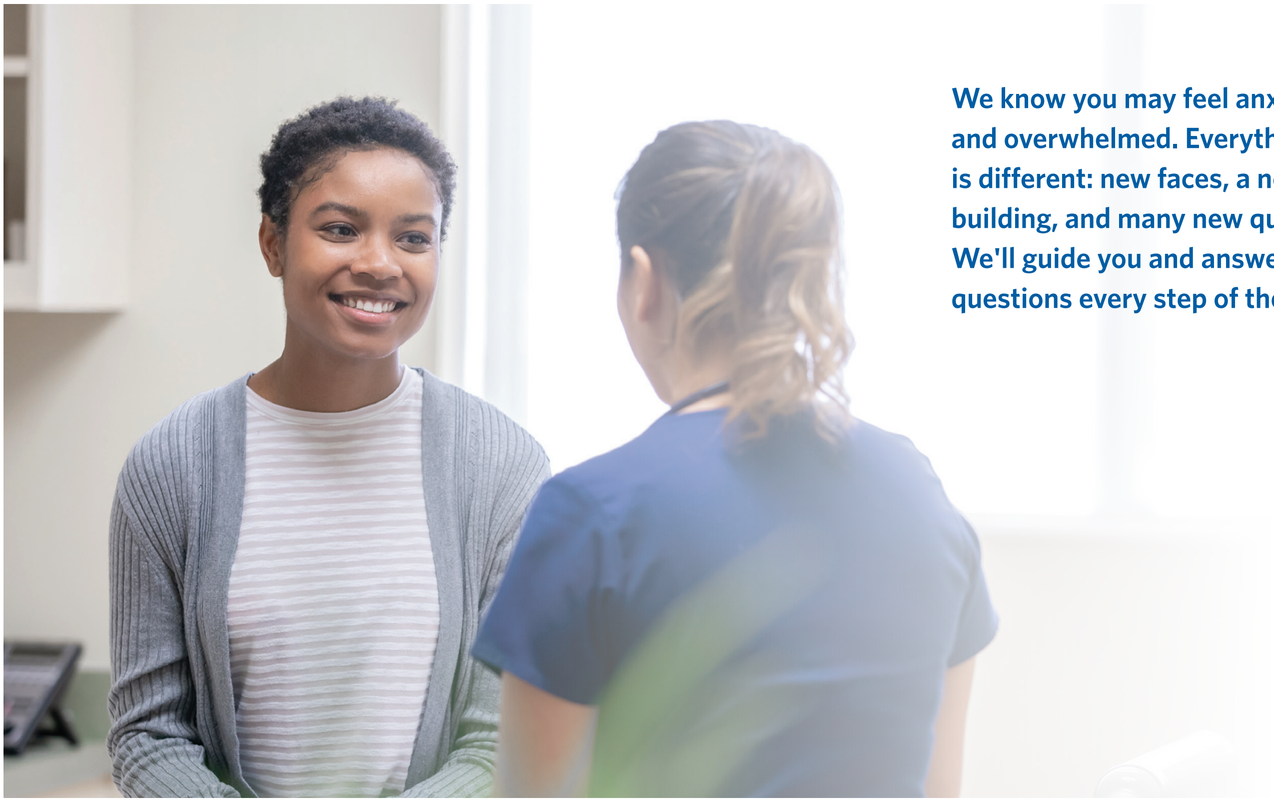
Vanderbilt Hemostasis Treatment Center

Bleeding Disorders

Your Guide to Adult Care

VANDERBILT HEALTH

Welcome to the Vanderbilt Hemostasis Treatment Center



We know you may feel anxious and overwhelmed. Everything is different: new faces, a new building, and many new questions. We'll guide you and answer your questions every step of the way.

Contents

Important contacts

Vanderbilt Hemostasis Treatment Center (615) 936-1765

Primary care provider ____________________

Phone ____________________

Insurance company ____________________

Phone ____________________

Pharmacy ____________________

Phone ____________________

My Health at Vanderbilt

If you haven't already done so, sign up for a My Health at Vanderbilt account.

▶ **MyHealthAtVanderbilt.com**

With your account, you can:

- schedule an appointment
- keep track of your appointments
- join an appointment wait list
- see test or lab results online
- pay your bill
- ask for prescription refills
- email your providers
- check your medical records

Get the app

The My Health at Vanderbilt app is available in Apple's app store and the Google Play store.

If you have any issues you can call our Help Desk at (615) 343-HELP (4357).

Bleeding disorders

What are they?

Bleeding disorders stop the blood in your body from clotting the right way. This causes you to bleed longer than normal.

When you have a cut or injury, platelets in your blood mix with multiple clotting factors to make a plug. This is known as a **clot**. Together, they form strong fibers that make the clot stronger and stop the bleeding.

The two most common bleeding disorders are von Willebrand disease and hemophilia.

Von Willebrand disease (VWD)

What is it?

Your body has a hard time making a strong clot. This can cause you to bleed longer, usually after an injury, surgery, or other trigger for bleeding.

How do you get it?

- It's genetic, meaning you get it 1 of 2 ways:
  - from a parent
  - from a change in your genes when you're in the womb
- It can happen in boys or girls.

3 types

- Type 1: most common (85 out of 100 patients)
- Type 2: less common (15 out of 100 patients)
- Type 3: most uncommon and severe (1 out of 1 million patients)

Hemophilia

What is it?

Your body can't make enough of one type of clotting factor.

How do you get it?

- Hemophilia is also genetic disease.
- It happens mostly in boys. Girls can carry the hemophilia gene and pass it on to their children.

2 most common types

- Hemophilia A: the body doesn't make enough clotting factor VIII (8).
- Hemophilia B: The body doesn't make enough clotting factor IX (9).

Other bleeding disorders

Other bleeding disorders we treat:

- Bernard-Soulier syndrome
- Glanzmann's thrombasthenia
- clotting factor deficiencies
- platelet disorders

Your clinic appointments

What to expect

At your appointments, you'll meet different providers who have special training in bleeding disorders.

Comprehensive Clinic

This is a good time to talk with your health care team about any concerns or questions you have. This includes your progress and what works or doesn't work with your care plan.

When we know what you need, we can give you the best care possible.

What to bring

Bring these things to every clinic visit:

☐ infusion log

☐ medicine log

☐ injury log

☐ bleed log

☐ insurance information

☐ list of current medicines

☐ questions about your care

☐ list of any mental, emotional, and social needs

Your health care team

Hematologist

Your hematologist has special training in bleeding disorders. They'll give you a physical exam and make a care plan for you.

Nurse practitioner

Your nurse practitioner goes over your bleeding history. They also decide if there are any risks to your health. They work closely with your hematologist.

Clinical nurse

Your clinical nurse goes over your home treatment records. They can talk about any health problems you may have.

Research nurse

A research nurse tells you about any research studies you can join.

Social worker

Your social worker talks to you about things that affect your care. This includes health insurance, school, work, and how you're able to handle everything.

Case manager

Your case manager works with your health care team to make a special treatment plan for you.

Pharmacist

Your pharmacist helps you understand and manage your medicines.

Physical therapist

Your physical therapist looks at your muscles, how strong you are, and how you move and walk.

Your medicines

Take control of your care

When you move to adult care, it's important that you're in charge of your own health care. This means understanding what medicines you take and why you take them.

Plan ahead

Let us know if you'll need extra medicine for an upcoming procedure, such as surgery.

Some things you need to know:

- medicine name
- how much you take each time
- when you take it
- why you take it
- how it affects your body
- how it works with your other medicines
- how to get a refill from your pharmacy
- your pharmacy name and phone number

Your medicines

Name	Dose	When you take it	Why you take it

Your lifestyle

When to call us

Call us at (615) 936-1765 if you have any of these joint bleed signs:

- the area feels warm
- the area swells
- it tingles inside the joint
- you're uncomfortable
- you're in pain
- you can't move the joint
- the joint feels stiff

Plan for an emergency

Medic Alert ID

Always wear your Medic Alert bracelet or necklace. If you don't have an ID, here are some websites to help you get started:

▶ **AmericanMedical-ID.com**

▶ **LaurensHope.com**

▶ **StickyJ.com**

Yellow DOT

Tennessee's Yellow DOT Program gives a person's medical information to first responders in an emergency on the road. This information can mean the difference between life and death immediately after a serious accident.

▶ **TN.gov/tdot/traffic-operations-division**

Home treatment

When you injure yourself, you can take some first aid steps to help treat the bleed.

An easy way to remember these steps is: **R.I.C.E.**

- **Rest**: Do not move the injured area.
- **Ice**: Put ice on the area to help stop pain and bleeding.
- **Compression**: Use soft pressure to help stop any bleeding.
- **Elevation**: Raise and rest the injured area so it's higher than your heart.

Stay safe and healthy

Keep a healthy weight

Extra weight can put too much pressure on different areas of your body. This raises your bleeding risk. A healthy weight helps stop pressure on joints and joint bleeds.

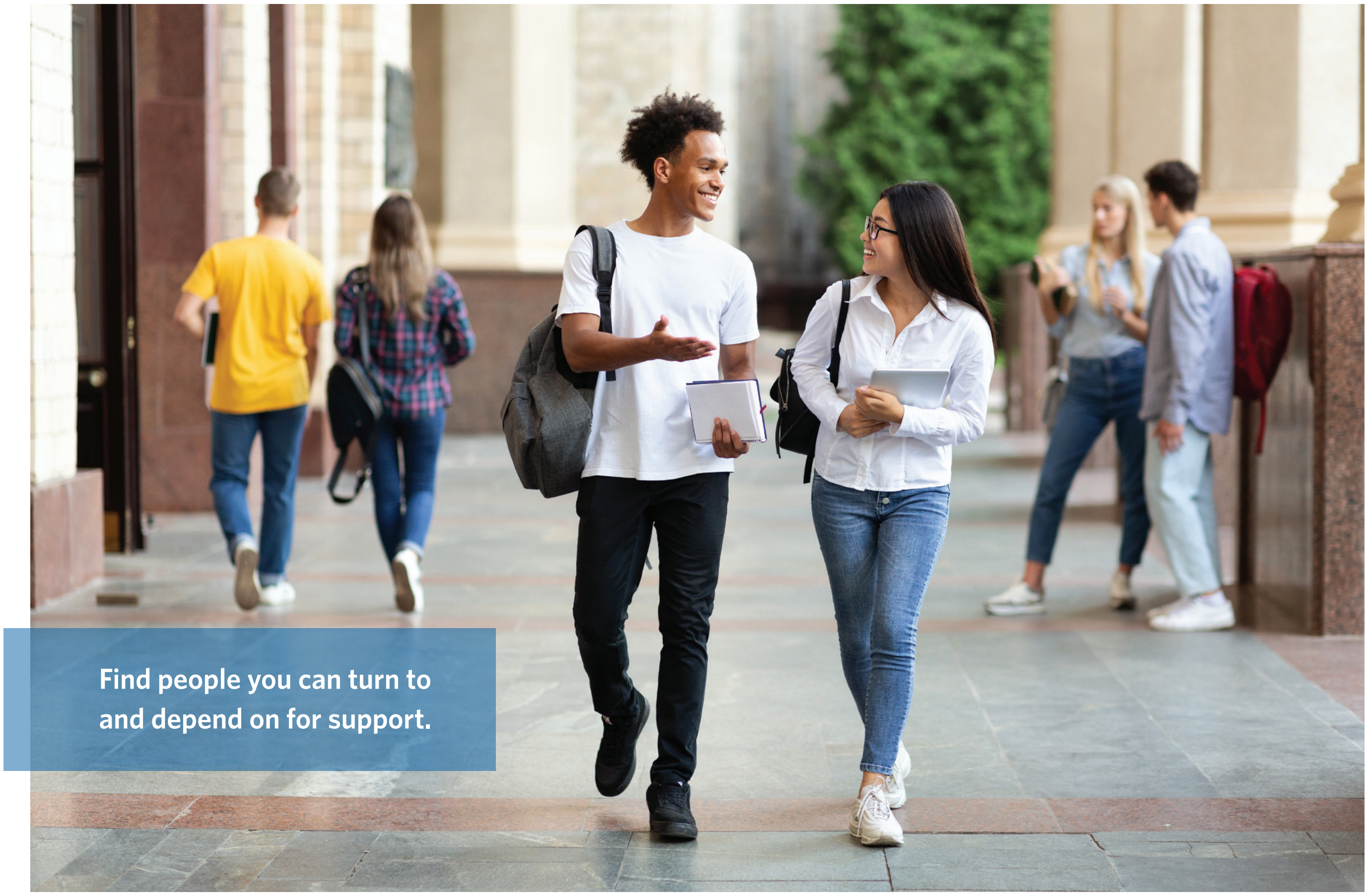
Talk with your provider about any diet concerns or ideas to help you keep a healthy weight.

Brush your teeth

Brush your teeth 2 times a day, every day, to help stop bleeding in your gums.

Change activities

Change your activities so that you're able to do them without getting hurt.



Find people you can turn to and depend on for support.

Exercise regularly

Exercise keeps your muscles strong. This can help stop bleeding when you get hurt. Talk with your physical therapist about safe exercise.

Stay safe at work or school

We can talk to you about good choices and how to stay safe.

Know how to handle conflict

Think about how you act during conflict or times you don't feel safe. Walking away may be hard, but it's important to your health and safety.

If you have a hard time with friends, coworkers, family, your home, or your mental health, talk to your provider.

Get ready for college

There are some things you need to do ***before*** you leave home.

☐ Contact the Office of Student Health Services at your school.

Phone ______________________________

They can work with your hematologist at home and help you find a hematologist near your school's campus if you need one. It's a good idea to make sure health services accepts your insurance and you know how to pay for non-covered health costs.

☐ Find a hematologist near campus.

Name ______________________________

Address ______________________________

Phone ______________________________

☐ Call the Office of Disability Services at your school.

Phone ____

- This office can help you with a place to stay in case you get hurt.
- They can also help you make a plan for your classes and studies, if needed.

☐ Find people who can help.

Share your health condition and what to do in an emergency with people such as your roommate, professor, and resident advisor (RA).

☐ Talk to your supervisor at work.

Tell your supervisor about your diagnosis and if it might affect your work.

☐ Talk to your primary care provider.

- Make a plan.
- Schedule follow-up appointments during school breaks.
- Take your health records to school:
  - Letter of Medical Necessity
  - list of your medicines
  - list of allergies
  - vaccine and test results

Follow good health practices

When you're at school, take care of yourself.

- Eat healthy foods.
- Make exercise a regular part of your life.
- Keep your stress level low. Try to find a balance between your social life and schoolwork.
- Get enough sleep. Try for 6 to 8 hours every night.

Common questions

Always ask questions

The more you know about your diagnosis, the better you can manage it.

My diagnosis

What is a bleeding disorder? Is it serious?

What are some long-term effects?

How does a person get it?

Can I pass it to someone else?

Are there any foods that I shouldn't eat or any activities I shouldn't do?

How do I stay safe at work or school?

How can I stop a bleed or injury?

What's a joint bleed?

How can I protect my joints?

What if I forget to take my medicine?

Will you keep my information private?

Procedures

What do I need to tell you before a procedure?

How do I get ready for a procedure?

How soon should I let you know about a bleed concern?

Lifestyle choices

What should I tell my family or significant other?

Do alcohol and drugs affect my disorder?

Will I be able to have children?

Other questions:

Your checklist

There are some things you need to do or know how to do when you come to our adult care clinic.

General health

☐ I visit my primary care provider on a regular basis for general health care.

☐ I tell all my health care providers about my bleeding disorder.

☐ My lifestyle plan includes regular exercise and a healthy diet.

☐ I can list the medicines I take. This includes the dose and when and why I take it.

☐ I carry these phone numbers: my HTC, primary care provider, pharmacy, and any other important providers.

Vanderbilt Hemophilia Treatment Center (HTC)

☐ I see my HTC provider when I should, and go to the Comprehensive Clinic.

☐ I tell the HTC about any changes in my information (address, phone, and insurance).

☐ I call the HTC in advance if I can't keep a scheduled appointment.

☐ I call the HTC at least 2 weeks before a scheduled procedure (such as surgery or a dental procedure) to make a plan to keep from bleeding.

Emergencies

☐ I do these things before I go on a trip:

- Tell the HTC about my trip.
- Know where the local emergency room is.
- Know where the closest HTC is.

☐ I wear a Medic Alert bracelet or necklace at all times.

Education

☐ I can get information and services from local and national bleeding disorder organizations.

My diagnosis

☐ I understand my diagnosis.

☐ I know the name of my treatment product and how much I need to treat bleeding episodes.

☐ I know my bleeding disorder is genetic.

☐ I understand why “at risk” people should contact the HTC for evaluation.

Treatment

☐ I call my pharmacy for medicine and clotting factor concentrate refills before I run out.

☐ I keep my clotting factor concentrate and supplies in a safe location.

☐ I throw away all bio-hazardous waste (such as needles).

☐ I know the signs of a bleeding episode.

☐ I can figure out how much medicine I need for bleeding, and when to treat it.

☐ I can self-infuse and know where to go for infusion, if I need it.

☐ I keep track of all my infusions in a treatment log.

☐ I treat within 3 hours of a bleeding episode or injury.

☐ Along with infusion, I can treat injuries in other ways, such as R.I.C.E.

Prevention

☐ I'm careful before doing activities that may cause bleeding.

- When I ride a bike, I always wear a helmet.
- I get an infusion before certain activities.
- I tell the coach of my sports team about my bleeding disorder.

Insurance

☐ I talk to my social worker before I choose a new insurance policy or lose coverage.

Health insurance

What is it?

Health insurance covers medical costs. These can include:

- doctor's appointments
- emergency room visits
- hospital stays
- medicines.

You need health insurance. Without it, your medical costs can be very high.

There are several ways to buy health insurance. We can help you figure out the type of coverage and plan you need.

Understand the terms

Common words used with health insurance:

- **Claim:** an explanation of medical services that you or your provider send to the insurance company in order to be paid back for the money you spent.
- **Co-insurance:** a part of the cost of a health care service you pay after you've reached your deductible.
- **Co-payment:** the amount you pay at the time of your appointment.
- **Deductible:** the amount of money you pay before an insurance company will pay.
- **In-network provider:** a health care provider that has a contract with your insurance company to give you medical care.
- **Non-covered services:** health care services your insurance company will not pay for.
- **Policy:** a contract between you and your insurance company that covers your health care costs.
- **Premium:** the amount you pay every month for health insurance.
- **Referral:** your health insurance company may require your primary care provider to send a referral to other doctors or specialists.

Resources

Vanderbilt

Junior League Family Resource Center
(615) 936-2558 Toll free: (800) 288-0391
Children's Hospital, Floor 2

Hematology/Oncology/Infusion Clinic
(615) 936-1762
Children's Hospital, Floor 6

Vanderbilt Hemostasis Treatment Clinic
(615) 936-1765
Village at Vanderbilt, 1500 21st Ave S, Suite 2500
▶ **ChildrensHospitalVanderbilt.org/program/hemophilia-and-blood-disorders**

Tennessee and Georgia

Tennessee Hemophilia and Bleeding Disorders Foundation: Supports people with bleeding disorders and their families in Tennessee through fundraising and education.
▶ **THBDF.org**

Hemophilia of Georgia: Supports people living in Georgia who have hemophilia, von Willebrand disease, and other inherited bleeding disorders.
▶ **HOG.org**

National

Microhealth: Website and app with treatment information and community resources.
▶ **Microhealth.org**

National Hemophilia Foundation: Research, information, support, and education for people with bleeding disorders and their families across the U.S.
▶ **Hemophilia.org**

Steps for Living: Helpful website with education and information for patients of all ages.
▶ **StepsForLiving.Hemophilia.org**

World Federation of Hemophilia: Improves care for people with inherited bleeding disorders around the world.
▶ **WFH.org**

Scholarships

These websites list many education scholarships for people with hemophilia.

Hemophilia Federation of America
▶ **HemophiliaFed.org/scholarships**

National Hemophilia Foundation
▶ **Hemophilia.org/community-resources/scholarships**

Notes

Vanderbilt Hemostasis Treatment Center

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(615) 936-1765

VanderbiltHealth.com (615) 322-5000