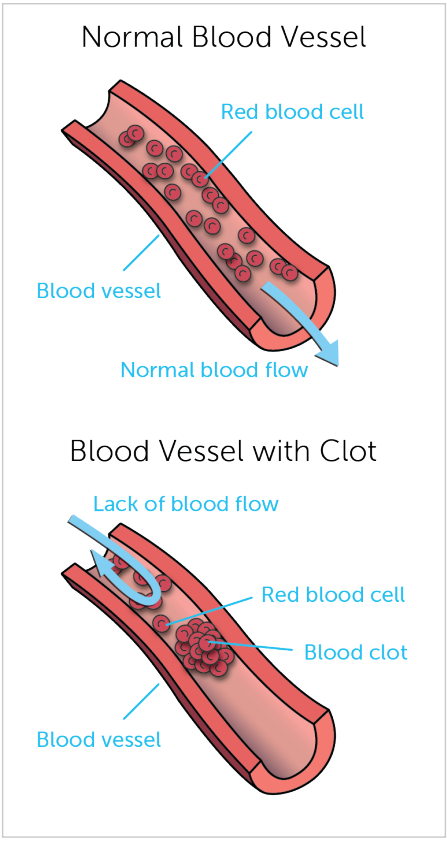


Figure 1

What conditions create a higher risk for blood clots?

- Artificial (mechanical or prosthetic) heart valves
- Certain types of heart arrhythmias (abnormal heart rhythms)
- Congenital heart disease (Fontan procedure, Glenn shunts)
- Cardiomyopathy
- Heart failure
- Kawasaki disease with/without coronary aneurysms
- Pulmonary hypertension
- Prevention/treatment for deep vein thrombosis
- Ventricular assist devices

4 Warfarin

Key point: Warfarin should be taken once a day by mouth, always at night.

Warfarin is an anticoagulant that makes it harder for blood to form clots. It is called a blood thinner even though it technically does not "thin" the blood. Warfarin is used to prevent dangerous blood clots from forming or prevent existing blood clots from growing.

How is warfarin taken?

Warfarin comes only in a pill form. It can be crushed and mixed with water and it can also be split once down the marked line. Warfarin comes in different strengths. The strengths—or how many milligrams (mgs) the pill has—are specific colors and the shape may be oval or round. For example, 1 mg tablets are always pink and 2 mg tablets are always purple (see Figure 2). We will prescribe 2 or 3 different strengths so it is easy to see the different dosages. **It should be taken once a day, always at night.**

Figure 2

Dosing

Dosing is based on blood levels called INR (International Normalized Ratio). This helps us determine how well the warfarin is working. An INR of a person NOT on anticoagulation is 1-1.3. With warfarin, the INR will increase. You will need regular blood work (every 1-3 weeks) to make sure that the INR is within the right range for you.

- INR goal: _____
- If an INR is out of range, more frequent blood tests are needed.

Key point: If an INR is more than 5, there is an increased risk for bleeding.

Are there side effects?

The major side effect of warfarin is bleeding. Warfarin does not cause bleeding, but will make any bleeding last longer than usual. Warfarin may not be safe during pregnancy. The risk of bleeding is largely based on the INR.

- If the INR is high (more than 5), there is a higher risk of bleeding.
- If the INR is low there is an increased risk of clots.

See the chart to the right for symptoms of minor and major bleeding.

Home INR monitors

The home INR monitor recommended by our program is the CoaguCheck XS® machine, by Roche Diagnostic®.

Home INR monitors are small portable hand-held devices that allow people to check their INR anywhere. They require a pinprick of the finger and a drop of blood. Home INR monitors are available to buy directly or through insurance companies. Talk to your insurance company to see if they will cover the cost of the monitor and of the testing supplies.

With each test, please contact the CAMP team with the results, and we will tell you that day how to adjust doses, if needed, and when to test again.

Be sure to tell us:

- Full patient name, INR, any changes (DIME: Diet, Illness, Medications, Error), current warfarin dose, any missed doses and a contact number/email.

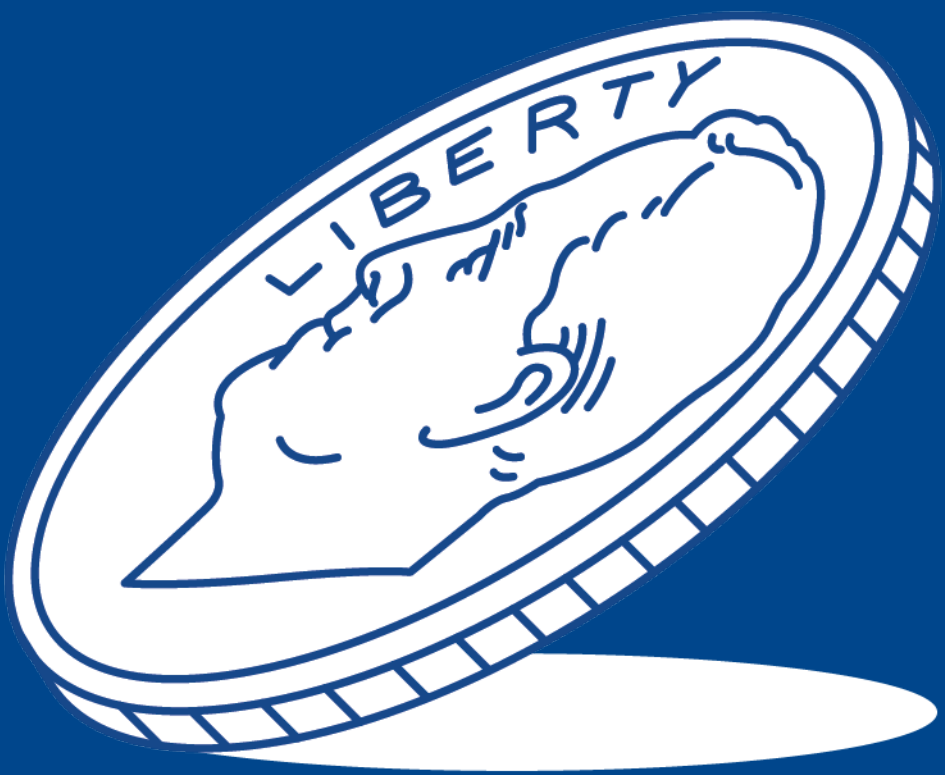
SIGNS OF MINOR BLEEDING
Nose bleeds and gum bleeds
Menstrual bleeding that is heavier than normal
Easy bruising
Bleeding from cuts that take longer to stop

SIGNS OF MAJOR BLEEDING
Red, dark, tea/coffee colored urine
Red or black stool (poop)
Coughing or vomiting bright red or "coffee ground" colored blood
A cut that does not stop bleeding after 10 minutes of pressure
After a serious fall or hit to the head: • A severe headache • Loss of consciousness • More tired than usual • Upset stomach or vomiting (throwing up) • Weakness on one side of the body
Any occurrence that brings you to an emergency department or hospital

If there is minor bleeding, DO NOT stop warfarin. Please call the CAMP team to talk about a safe plan. If there is major bleeding, call 911 immediately or go to the nearest emergency room.

INR can change on a...

Diet change
Illness
Medication
Error



What can change the effect of warfarin?

Warfarin effect (INR) can change on a DIME!

Diet Change: Eating more green vegetables can affect the INR, but please do not stop eating them (see page 10 for more details). We can adjust dosing to fit any diet. It is helpful to try to eat the same amount of everything (greens, proteins, grains) each week so that we can give the correct dosing of warfarin and maintain consistant dosing to reduce the need for blood draws.

*Alcohol can affect warfarin too, but 1-2 drinks are OK if the patient is old enough to drink.

Illness: Eating less or a stomach illness with vomiting or diarrhea can make an INR go very high. Call the CAMP team for more than 1 day of illness. If you have a home INR monitor, check the INR if there has been more than 1 day of diarrhea, vomiting or nausea.

Medication: They are many medications and herbal supplements that interact with warfarin. These include prescriptions, over-the-counter medicines, vitamins and herbal supplements. If a new medication is started or a medication is stopped, please contact the CAMP team.

- **Avoid NSAIDS including Ibuprofen** (Advil®, Motrin®, Midol®, Aleve®). These can increase the risk of bleeding. Contact your provider and the CAMP team before using these medications to make sure it is safe. **Avoid products containing aspirin** until you speak with the CAMP team unless prescribed by your cardiologist.
- **Tylenol** is safe to take to treat pain and fever.
- **Marijuana** use (edible or smoked) will impact an INR. Let the CAMP team know of any marijuana uses. Second-hand marijuana smoke can also impact the INR, so let the CAMP team know if someone in the home uses marijuana, so they can adjust the warfarin dose.

Error: Any missed doses or extra doses of warfarin will affect an INR. When a dose is missed, let us know as soon as possible. The missed dose should be taken as soon as possible. But if it is more than 12 hours late, call the CAMP team to form a plan.

Key point: More vitamin K can lower the INR, while less vitamin K can increase the INR.

How does vitamin K affect warfarin?

Vitamin K is used by the body to help blood clot. Warfarin works to slow down bleeding by affecting how the body uses vitamin K. More vitamin K can lower INR, while less vitamin K can increase the INR. It is important to eat a similar diet every day so that the INR does not change and we can give the correct dosing of warfarin.

Below is a chart of foods and their vitamin K content:

HIGH VITAMIN K	SOME VITAMIN K	LOW VITAMIN K	NO VITAMIN K
Cooked broccoli	Asparagus	Artichoke	Bread and cereal products
Brussels sprouts	Raw broccoli	Avocado	Cheeses
Fresh/frozen kale	Cabbage	Green beans	Eggs
Raw kale	Kiwi	Blackberries	Fish and shellfish
Scallions	Green leaf lettuce	Blueberries	Fruit except those listed
Cooked spinach	Romaine lettuce	Carrots	Meat/poultry
Raw spinach	Spinach noodles	Cauliflower	Milk and dairy
Swiss chard	Okra	Celery	Nuts not listed
Beet greens	Prunes	Cucumber with peel	Vegetables not listed
Collard greens	Watercress	Grapes	
Mustard greens	Viactiv chews	Iceberg lettuce	
Turnip greens	Green tea	Mango	
Parsley		Light mayonnaise	
Raw endive		Pine nuts	
Seaweed		Cashews	
Regular mayonnaise		Soybean oil	
		Peas	
		Pickles	
		Pear	
		Pumpkin seeds	
		Soy milk	
		Soybeans	
		Tomatoes	

Note: Some vegetables' vitamin K values increase once a food is cooked. See below for examples:

- 1/2 cup of kale is 250 mcg of vitamin K raw, and 530 mcg cooked.
- 1/2 cup of broccoli is 45 mcg of vitamin K raw, and 110 mcg cooked.

Vitamin K apps for smart phones

Vitamin K - iNutrient: Vitamins K1, K1D and K2
This app allows you to record vitamin K intake. It provides information about foods' vitamin K content. They are rated on a color-coded scale based on serving sizes from No Vitamin K to Extremely High in Vitamin K.

Vitamin K in Foods - Mark Patrick Media
Browse database of more than 6,000 foods rated on a scale of Extremely Low to Extremely High in Vitamin K.

5 Enoxaparin

Key point: A LMWH level test is time sensitive. Blood must be drawn 4 hours after the last dose.

Enoxaparin is another type of antithrombosis medication used to prevent and treat blood clots. Enoxaparin is a type of heparin given twice a day by injection through a small needle into the tissue just under the skin.

Dosing

Enoxaparin is dosed based on weight. To make sure right dose is given, we do a blood test called "low molecular weight heparin (LMWH) level" (also called anti-Xa level) **4 hours after the dose is given.** Once there is a stable dose, you will have your LMWH level checked every 3 weeks. Typical target range is between 0.5-1. It may take a few days to a week to get the results of blood work drawn at a lab outside of Boston Children's Hospital, so please let us know which lab you go to and when, so that we can call for the results.

- Your LMWH level target range is: _____

Enoxaparin may be available in prefilled syringes with small needles attached. Depending on your weight, you may need other doses that will require you to fill a syringe with the right amount. We will teach you this. We can also prescribe the smallest needles possible to lower the risk of pain, anxiety and discomfort.

Enoxaparin can be stored at room temperature.

Are there side effects?

Like all anticoagulants, the main side effect is bleeding. While taking this medication, bruising and bumps may appear where the enoxaparin is given. If there is a lot of bruising that limits the ability to give the injection, please contact the CAMP team to find another solution.

How do I give enoxaparin?

The CAMP team is here to help you learn how to give the injections and feel comfortable doing it. Areas for giving the injections are the back of the arms, thighs and abdomen. We will talk about which area is best.

Step 1: Collect all supplies: alcohol swab, enoxaparin (a prefilled syringe or the vial and syringe/needle).

Step 2: Wash your hands (if you have prefilled syringes, skip steps 3-7).

Step 3: Attach needle to syringe.

Step 4: Remove plastic cap from vial if not already done.

Step 5: Wipe surface with alcohol swab.

Step 6: Push the needle through the top of the vial and hold the vial upside down at your eye level.

Step 7: Pull plunger back to correct dosage– you may need to pull past the correct amount and push back into the vial to remove air bubbles.

Step 8: Choose your injection site and clean with alcohol wipe. Let air dry for a few seconds. Remember to change sites and never inject into a bruise. Right side at night. Left side during the day.

Step 9: Remove cap and hold the needle at a 45 degree angle. Gently squeeze skin with 1 hand and quickly insert needle with the other hand. Inject the drug.

Step 10: Remove the needle and if bleeding, press the site gently with gauze or use a Band-Aid.

Step 11: Use the safety feature to hide the needle and put the syringe and needle in a proper container.

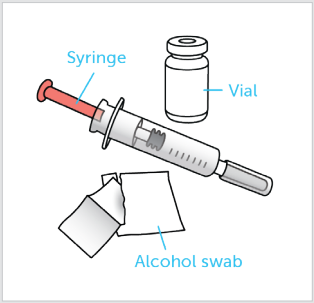
Throwing out used needles

You can buy a sharps biohazard container at a medical supply store or you can call one of these services:

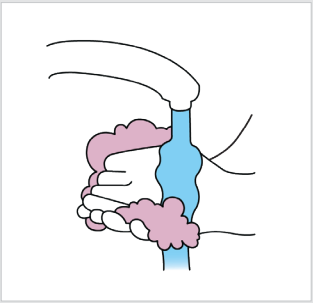
- Medasend 1-800-200-3581
- Sharps Compliance 1-800-772-5657
- Sharps, Inc 1-877-633-7328
- Stericyle 1-800-355-8773

You can create your own sharps container with an old milk carton or old laundry detergent bottle. Cover both with coordinating cap. Cut a small hole at the top and put used needles in there. Be sure to keep it out of children's reach.

When your sharps container is full, bring it to a drop off site or use a mail-back service. Visit your state's Department of Public Health Website (such as **mass.gov/dph**).



Step 1



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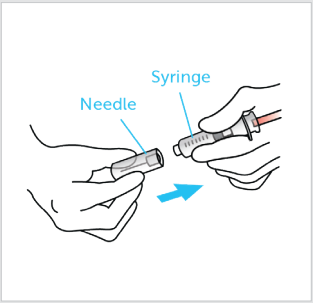

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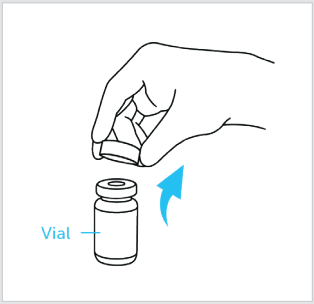

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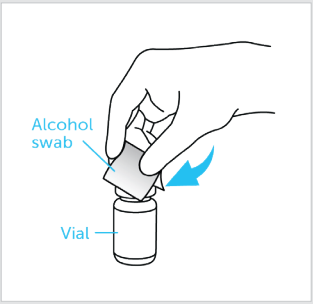

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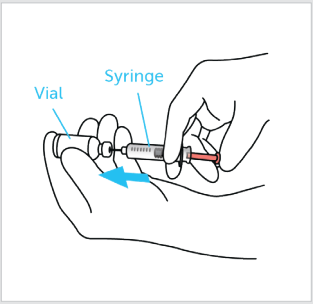

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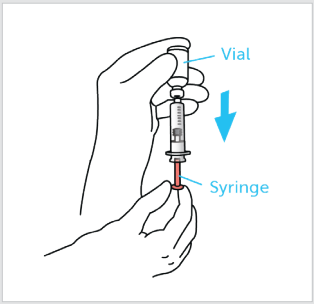

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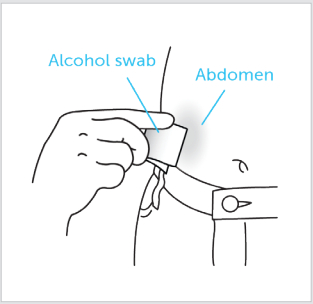

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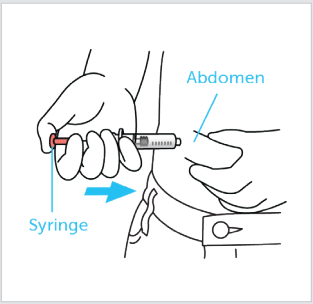

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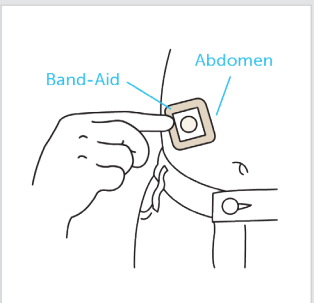
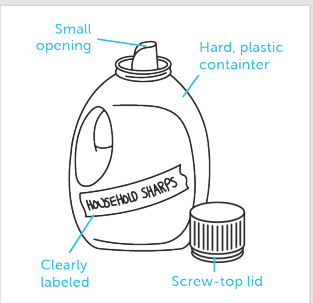


Step 10



Step 11

Can people on AT still be active? Yes! There are many fun activities people can still do while on antithrombosis therapy. If you don't see an activity on the list on the next page, ask a member of your CAMP team about it.

6 Living with AT

What activities are safe?

As you can imagine, serious falls or injuries can be very dangerous for someone on antithrombosis therapy. We will help you set up a safe plan so that favorite activities can be enjoyed safely. Feel free to ask us questions about any activity you do not see on the list below.

SAFE ACTIVITIES		
Running Swimming Frisbee	Golf Tennis	Walking Playing

SAFE ACTIVITIES, AS LONG AS YOU 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 Lacrosse Motorcycle riding Rock climbing	Rugby Tae Kwon Do Wrestling

Please make sure safety equipment is used whenever possible, and always wear a helmet! Use knee pads and wrist guards if necessary. Remove or secure things that could cause a fall at home. This is important especially for younger children on AT.

Please use either the medical alert bracelet we offer or have one made. Always tell school nurses and teachers about bleeding risks.

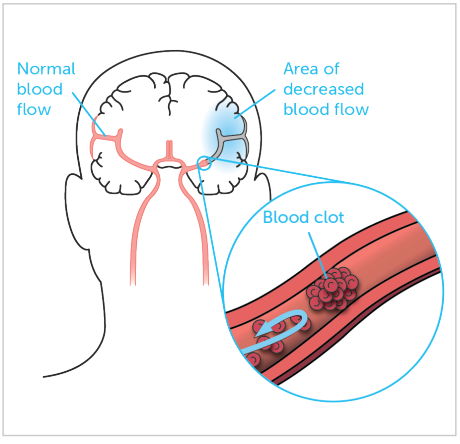


Figure 3

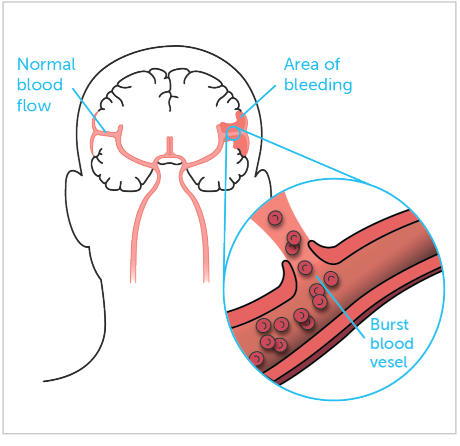


Figure 4

How to recognize a stroke

A stroke happens when blood flow to part of the brain stops. If blood flow is cut off for longer than a few seconds, the brain does not get the nutrients and oxygen it needs. This causes brain cells to die. There are 2 major types of stroke:

- **Ischemic stroke (thrombotic stroke)** occurs when a blood vessel that brings blood to the brain is blocked by a blood clot **(see Figure 3).**

  A clot may form in the blood vessel, or may break off from another part of the body and travel up to the brain. An ischemic stroke can cause internal bleeding and become a hemorrhagic stroke (see below).

- **Hemorrhagic stroke** occurs when a blood vessel in the brain becomes weak and bursts open, causing blood to leak into the brain **(see Figure 4)**. This can occur because someone is on medications to thin their blood.

Noticing the signs of a stroke early on and immediately calling 9-1-1 is the best way to get someone help and treatment. Generally, the faster someone having a stroke gets to the hospital, the better their chances for recovery.

Use FAST to remember the warning sings of a stroke:

FACE Ask the person to smile. Does one side of the face droop?

ARMS Ask the person to raise both arms. Does one arm drift downward?

SPEECH Ask the person to repeat a simple phrase. Is their speech slurred or strange?

TIME If you observe any of these signs, call 9-1-1 immediately.

What can I do about bloody noses?

A common side effect of anticoagulant and antiplatelet therapy is nosebleeds. These medications do not cause nosebleeds, but they make any minor trauma to the nose more likely to bleed, and for a longer time. The goal is to prevent nosebleeds from happening. We will teach you ways to do this.

To keep nosebleeds from happening:

- 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.
- Apply a pea-size amount of Vaseline to the middle divider inside the nose after using the saline spray.
- Use a cool-mist humidifier in the bedroom.

Treatment (see Figure 5):

- 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 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 ½ a cotton ball with Afrin (available over the counter). Stuff it gently into the bleeding nostril. Continue to pinch the nose firmly for 10 minutes.
- Do not put anything inside the nose to stop the bleeding except cotton balls soaked with Afrin.
- If this does not work and the nose is still bleeding a lot, call the CAMP team. You might need to go to an Emergency Department if it lasts longer than 1 hour.

Figure 5

Do blood thinners affect menstrual cycles?

Blood thinners usually do not affect how often one gets their period, but they can lead to menorrhagia (abnormally heavy or prolonged periods). They can also slightly increase the chance of passing clots during your period. However, there is nothing special to prepare for. Just be aware of the possibility of increased bleeding, and let us know if tampons/pads need to be changed more than every 2 hours during the first two days, or if clothing is being soiled.

If periods are hard to manage, we will discuss some options that could help and we will recommend scheduling an appointment with a gynecologist. A gynecologist might recommend taking an oral contraceptive to lighten the menstrual cycle. Always let us know about contraceptives before they are started because some can increase the risk of blood clots.

Key point: Always carry the medication while traveling by plane. Do not leave it in a checked bag.

What do we do if we are traveling?

If travel is planned, please let us know. We may check levels sooner if you will be gone when the test is due. If it is a long plane ride, please get up to walk around a few times and drink lots of water. Have the medication with you at all times in carry-on luggage. **Do not check medications and never leave them in the car.** Transportation Security Administration (TSA) should not have any problems with medications. However, we are happy to write a letter explaining that the supplies need to be carried on the plane.

What do we do if we have a surgical or dental procedure?

Before certain procedures, anticoagulant or antiplatelet medications may be stopped. Please get in touch with us as soon as a procedure is planned so we can talk about a safe plan. Please do not stop giving a medication until you speak with us. We will also form a plan to restart the medication.

In some cases, we may suggest **"bridging"** from warfarin to enoxaparin. This means that enoxaparin injections may take the place of warfarin so that the warfarin effect values will be within the target range. We may need to do this in anticipation of surgical procedures as well.

Consent to Antithrombosis Care

This new medication is considered high risk due to the possible risks of bleeding or clotting complications. This is why we want all our patients and their families to feel informed about the medication and the care required to make sure it is effective and safe. This form says that you have read and understand the material presented. A member of the CAMP team will go over this information with you in detail in case you have any questions.

REASON FOR ANTICOAGULATION

ANTITHROMBOSIS AGENTS

GOAL RANGE

DURATION OF THERAPY

Your cardiologist has requested that we manage antithrombosis therapy for you. Patients taking anticoagulants need careful monitoring to prevent serious complications. To help stay safe, frequent blood tests may be necessary. After reviewing blood test results, an adjustment to medication may be needed.

By enrolling with the CAMP (Cardiology Antithrombosis Management Program) at Boston Children's, you accept the following responsibilities:

- We will work as a team with the common goal to prevent thrombus from forming and prevent bleeding with careful monitoring of warfarin/enoxaparin (circle one).
- Blood work will be tested as instructed.
- Dosages of medications prescribed will be changed as requested.
- Constant communication will happen with the CAMP team about: any changes in DIME: Diet, Illness, Medications, Error (missed doses); new or discontinued medications; hospitalization; upcoming surgical or dental procedures; any signs of bleeding
- Contact us if blood work is done and you have not heard from the CAMP team in 24 hours.

PREFERRED MODE OF COMMUNICATION

PARENT/GUARDIAN SIGNATURE

DATE

CHILD ASSENT

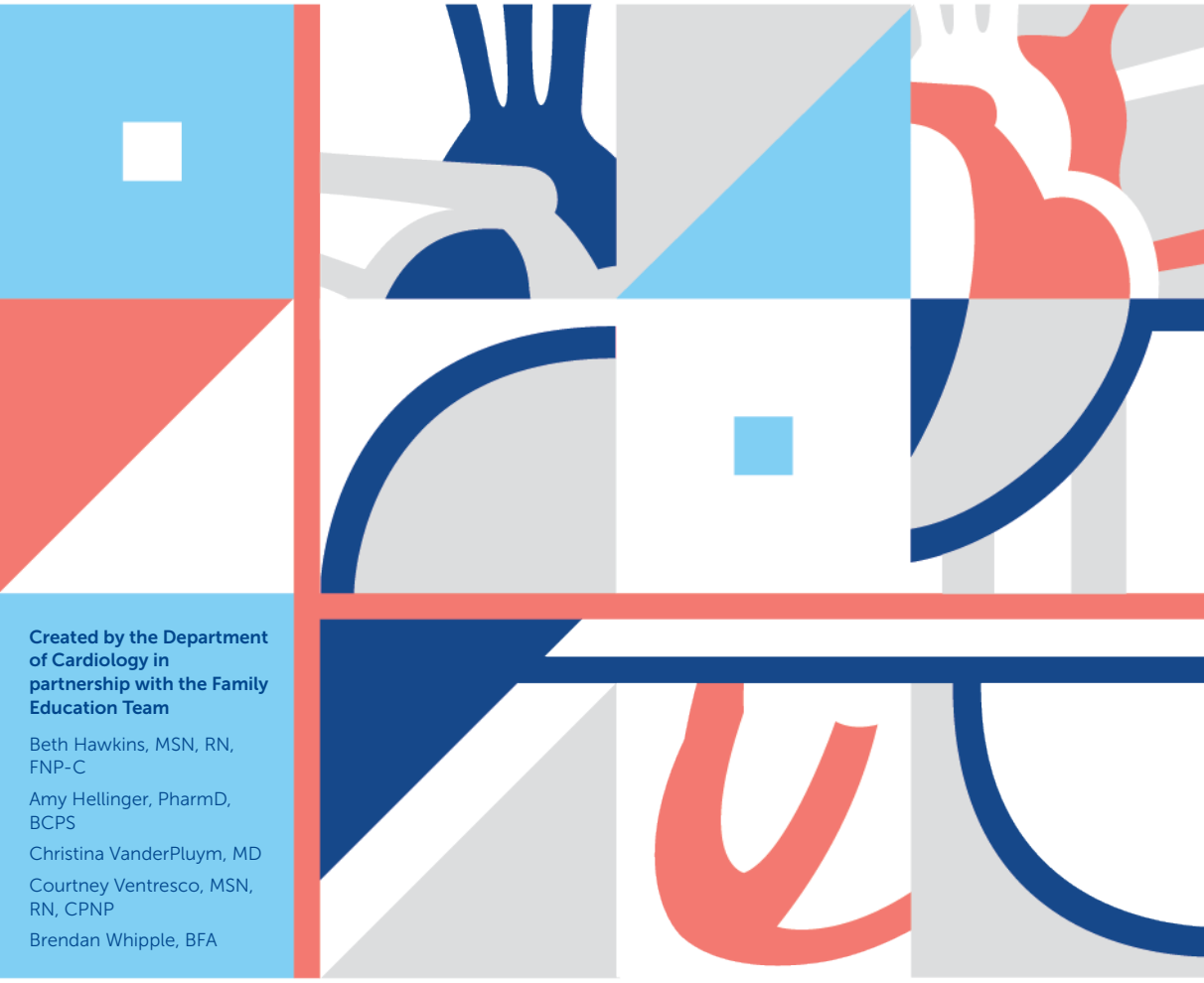
DATE

CAMP MEMBER SIGNATURE

DATE

Notes

Boston Children's Hospital
Cardiology



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