

TIME TO TALK PUBERTY:



A Guide for Girls with Bleeding Disorders



NATIONAL HEMOPHILIA FOUNDATION

Hey Everybody!

It's great to meet you! We are so glad you decided to pick up this book. We are the Victory for Women team and we work at the National Hemophilia Foundation (NHF) on educational materials for girls with all different types of bleeding disorders. We wrote this book with a group of experts, that is, doctors, nurses, parents and, of course, girls like you — girls with bleeding disorders! We're going to cover a lot of material together, but let's start with some basics.

We understand there's not one definition for what it means to be a girl. While being female may have been assigned at birth, we know that what it means to be a girl may look, feel, and be expressed differently depending on the person. In this book we used the term "girl" a lot, but to us that is a very broad term and we want you to know that can include a range of gender identities. This book focused on the body parts and organs that change during puberty for those who menstruate (aka those who have periods). Some of the information in this book may be new and some of you may have heard it before. Either way, it is totally okay. We're aware that every person is at different stages of puberty and so is their experience. This book can be informative for anyone.

Everyone on the planet goes through puberty, that period from adolescence to adulthood. Although at times you may feel like you're the only one with questions, **we GUARANTEE you everyone has similar questions.**

How did this book come about? We heard from girls just like you that they wanted a puberty book and a few of our strong beliefs drove us to write it.

**We Have
Some
Answers.**

We believe that every girl deserves:

- 1 To know about her bleeding disorder, changes her body goes through during puberty, and how, if at all, having a bleeding disorder may impact those changes.
- 2 To understand that it is okay to talk about your body and get any questions answered. Puberty and bleeding disorders are not something that you have to hide.
- 3 To feel that puberty and her bleeding disorder are manageable. There may be some awkward moments along the way, but you got this. You are not alone!

That's why we wrote this book.

We'll explain about different bleeding disorders, about how your body changes during puberty (with just enough science included) and about the various feelings that come along with it. Throughout the booklet, you'll hear real stories from those who've been through it, because it's always easier when you have someone share your experiences of growing up!

Inside the book, there are tips on how to have healthy conversations with your friends, doctors and family. We totally get that puberty is not always easy to talk about. Hopefully these tips will help you feel more comfortable asking questions and talking with trusted adults in your life.

We also know that the puberty experience can allow you to take control of your body, know what's happening and learn what works for you.

Most of all, we hope that after reading this book, you'll feel knowledgeable about your bleeding disorder and ready to take on puberty!

**The Victory for
Women Team!**



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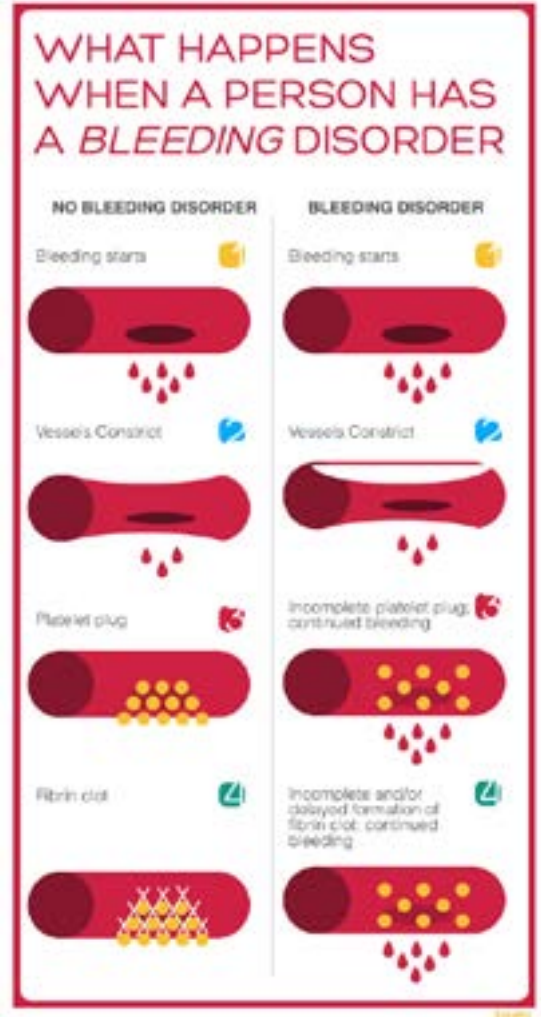


TIP:

All terms bolded
in blue or white will be
in the glossary in the
back of this book.

Bleeding Disorders Basics

A bleeding disorder is an **inherited chronic** condition where a person bleeds longer than normal before a clot forms to stop the bleeding or the formed clot breaks down too early, leading to longer bleeding. When a person bleeds, parts of the blood called **proteins** (clotting factors) and **platelets** work together and in the correct order to create a clot strong enough to stop the bleeding. All the proteins and platelets involved in the process are called the **clotting cascade**. If a part of the clotting cascade isn't working right, then a bleeding disorder occurs. Which bleeding disorder and the **severity** of it is based on which protein is affected and the amount of that protein that's missing or not working well enough in the blood.



Q:
How many girls have a bleeding disorder?

A: Up to 1% of women and girls have a bleeding disorder, but many don't even know it. Some women and girls live with symptoms but don't know that the symptoms may be due to a bleeding disorder. We want to help more girls and women get properly diagnosed and learn how to manage their symptoms.

“Inherited” means that a condition or trait is passed down from your parents. “Chronic” means ongoing for a long time; you have chronic conditions for life.

“platelets” are tiny, disc-shaped parts of blood that help seal injured blood vessels and stop bleeding.

Proteins in the blood, known as a **clotting factor**, act in a certain order to stop bleeding and form a clot. The factors are numbered from 1 to 13 using roman numerals

My Bleeding Disorder and Me

There are many different types of bleeding disorders. Below are some details on the different types. You may only be familiar with the one you have, but it's important to know a bit about the other ones too. After all, it's what connects you to all the amazing girls with bleeding disorders in your town, across the country and even around the world!

Hemophilia

As we said earlier, blood has different proteins called clotting factors. Two important clotting factors are factor VIII (8) and factor IX (9). When a person's clotting factor doesn't work correctly, is low or is missing from their blood, they may have hemophilia. The less clotting factor in your blood, the more serious your hemophilia may be. There are two types of hemophilia, called **hemophilia A** and **hemophilia B**.

Hemophilia A

is caused by a factor VIII (FVIII) deficiency. The amount of factor VIII in your blood tells you the severity of your bleeding disorder.

Someone with mild hemophilia will have 6–49% of FVIII in their blood, someone with moderate hemophilia will have 1–5% of FVIII in their blood and someone with severe hemophilia will have less than 1% of FVIII in their blood.

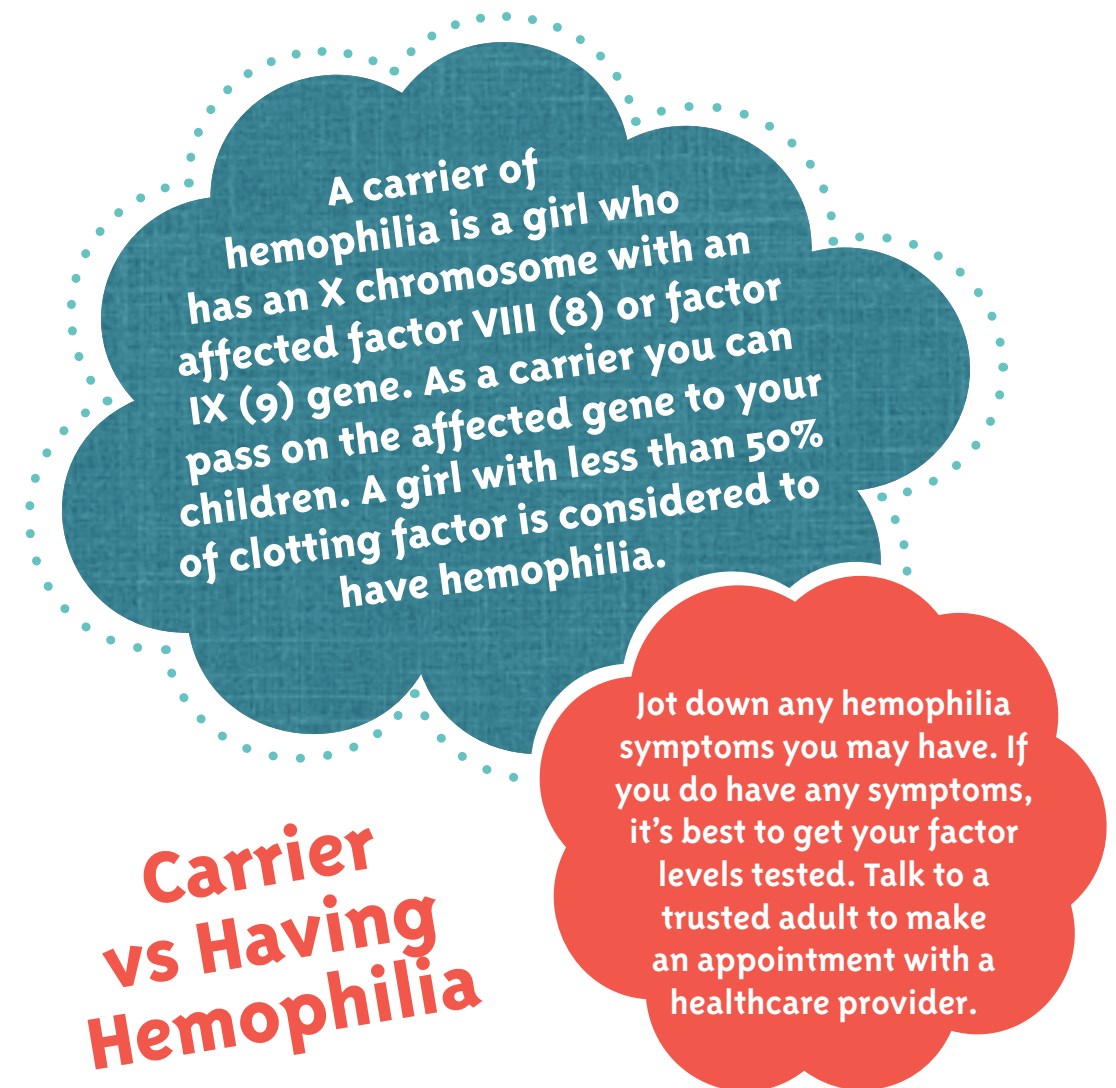
Hemophilia B

is caused by a **factor IX (FIX) deficiency**. The amount of factor IX in your blood tells you the severity of your bleeding disorder. Someone with mild hemophilia will have 6–49% of FIX in their blood, someone with moderate hemophilia may have 1–5% of FIX in their blood and someone with severe hemophilia will have less than 1% of FIX in their blood.

You may have heard that only boys can have hemophilia. Although it is more common for boys/men to have hemophilia, we now know that any gender can have hemophilia. In the United States about 20,000 people have hemophilia. The hemophilia **gene** can be passed down from either parent if they have an affected X chromosome. Women (and girls!) have two X chromosomes; they pass one of those **chromosome** onto each child. So there is a 50/50 chance that the X chromosome passed on to a child is the affected one. Men have an X and a Y chromosome; he will pass his only X chromosome onto his daughters. So if a man has hemophilia, he will pass the affected gene to his daughters.

This is why in some families there may be more than one child with hemophilia, but in others some siblings have it and others don't.

Based upon your clotting factor levels, you may have hemophilia or be considered a **carrier** of hemophilia.



Some carriers may have bleeding symptoms, while others may not. See the chart on page 12 for the symptoms of hemophilia and jot down any symptoms you may have. If you do have symptoms, it's best to get your factor levels tested. Talk to a trusted adult to make an appointment with a doctor.

Von Willebrand Disease

Von Willebrand (WILL-bränt) disease (VWD) is an inherited disorder caused by a problem with the clotting protein in the blood called **von Willebrand factor (VWF) or by not having VWF**. This means that your body is unable to form a proper blood clot.

The VWF gene can be passed down from either parent. VWD can affect all genders equally, but not all children in one family will necessarily have VWD (see the Hemophilia section above to learn about chromosomes).

VWF plays two important roles in the clotting process:

- 1 It acts like the glue to make the platelets stick together to form a platelet plug.
- 2 It carries the clotting protein FVIII to where it needs to go in the body and makes sure there is enough FVIII in your bloodstream.

There are three types of VWD: Type 1, Type 2 and Type 3.

The types are based on how much VWF you have in your blood and whether or not it is working properly. There are even VWD subtypes (1C, 2A, 2B, 2N, 2M). For more information about the subtypes, check out www.stepsforliving.hemophilia.org.

Type 1

The body usually has lower than normal levels of VWF.

Type 2

The body produces slightly lower or normal levels of VWF, but it doesn't work correctly.

Type 3

The body has little or no VWF and low levels of FVIII.

It's important to know which type of VWD you have because symptoms and treatments can be different for each person. Make sure to talk with your healthcare provider about your diagnosis.

Platelet Disorders

Rare platelet disorders are disorders where you may not have enough platelets to make clots, the platelets don't stick to each other as they should, or parts of the platelets may be missing or not working right. Platelet disorders can be inherited or may develop after birth.

Some platelet disorders are:

Platelet Storage Pool Deficiency

Bernard Soulier (soo-lē-ā) Syndrome

Glanzmann thrombasthenia (thrām-bəs-THĒ-nē-ə)

Rare Factor Deficiencies

Rare factor deficiencies are inherited bleeding disorders caused by a problem with one or several clotting factors. They are even more rare than hemophilia and VWD, some affecting only 1 in 5 million people. A rare factor deficiency means the blood clotting factor doesn't work correctly, is low or is missing from your blood.

Common Factor Deficiencies Affecting Girls

Bleeding Disorder	Name of Protein
Factor I (1) deficiency	fibrinogen (fī-BRIN-ə-jən)
Factor II (2) deficiency	prothrombin (PRŌ-thrām-bən)
Factor VII (7) deficiency	factor VII
Factor XI (11) deficiency	factor XI
Factor XIII (13) deficiency	factor XIII

Q: What's the most common bleeding disorder?

A: VWD is the most common bleeding disorder in the United States, affecting about 1% of the population, or 3 million people. It affects all genders equally. Platelet disorders are the second-most common bleeding disorder among women.

**Want to know more about how all this works?
Visit www.stepsforliving.hemophilia.org for a closer look at the genetics of bleeding disorders.**

Bleeding Symptoms

Do any of the symptoms in the table apply to you? Many disorders have similar symptoms. Some people may have all, some, or no bleeding symptoms and may not fit perfectly in this chart.

DISORDER	Heavy menstrual bleeding	Nosebleeds	Easy bruising	Bleeding in the mouth or after dental work	Prolonged bleeding after surgery	Joint bleeds
Hemophilia	★	★	★	★	★	★
Von Willebrand disease	★	★	★	★	★	★
FI deficiency	★	★	★			★
FII deficiency	★	★	★			★
FVII deficiency	★	★	★			★
FXI deficiency	★	★	★	★		
FXIII deficiency	★	★	★			
Bernard Soulier Syndrome	★	★	★		★	
Glanzmann Thrombasthenia	★	★	★	★		
Platelet Storage Pool Disease	★	★	★	★		

Note: many disorders have similar symptoms.

Your experience with symptoms may be completely different than your friend’s experience. Some people may experience symptoms from a young age, while other people may not experience their first symptoms until they start **puberty**. The severity of symptoms can vary based on the severity of your bleeding disorder diagnosis. Everyone’s experience with a bleeding disorder is unique.

Q: Is there a cure for bleeding disorders?

A: Currently, there is no cure for bleeding disorders. But there are many research studies that are looking into how the different blood proteins work in the body. Researchers are trying to develop new treatments to help people live as bleed-free as possible.

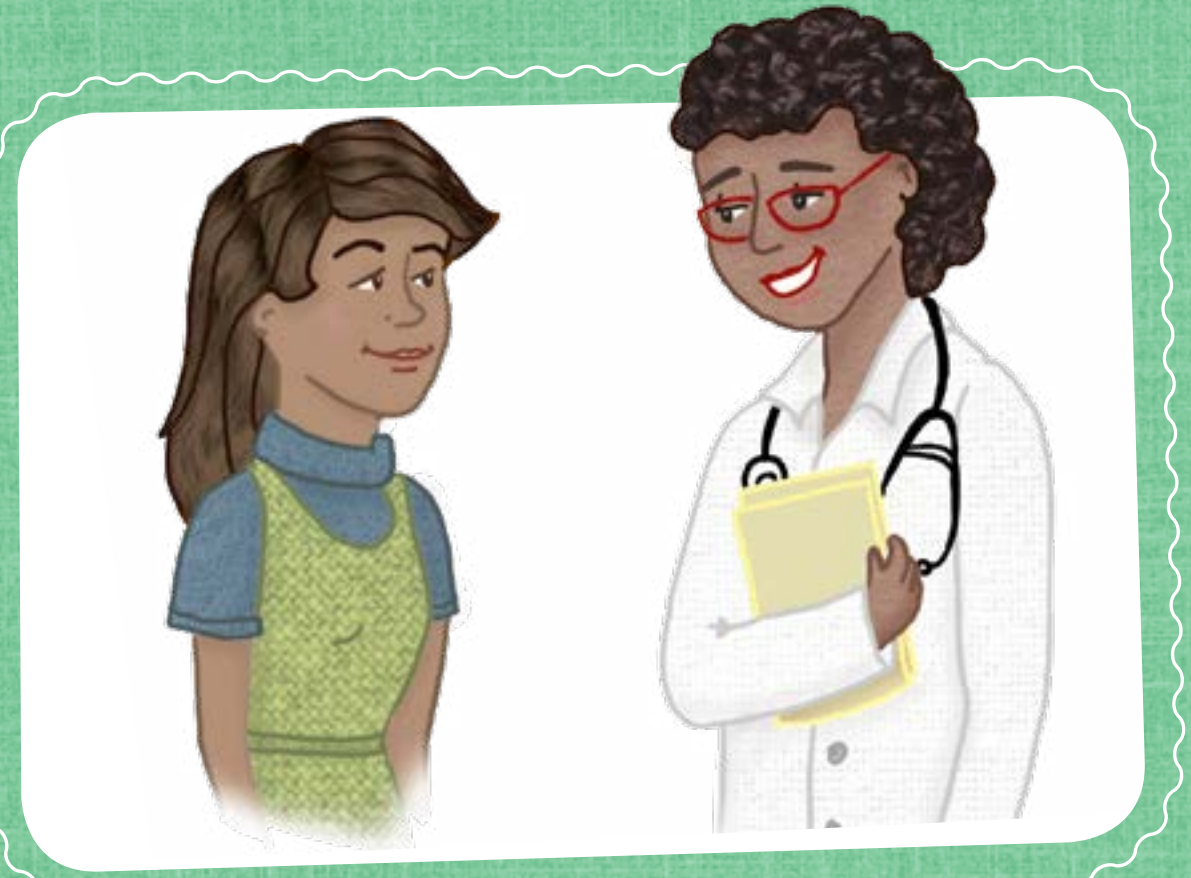
Doctors Who Treat Bleeding Disorders

A **hematologist** is a doctor that works specifically in disorders of the blood. Some hematologists see patients in private offices, while others work in a specialized **hemophilia treatment center (HTC)**. No matter where they work, hematologists see patients with all types of bleeding disorders, not just hemophilia. There are HTCs all over the country. At an HTC you may be able to have your very own team, including your hematologist, a **nurse**, a **physical therapist** and a **social worker** — all to help you manage your bleeding disorder. This type of care is called the **comprehensive care model**. Some girls with bleeding disorders may go to an HTC for care, and others may only see a hematologist.

A hematologist is not the only doctor you may work with for your care. You may also see a doctor called an adolescent gynecologist.

They usually work outside of an HTC. **Adolescent OB/GYNs (obstetricians/gynecologists)** are doctors that focus on reproductive system needs of those with vulvas and know a lot about heavy **periods**. Often, you may see a nurse before you see the doctor. Nurses can teach you about your symptoms and how to take care of yourself. Nurses work with doctors to keep track of your condition, such as monitoring your temperature and blood pressure. Nurses will also draw blood, insert IVs and give you medicine. For some girls, the main healthcare provider they see is a nurse practitioner, not a doctor. A nurse practitioner is a nurse who has advanced training in medicine and in working with families and young people.

It's important that you feel comfortable with your health providers. You want to be honest and ask questions, so you can get what you need. Remember, they are there to help you. Feel free to talk to them about what's on your mind.



If you're living with a bleeding disorder, there are treatment options to help manage symptoms and prevent bleeds. Depending on what bleeding disorder you have and what symptoms you are trying to prevent or heal, treatment may mean that you ingest a pill or liquid, inject the medicine into your vein using a needle, or take a nasal spray.

Hormone therapy is one treatment option that helps with regulate heavy periods. People sometimes call hormone therapy "birth control" because of how it affects the **ovaries** (ŌV-ə-reez) and the lining of the **uterus** (YŪT-ə-rəs).

Treatment options vary from person to person. You may only have one type of medicine, while other people may have more than one medicine. To learn more about treatment options, visit the Treatment Basics section of www.stepsforliving.hemophilia.org.

Puberty: Just The Facts

Fact #1: You Are Not Alone

All bodies — change as kids grow older. It is all part of growing up. Your body may do things you're not familiar with. The best thing you can do is to learn what to expect!

Puberty, that is, the physical and emotional changes your body goes through on its way to adulthood, usually starts between ages 8 and 13 for girls. Usually by ages 15 to 17 your body is done developing and is officially an adult body!

All bodies change in their own way and in their own time. It can be hard when you see other girls changing faster or slower than you, but, remember, it isn't a race. Your body is amazing and allows you to do so many cool things. No need to rush it or feel bad if it is going at a different pace than others' bodies. These girls experienced their first signs of puberty at different times in their life.

Everyone's Journey is Different.



Lowanna started wearing deodorant and grew 2 inches at age 9.



Jamaica grew 4 inches the summer before high school.



Ana Maria started wearing a bra at age 11 but only grew an inch.

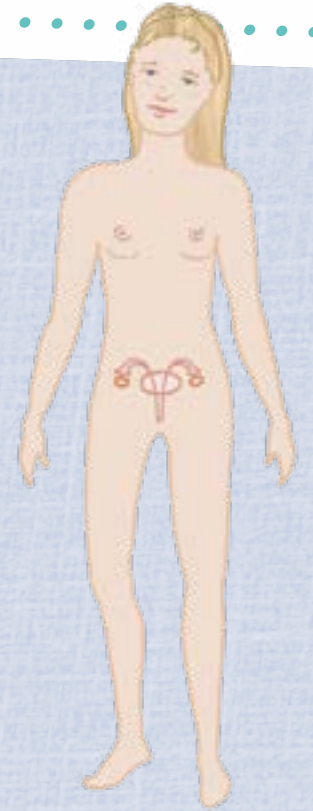


BRAIN BUSTER: While the rest of your body may get through most of the big changes by your late teenage years, your amazing brain keeps going! Some parts of your brain continue to develop into your mid 20s, which is when some experts say adolescence truly ends.

Fact #2: There Are Signs to Look for When Your Body Changes

Look for these signs to know when your body is starting to change:

- You're growing taller quickly (that is, a **growth spurt**).
- Your feet are getting bigger.
- You are getting curvier/wider through the hips and thighs.
- Your **breast buds** are developing (that is, you are starting to swell a little bit under the nipple).
- Your nipple area is growing and may be getting darker.
- You are growing hair in your armpits, on your legs, and around your **vulva** (**VəL-və**), which is the area around your **vagina** (**və-JĪ-nə**).



Did You Know?

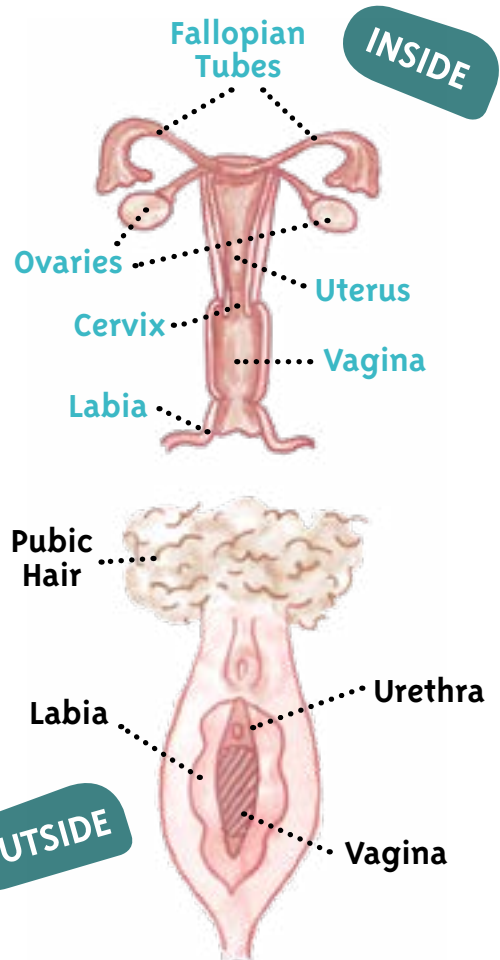
Puberty really starts in your brain!

A tiny, pea-shaped gland in the brain, the **pituitary** (**pə-TŪ-ə-ter-ē**) gland, sends out chemical messengers, called **hormones**, to certain parts of the body that triggers these changes. Lots of hormones go through your body during puberty, and they cause both the physical and emotional changes you may have. More on that later!

Fact #3: There Are Names for All Your Body Parts

When talking about all these changes, you may hear body part words you haven't heard before. Your body is nothing to be ashamed of, so it is good to know what all the parts are called.

You may hear adults talk about "private parts." Those are really just any areas you would cover with a bikini swimsuit. No one can look at or touch them without your **consent**. But it doesn't mean that we shouldn't talk about those parts, especially if you have questions about what is going on with yours.



The top image shows an internal front facing view of the reproductive system. The bottom image shows an external view of the anatomy. The external part of the reproductive system, as a whole is called the vulva.

BODY TIP
Grab a mirror and take a peek at your body parts. It's good practice to know where your parts are and what they look like.

What Does My Bleeding Disorder Have to Do with Any of This?

Each girl is different. For some, having a bleeding disorder may not make any difference during puberty, but for others it might. Girls with bleeding disorders often have longer and heavier periods (more on periods later). Frequent nosebleeds or bruises are also common. We sometimes hear that

Fact #4: There Are Stages of Puberty

Puberty doesn't all happen at once! Check out what changes happen when. Remember: everyone's path through these changes may be a little different. That's okay!

1

Between ages 8-12
No visible signs of puberty

2

Can start between ages 8-14

- Height and weight increase quickly
- Nipple area is raised and tender
- Breast buds appear
- Fine, straight hairs start growing near the labia

3

Can start between ages 9-15

- Continue to grow taller
- Breasts become rounder and fuller
- Pubic hair becomes darker, thicker and curlier
- Hips become wider
- Vagina secretes and discharge
- For some girls, ovulation and menstruation starts later in this stage

4

Can start between ages 10-15

- Underarm hair appears
- Nipple and areola begins to stick out from the rest of the breast
- Pubic hair starts to form a triangle patch in the genital area
- For some girls, ovulation and menstruation start in this stage

5

Can start between ages 12-19
Adult stage:

- Appearance of a young woman
- Areola and breast are joined and breast development is complete
- Pubic hair forms a thick, curly and triangular patch
- Reached full adult height
- Ovulation and menstruation occur regularly

nosebleeds or bruises weren't a big deal to girls with bleeding disorders when they were younger, but now they may feel embarrassed or may shy away from activities they used to love. For other girls, if they have lots of bleeding they will lose iron in their body. Having low iron causes anemia which means they may feel more tired than usual.

If you have questions about any of your bleeding symptoms (see chart on page 12 even if it feels like an embarrassing one, talk to a trusted adult or the nurse or doctor that you see for your bleeding disorder.

They have heard it all!

'FESS UP: Questions from Young People. Answers from Experts.

Are the changes that are happening in your body “normal”? It is really common to ask this! Here are questions from young people in the community and answers from our experts.

Q: I decided to start shaving my legs. I'm a freshman in high school. Every time I shave I nick myself at least once. I was hanging out with my friends and one of my friends noticed a string of blood down my leg. Is that normal? — Zonta



A: That's totally okay. It happens to a lot of girls, those with bleeding disorders and those without them. When you nick yourself, put a band-aid on the spot or stick a piece of tissue to it to help it clot.

Q: My socks and shoes have started to smell at the end of the day. Is that normal? Sincerely, Shaam

A: Completely normal! Your **sweat glands** start to work more during puberty, which can mean more odor in various parts of your body, feet included. Everyone sweats — really — even if you don't always see it. Sweating is one way your body works to keep you cool. If you notice your feet sweat more, such as during gym or playing sports, carry an extra pair of socks just for that activity and change afterward. Always make sure your feet are clean and dry before wearing shoes and wear clean socks every day. Oh, and make sure your feet get plenty of time to air out with no socks or shoes!

Q: I sometimes have some white creamy stuff in my underwear. Is that common? — Bindi

A: COMMON! If you have a vagina, you will have what is called **vaginal (VAJ-ən-əl) discharge**. It is your body's natural way to keep your vagina clean, so it is a good thing. It is typically clear or whitish, with little or no smell. Discharge with color to it or a strong smell could be the sign of an infection, so talk to your parent or guardian and doctor about it.

Q: I get pimples on my face and sometimes on my back and arms. Am I the only one? Ughh, I hate pimples so much, so I pick them but then they bleed. Sincerely, Dilber



A: You are definitely NOT the only one! Pimples and other forms of **acne (AK-nē)** can happen anywhere you have skin, but they typically happen more on the face, neck, chest, back and upper arms. You get pimples because your skin is making more oil, thanks to puberty hormones. Scratching at pimples is like scratching at a scab: it will bleed. Instead, stick a small piece of tissue paper on it or even cover it with a cute bandage to help stop the bleeding.

Q: I'm 12 years old and I just started my period last year. It was so super heavy that I was using a pad every hour. My aunt and I went to see my hematologist and then an adolescent gynecologist. We decided it was best for me to take “birth control” to help manage my periods. I take my medications at night before I go to bed. When I went to my friend's sleepover I had to take my medication, and all her friends were looking at me funny. I don't want to be judged. How do I deal with the stares? Sincerely, Adelaide

A: Birth control can be used for many reasons, and everyone has an opinion on what age is best to start using it. Remember, you know yourself better than anyone else and you know why you're taking birth control. There is nothing to feel ashamed of. In situations like these, you could teach your friends about bleeding disorders. You get to decide, though, what you're comfortable sharing about your bleeding disorder. You can share you are taking medicine to help manage your period.

Sleepover Surprises

Meet Erica

I am 10 and have VWD. Once I was invited to a friend's birthday sleepover. It started out really fun. We were laying out our sleeping bags, getting ready to play board games and eat cupcakes when all of a sudden I got a horrible nosebleed. I mean *horrible*. It wouldn't stop! I got blood on my shirt and sleeping bag. Some of the girls I didn't know as well were really freaked out. I *ran* into the bathroom! I wished I had never come and wanted to stay in the bathroom the rest of the night. I never used to care so much about any nosebleeds I had. The birthday girl's mom came to



check on me. I said I was fine even though I was so embarrassed. My good friend knew I had a bleeding disorder and explained it all to the other girls. She told them that I even had medicine to help with the bleeding. They all came knocking on the door, apologizing for being freaked out and begging me to come join them again. One girl even shared that she has something called **diabetes** and has to get shots every

day. She really understood what it was like to feel different than rest of the group. We all ended up staying up super late, telling jokes and trying to scare each other with ghost stories. It was a great party after all!



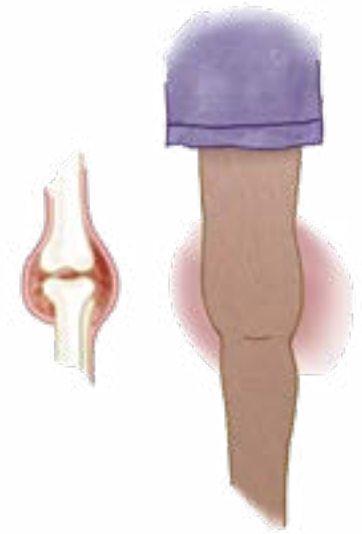
Soccer Strengths

Meet Julyana

I have mild hemophilia and love to play soccer. When I was younger I didn't worry about playing with a bleeding disorder. I never really thought about it; it was just all fun! Now that I am 12, the teams have gotten a lot more competitive and I grew two inches in six months, so I kept tripping and falling and getting bruises. On top of that, I got a joint bleed. I was embarrassed and sad. Everyone wondered why I was getting so bruised. I was worried they thought I was weak. And to top it off, I was scared my parents would make me stop playing. I eventually told my dad, and we went to my hematologist and they switched my medicines so now I don't bruise as much. I am so glad I spoke up and can keep playing!

Q:
Julyana mentioned that she got a joint bleed. What does a joint bleed feel and look like?

A: A joint bleed can feel warm on the skin and near the front of the joint. It can also feel tingly and bubbly on the inside. The area could look swollen, and it may be difficult to move or put your heel on the ground. It can hurt when you put weight on it or try to stand on it. Joint bleeds can occur in the knee, ankle, wrists and elbows.



Do you have more questions on sports and bleeding disorders?
Check out NHF's Playing It Safe on www.stepsforliving.hemophilia.org.

Time to Talk Periods

One of the biggest changes for those with ovaries during puberty is starting starting **menstruation (men-strə-WĀ-shən)** (that is, getting your **period**). Some topics around periods may feel uncomfortable or embarrassing. We get it.

You may have a lot of questions about what is going on, why it's happening and how to handle it all. That's why we're here! If we don't cover your question, remember it is okay to ask a trusted adult or doctor. No question is too silly to ask when it comes to your body.

The Facts. What is a period?

A period is one stage of the **menstrual (MEN-strə-l) cycle**. But it isn't the first stage, so let's start at the beginning: **eggs**. They're not the kind you buy in a carton at the store. Menstruators have two ovaries. Each ovary holds thousands of eggs, which are tiny (each no bigger than the tip of a pin). Every menstrual cycle begins with blood and tissue building up in the uterus (see Fact 4, above) to prepare for pregnancy. An egg is released from one of the ovaries and travels down the **fallopian (fə-LŌ-pē-ən) tube** to the uterus, which is also called the womb. If a **sperm** cell does not **fertilize** the egg, the unfertilized egg and the lining from the uterus leave the body through the vagina. In other words, a girl has her period. The blood is the lining from the uterus.

When you are done bleeding, the cycle begins again. The lining of the uterus will build back up, and about two weeks after your last period another egg will be released. If a sperm cell fertilizes an egg, the fertilized egg attaches to the lining and begins growing into a baby.

Getting your period allows you the ability to have babies. Babies grow in the uterus. That is, if you choose to have babies. But our bodies start to prepare us early, no matter what our future may bring.

When will I get my period?

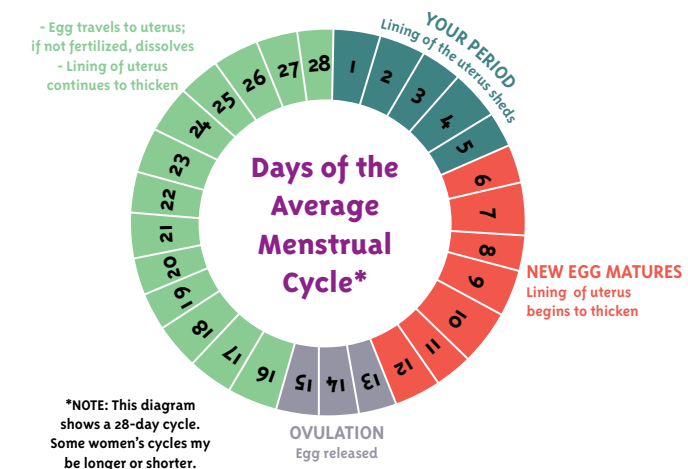
We can't predict exactly when, but a person's first menstrual period, called **menarche (MEN-är-kē)**, usually occurs between the ages of 11 and 14 years. Some people start as early as age 8 and others as late as 16.

How long will my period last?

Everyone's period is a little different. A normal period usually lasts about two to seven days. The first day of your period begins a new menstrual cycle. It ends when the bleeding of your next period starts. If you have a bleeding disorder, your first period may last longer than seven days.

You may hear people say things like "It's that time of the month" because the whole cycle — the uterus lining building up, an egg being released and your next period starting — can take about a month.

In younger girls, the cycle can be from 21 to 45 days long. So your cycle may not match up exactly with the months on the calendar.



A period longer than seven days is one sign of **heavy menstrual bleeding (HMB)**. Other signs of HMB include:

- Having to change a pad or tampon every hour
- Passing blood clots larger than a grape
- Having to use two sanitary products at once (like a pad and a tampon)
- Having **anemia**
- Having flooding or gushing blood that limits your ability to participate in social activities, school or exercise

For most girls and women with bleeding disorders, HMB is their most common symptom. One study found that 78% of girls and women with bleeding disorders have HMB. Many girls and women have been through this experience and we get it! If you feel like you have these signs, it's very important to make a doctor's appointment to chat about your symptoms and find out any treatment options. We have tips on managing heavy periods later on in this book, so keep reading!

Today there are many free apps to help you track your period. Tracking your period can be useful to help you learn about your body, symptoms and any changes in your cycle. This is one way you can feel in control of your bleeding disorder. Depending on which app you choose, you can track and predict menstruation, predict ovulation, record your physical activity and feelings and identify any patterns. Regardless of whether you use an app or not, it's good practice to track your periods for your doctor's appointments and next steps.

SOME EXAMPLES OF ANDROID AND IOS APPS:

- Blood Sisterhood (for girls and women with bleeding disorders!): sisterhoodapp.com/
- Flo Period Tracker: flo.health/
- Clue: helloclue.com/



How much blood will I lose during my period?

Typically, women and girls lose about 2 to 3 tablespoons of blood during a period.

During your period, it is normal for blood to pass in various amounts. Each day might be a bit different. Often one or two days have heavier flow (more blood). The blood may appear clumpier rather than drops. That is called a blood clot. The consistency of blood and color (think shades of red to brown) may change from day to day.

Let's Talk Family

You may have heard things from older girls and women in your family such as "All women in our family started their periods at the same age." Every girl is different, and it is totally okay if you don't get your period at the same age as other women in your family did.

You also might hear, "We all have really heavy periods in our family. That is just how it is." Mostly likely your bleeding disorder was **hereditary**, meaning it came from one or both of your parents when they passed their genes on to you. It is possible for both a mom and daughter to have the same bleeding disorder and to have periods that are nothing alike! Regardless of how it is for the other women in your family, if you feel your period is too heavy and interfering with school and your social life, you should talk to an adult about checking with a doctor.

Will it hurt?

People often associate blood with pain, so we understand why people ask if getting your period will hurt. It is possible your period may not hurt at all. For some though, they can experience cramps, which are achy pains in your stomach, back or legs when the lining of the uterus is being shed. Some people may even have cramps before their period starts. It really varies from person to person. Cramps can change over time, too. For some women and girls, they go away altogether. If your cramps are affecting your daily and social life, it's best to talk to your healthcare provider.



BRAIN BUSTER: The uterus has muscles that tighten and relax, which allows the blood lining to be shed. That movement creates what we call cramps.

COPING WITH CRAMPS:

- Put a heating pad over your lower belly
- Exercise
- Soak in a warm bath
- Rest or take a nap
- Eat healthy foods and drink plenty of water (candy and soda can make cramps worse)

If the cramps are really bad, are affecting your school and social life and won't go away, talk to an adult and doctor about medicines that can help.

Plenty of protection

Long gone are the days where girls used “belt and towel” contraptions to protect against blood leaking during their periods. Yeah, not kidding, that was a thing. These days there are a lot of options:



Pads: A pad is an oblong-shaped, absorbent material that you stick to the inside of your underwear to soak period blood. Some pads have extra material folds on the sides, called wings, that you fold over the sides of your underwear to help keep the pad in place and prevent leaks. Most pads you throw out after each use, but there are washable, reusable ones too. Pads come in different lengths and sizes to provide more or less protection as needed.



Panty Liners: Panty liners are similar in shape to pads, but they do not absorb as much blood because they are a lot thinner. Some people use them as protection on lighter menstrual flow days or as a backup protection with tampons.



Tampons: A tampon is made of absorbent material in a tube-like shape that can be inserted into the vagina to soak up the blood. You also throw them out after each use. Tampons should not be used for more than eight hours. Also be mindful to change them more often if they are **saturated**. They come in different sizes. They can have plastic or cardboard applicators to help insert them in the vagina. If inserted correctly, a tampon won't hurt and you won't really feel it. Some people find these tricky to insert at first, but others prefer them, especially when playing sports or swimming.



Menstrual Cups: A menstrual cup is a small, flexible cup that is inserted into the vagina to catch and collect the blood. It doesn't absorb the blood like a pad or tampon; instead it forms a seal so no blood will leak out. When you remove the cup, you dump the blood in the toilet, wash it and reinsert it. Once your period is over, you can sterilize the cup in boiling water so it's ready to be used the next month.



Period Underwear: Period underwear is made of special absorbent material that you can wear like regular underwear. Depending on how heavy your flow is on a given day, it can last most or all day or can be a backup for a tampon. At the end of the day you rinse them out, usually by hand, and then throw them in the wash. It is likely you may need to have more than one pair to make it through their periods, but they are reusable month after month.

It's a good idea to track not only your period length but also your menstrual flow. If you are having heavy periods, the goal is not only to manage your heavy periods but also reduce the flow. This means writing down the number of pads/tampons used per day and how saturated they are for each day of your period. When describing your period to your doctor or nurse, telling them these specifics can help them understand your experience and how to best to work with you. Visit www.betteryouknow.org for a copy of our menstrual flow diary.

“To be honest, getting my period before my friends felt a bit awkward. I was the first one in my friend group to talk about periods. But then it was kind of cool that I was able to be open with them and that I had people my age to talk about it with. Not to mention I'm now the go-to-person for my friends when they forget to bring pads or tampons. It makes me feel good that I can help my friends when they're in need. It also makes me feel mature that I know A LOT about how the body works. — Bobby, age 12”

Having all these options can be a good thing! Some people may use tampons on heavy flow days and pads on lighter days, or only use menstrual cups during their periods. It's really up to you to decide. What might be right for your friend, cousin or aunt may not be right for you. And what might be right for you this year might change next year. Go ahead and linger in the “feminine hygiene” aisle at the store one day to look at and compare the different boxes. You can even buy a bunch of the different options and try them out to see what works for you.

Tips for managing heavy periods

Here are some tips from young people on how they deal with their heavy periods:

"The best way to deal with this huge change in your life is to be informed and educated."

"I've noticed that toward the beginning of my period, when I have more clots, I may sometimes need to change my tampon sooner. Clots cling to the outside, and I think it doesn't allow the tampon to absorb as well."

"I avoid wearing light colors or white on my heaviest days of my period, just in case."

"When I'm out and about and active during my period, I keep a bag of at least two extra pairs of panties, an extra pair of pants, and a long-sleeved sweater or jacket (in case of any accidents; this comes in handy to tie around your waist!)."

"Nylon underwear is a lifesaver!!!! Blood comes out of nylon underwear very, very easily, as compared to cotton."

"Fels-Naptha is a heavy-duty laundry bar soap that removes blood stains in clothes. So does dish soap."

"One of the problems I encountered with pads are limited mobility. I was in dance classes and if I moved around too much, the pad would move out of place. I felt I had to constantly check to see if I needed to change. It worried me, so I talked to my dad about other options and started using tampons."

"I had to experiment with different brands, sizes and lengths of pads. Eventually I found that I use different things on different days, depending on how heavy my period is. I was glad I kept trying new pads and tampons until I found what was comfortable and worked well for me."

"On my heaviest days, I would set alarm clocks during the night to make sure I would get up to change my pads; otherwise I would leak through. Once I moved on to tampons I felt safer."

"So that I don't continuously ruin new ones, I have underwear dedicated to wearing at night during my period."

"A laundering hint: Very cold water helps to take out blood stains, and so does hydrogen peroxide. Try to rub out the stain using one or both before washing. Keep in mind that the dryer will set the stain in permanently."

"I always have a backup pad, tampon, and panty liner in my bag all the time, in case I get my period unexpectedly."

We all know you can find everything on the internet, which means some of the information is reliable and true, while other information can be confusing, overwhelming and incorrect. When you add social media in the mix, you really have to be careful of what you click on.

In the Resources section, we've listened some trusted sites the Victory for Women team recommends. Word of advice: Always do your research and run it by an adult you trust before you hit the "follow" button or hashtag it.



I was in class taking a test and I felt a gush of blood. I'm getting better at tracking my periods, and so it was probably time to change my pad. I'd had it on for two hours. I had to go to the substitute teacher and explain to him that I needed to be excused to go to the restroom and my 504 plan allows me unlimited bathroom passes. He wasn't informed on my 504 plan, so he was hesitant at first to let me go. Fortunately for me, I had to have the same conversation with another substitute a few weeks back, so I felt ready to handle the conversation with him. Plus, at camp this past summer, I heard the other campers talk about how they had to be their own advocate and voice their needs at school, so that made me feel better that my friends were encouraging me.. Oh, also, I told the substitute that my 504 plan allowed extra time on tests. I actually did alright on the test, considering I crammed for the test the night before! — Dani, age 14

Doc Talk

When it comes to talking to your doctor, it is normal to feel a little (or very!) uncomfortable talking about your periods, your body and your personal life with someone you don't know very well or see every day. Try to be as honest as possible. Try writing down your questions and symptoms and having your doctor read them if you're nervous! You can ask for your parent or guardian to be in the room with you during your visit, or you can ask for privacy and the doctor will not tell your parent your concerns.

You, your OB/GYN and your hematologist can all work together to reduce menstrual flow, even if the two doctors are not in the same hospital, HTC or office. Your appointments with your provider may not be physical exams; they may just be a conversation about your period, bleeding symptoms family history of bleeding disorders and taking blood for testing.

Working together means each doctor and healthcare team (for example, OB/GYN and HTC team) has access to your records and lab test results, and they talk to each other and you to determine the best possible care. Most importantly, the plan should be one that you are comfortable with putting in place. Your voice is the most important in any decisions being made!

HEMATOLOGIST



OB/GYN

The Emotions of Puberty

All the feels

When going through puberty, it may feel like there is no one who understands what you're going through. You may be worried about fitting in, being healthy or having something that makes you feel different. As your body is developing, you may notice your feelings go up and down more quickly than before. During this time, you may even start to compare yourself more to others. Don't worry. You are not alone. We have some tools to help you remember just how great you are.

Here are some questions to ask yourself that may help you figure out what makes you *you*:

- What are my best qualities?
- What do I hope and dream for the future?
- What do I like most about myself?
- What types of activities do I like to do inside and outside of school?
- What is my favorite subject?
- If I could be anything right now, what would I be?
- What do I want to be when I grow up (it's okay if you don't know this yet!)?

While it is super important to figure out how to love yourself and find what makes you happy, we all know that sometimes you just don't feel happy. Remember those things called hormones? Hormones going through your body can have an impact on how you feel. One minute you're happy and the next you feel so angry or sad. It can be hard to know how to deal with all those different emotions. That's why taking care of your feelings is as important as taking care of your body during this time.

As you grow and mature, your interests may change too. You may start to develop romantic feelings toward someone who you didn't notice before.

You may start to have ups and downs with your friends. Remember, all of your friends are going through changes as well, so it can be important to consider how they are feeling too.

But just because all of your friends are doing something doesn't mean you have to go along, especially if it doesn't feel right to you. Don't lose sight of what is right for you. Even though you may be adding some new interests or friends, you don't have to leave all your old ones behind. This is an exciting time of figuring out who you want to be..



Did You Know?

Here's a little secret: Everyone has something they are going through that is hard for them. It may not be a bleeding disorder, but it may be something that makes them anxious, frustrated or nervous. One girl may be upset that her parents are getting divorced, while a classmate with braces may be worried about what people will think of her smile. Sometimes we have to remind ourselves that everyone has something that may make them feel different. If we stick together we can support each other in those difficult times!

Q: Sometimes I feel really sad for no reason and just feel like I want to cry for hours. What do I do? Sincerely, Abena

A: It's okay to feel down. Talk to

someone — a friend, aunt, uncle or guidance counselor, for example — to help you sort out your feelings. Even getting outside with a friend or going for a walk can be a simple distraction and break from your thoughts. If you feel you're always sad and it's affecting your everyday life, talk to your parent or guardian so they can get you more help from a doctor. Take a look at our resources section for hotline information.

Self-Esteem

Feeling good about yourself and believing in yourself is called self-esteem. Having **self-esteem** gives you the courage to try new activities and make new friends.

Feeling positive about yourself doesn't always come naturally, though. Most people have to work at it a bit — that's okay! Work to love yourself and embrace who you are. Here are some things you can do to help feel good about you:

Find things you love to do. Maybe you think you aren't great in art class or gymnastics; try other activities until you find something that brings a smile to your face. It may be playing chess, riding horses, knitting, cooking, building robots or diving for the ball on the volleyball court. It may take some time to find what you like and that's okay! Give new activities a few tries.

Everybody makes mistakes, especially at first. You don't have to be perfect or even very good at all activities to have fun doing them. Trying new things can be scary but can have a big payoff!

Surround yourself with people who build you up. Stick with friends who make you feel good about yourself and don't put you down.

THINK POSITIVE. Sometimes we have to work at thinking positively about ourselves. It can be so easy to focus on the negative even when there is positive around us.

Make a list of three things that you did well this week and post it somewhere in your room as a reminder. Or share with your family what makes you feel proud. Celebrate all your successes, regardless of how big or small they may seem.

Explore some options for dealing with those emotional ups and downs, so you don't hurt others or yourself when your feelings seem out of control.

Meet Meaghan

"When I feel sad, I like to go in my room for some quiet time and just listen to music."

Meet Sharon

"Sometimes I get so angry at my mom. She just doesn't seem to listen! I said some really mean things to her once, though, and later felt bad. Next time I got really upset with her, I ran into my room and just screamed into my pillow. I was so exhausted from all the drama that I fell asleep right there. I woke up feeling so much better, and I felt a lot calmer and ready to have a conversation with my mom about what made me mad."



Meet Ling Mei

"I am 13 and have a platelet storage pool deficiency. I was feeling pretty down about it, like I was the only one who had something different going on in their body. Then I went to a bleeding disorders camp and met so many other kids with bleeding disorders."

I am not alone. Now I believe that having this condition makes me more amazing! I know how to listen to my body really well and can tell when something isn't right. I have learned how to speak up for what I need at school and in my community. I was so shy before. My bleeding disorder doesn't make me weak or weird but really strong!"



Meet Andra

"When I get stressed, I ask if I can go out on my own."



Meet Calista

"I worry a lot about my grades and what the kids at school think of me. I was keeping it all bottled up. I felt horrible. Now I keep a journal and write all my thoughts down. I found a pretty journal with inspirational quotes that remind me to feel great about me and it helps a lot!"

TALK IT OUT

How to talk with your friends

How your bleeding disorder affects you, what you’re going through now and how that makes you feel can be a lot to think about. Talking to others about it can help.

Your bleeding disorder makes you special, even if you may not feel that way all the time. Yet when it comes to friends, you may just want to fit in and your bleeding disorder makes you feel different. Remember: every girl has *something* going on.

Here are a few ways to talk to your friends and classmates:

- Before sharing with friends, make sure you know some facts about your bleeding disorder. Your parents or doctors can help you come up with some!
- If you feel comfortable, ask your teacher to share some facts about your bleeding disorder with your class. Or ask if you can share about it. You might explain that you have a bleeding disorder, which means that your blood doesn’t work quite right. You can share that you bruise a little more easily and sometimes your nose bleeds. Depending on what kinds of medicine you take, you can explain that you take medicine to help your blood work a little better.
- If you don’t feel comfortable talking to the whole class or having the whole class know, you can have talk with a smaller group of friends you trust in a private environment. It’s okay to not want to share your bleeding disorder with everyone you encounter! Having just one or two friends that you can talk to can help you.
- There are bleeding disorder communities in each state, called chapters. These chapters have camps and events just for girls with bleeding disorders. It’s an awesome place to meet other girls who can relate to your experience and provide advice and support.

How can you answer questions your friends may have? How do you handle it when you feel like no one understands what you’re going through? If people make comments about your symptoms, you can look at it as a time to teach people about bleeding disorders and clear up some misconceptions.

What Would You Say?

Remember 13-year-old Ling Mei who has a platelet storage pool deficiency. (See p. 37 to read her story again.) Ling Mei felt strong knowing that there were other kids at camp who also had bleeding disorders and understood her. She felt more comfortable speaking up at school and in her community. All her teachers at school know she has a bleeding disorder. She was thinking about telling her classmates in homeroom about her bleeding disorder. She was nervous and not sure how to start the conversation. She didn’t want her friends to look at her differently.

If you were Ling Mei, what would you say to your classmates?
Write it out here:

~~~~~

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### How to Talk to Trusted Adults

The conversation you have with trusted adults may be different than the one you have with your friends. The adult you talk with may be a parent, doctor, coach, family friend, aunt, grandparent or teacher — just to name a few!

When it comes to asking questions about puberty and managing your bleeding disorder, remember adults made it through puberty! They may not have a bleeding disorder, but they do understand what it's like to be your age. when you're ready, ask them for some time to talk and choose a place that's comfortable for you. This way, they will be free from other distractions and you will feel more relaxed. If it feels hard to ask for time to talk, you can also wait until you two are alone.

**Before the conversation, you could write down a few questions or points you want to talk about:**

Point/Question 1: \_\_\_\_\_

Point/Question 2: \_\_\_\_\_

Point/Question 3: \_\_\_\_\_

Where would you have the conversation and with who? \_\_\_\_\_

You can bring these points with you to make it easier to start the conversation. If you're having a hard time saying the words, you can always ask them to read what you wrote instead! This works for a conversation with a doctor or nurse, too. It doesn't matter how you do it; the important thing is just to get the words out!

### FINAL THOUGHT

Being this age can be exciting, but it can also be rough. So many new things are happening. It is a time where you are trying to figure out who you are and where you fit in. Sometimes you may feel like your bleeding disorder is making this whole process even harder. Remember that you have so many talents and experiences that make up who you are and there is only *one* you in this whole world! Only you get to decide who you are!

### Resources

Whew, we sure covered a lot of information! Thank you for coming along on this journey with us. We hope the stories you read and information you learned helped you better understand what you're going through and how your bleeding disorder fits into all of it.

We've only scratched the surface, though. If you have more questions or want more information, you can find a ton of amazing resources out there.

**This list will help you keep learning, no matter what your age:**

1. AMAZEmaze: <https://amaze.org/>
2. Crisis Text Line: Crisis Text Line is free 24/7 support from anywhere in the US for those in crisis. <https://www.crisistextline.org>
3. *Discovery Girls Guide to Growing Up: - Everything You Need to Know About Your Changing Body* by the Editors of Discovery Girls Magazine. Illustrations by Aruna Rangarajan
4. Gender Spectrum: Gender Inclusive Puberty Education
5. Girlology: <https://www.girlology.com>
6. Helloclue: Talking About Periods Beyond Gender
7. *HelloFlo: The Guide, Period.* by Naama Bloom
8. Kids Health: <https://kidshealth.org>
9. Kids Health 504 Education Plans: <https://kidshealth.org/en/parents/504-plans.html>
10. *Period.: A Girl's Guide* by JoAnn Loulan and Bonnie Worthen
11. *The Care and Keeping of You 1: The Body Book for Younger Girls* by Valorie Lee Schaefer, Cara Natterson, MD, Medical Consultant. Illustrated by Josee Masse (American Girls Series)
12. *The Care and Keeping of You 2: The Body Book for Older Girls* by Dr. Cara Natterson, Illustrations by Josee Masse (American Girl Series)
13. *This is Me ... : A Girl's Journal* by Julie Metzger, RN, MN
14. *Will Puberty Last My Whole Life?: Real REAL Answers to Real REAL Questions* from Preteens aAbout Body Changes, Sex and, and Other Growing Up Stuff by Julie Metzger, RN, MN and Robert Lehman, MD Illustrated by Lia Cerizo

Want even more information on bleeding disorders? Visit our website, [www.stepsforliving.hemophilia.org](http://www.stepsforliving.hemophilia.org), to learn more about living with a bleeding disorder during all life stages!



# GLOSSARY

**504 education plan:** is an education plan that legally ensures students with physical or mental disabilities can have a customized education plan and be treated fairly at school

**acne:** Bumps on your skin (especially your face, neck, back and upper arms) that is caused by extra oil your skin makes. Acne is also called “pimples” or “zits.”

**adolescence:** The time after puberty starts when a young person develops from a child to an adult.

**advocate:** A person who asks others for what you need in a respectful manner

**anemia:** When there are too few healthy red blood cells due to too little iron in the body. Heavy menstrual bleeding can cause anemia. Symptoms of anemia can include tiredness, dizziness, shortness of breath and having a hard time concentrating.

**Bernard Soulier syndrome:** A disorder caused by a missing or nonworking protein on the surface of a platelet called the glycoprotein Ib/IX/V.

**bleeding disorder:** An inherited chronic condition in which a person tends to bleed longer than normal before a blood clot forms to stop the bleeding.

**breast bud:** The nickel- shaped bump under your nipple during the breast development phase of puberty.

**carrier:** A person who has the gene for a condition but does not always display the symptoms for the condition.

**chromosome:** The structure in a cell's nucleus that contains genetic information in the form of DNA.

**chronic:** Long term; long lasting. Bleeding disorders are chronic illnesses.

**clotting cascade:** A series of steps that occur when a clot forms, involving the clotting proteins and other substances.

**clotting factors:** Proteins in the blood that act in sequence to stop bleeding and form a clot.

**comprehensive care model:** When healthcare providers work together to provide higher levels of care. For example, people with bleeding disorders can receive comprehensive care at hemophilia treatment centers.

**consent:** permission for something to happen or agreement to do something.

**diabetes:** A disease that affects how well glucose (a sugar) is used as energy in the body.

**eggs:** The female reproductive cell.

**expression:** How we present our gender in the world and how society, culture, community and family perceive, interact with, and try to shape our gender.

**factor I (1) deficiency:** A bleeding disorder in which the body does not have enough of the blood protein fibrinogen or none at all or the protein does not work correctly.

**factor II (2) deficiency:** A bleeding disorder in which the body does not have enough of the blood protein prothrombin or none at all or the protein does not work correctly.

**factor VII (7) deficiency:** A bleeding disorder in which the body does not have enough of factor VII or none at all or factor VII does not work correctly.

**factor XI (11) deficiency:** A bleeding disorder in which the body does not have enough of factor XI or none at all or factor XI does not work correctly.

**factor XIII (13) deficiency:** A bleeding disorder in which the body does not have enough of factor XIII or none at all or factor XIII does not work correctly.

**fallopian tube:** The part inside your body that carries the eggs from your ovaries to the uterus.

**fertilize:** When an egg and sperm come together.

**fibrinogen:** A protein (also known as factor I) that helps blood clots to form.

**gender:** Includes a person's body, gender expression, and gender identity each of which can be viewed on a spectrum

**gender identity:** A person's sense of having a particular gender, which may or may not correspond with their birth sex

**gene:** A piece of DNA that is located on a chromosome and that determines a certain trait.

**genetics:** The study of how certain features and traits pass from parents to their children.

**Glanzmann thrombasthenia:** A condition caused by a missing or nonworking protein on the surface of a platelet called the glycoprotein IIb/IIIa

**growth spurt:** When you grow a lot taller in a short time.

**heavy menstrual bleeding (HMB):** Menstrual periods with abnormally heavy bleeding that limits daily activities and places women and girls at increased risk of health problems if left untreated.

**hematologist:** A doctor who treats diseases and disorders of the blood.

**hemophilia A (factor VIII deficiency):** A genetic disorder caused by missing or nonworking factor VIII, a protein needed for the blood to clot.



**hemophilia B (factor IX deficiency):** A genetic disorder caused by missing or nonworking protein called factor IX, making it difficult for the blood to clot. Hemophilia B is also known as factor IX (FIX) deficiency.

**hemophilia treatment center:** A group of federally funded hospitals that specialize in treating patients with bleeding disorders.

**hereditary:** When a trait or feature is passed down from parent to child.

**hormones:** Chemical messengers that trigger physical and emotional changes in the body.

**hormone therapy:** medication that helps balance hormone levels and can regulate periods. Hormone therapy is sometimes called “birth control.” There are various options such as the patch, oral contraceptive pills sometimes called “the pill” and intrauterine devices (IUDs).

**identity:** our deeply held, internal sense of self as masculine or feminine, a blend of both, neither or something else. Identity also includes the name we use to convey our gender.

**inherited:** A trait, quality, or characteristic from your parents was passed down to you through their genes. An inherited bleeding disorder is passed down to you from one or both of your parents.

**menarche:** Your first menstrual period.

**menstrual cup:** A small, flexible cup that is inserted into the vagina to collect the blood.

**menstrual cycle:** The number of days from the start of one period to the start of the next period. Younger girls may experience cycles every 28 to 45 days. On average, the menstrual cycle is 28 days but can range from 21 to 35 days.

**menstruation:** The technical term for a period.

**nurse:** A healthcare provider trained to teach you about your condition and assist in providing you with care.

**ovaries:** The part inside your body that makes eggs.

**pad:** A oblong- shaped, absorbent material that you stick to the inside of your underwear to soak up the period blood.

**panty liner:** Similar to a pad, but it does not absorb as much blood because it is a lot thinner. Some girls may use them as protection on lighter menstrual flow days or as a backup protection with tampons.

**period:** The time of the month when the uterus lining sheds and blood comes out of your vagina. Normal periods usually last two to seven days.

**period underwear:** Underwear that is made of special absorbent material that you can wear like regular underwear.

**physical therapist:** A healthcare provider who help patients lessen pain and work on their ability to move their body parts effectively.

**pituitary gland:** A pea- shaped gland under the brain that releases hormones and tells the body to begin puberty.

**platelet:** A tiny plate-like component of blood that helps seal injured blood vessels and stop bleeding.

**platelet storage pool deficiencies:** A group of bleeding disorders that are caused by problems with platelet granules. Granules are little bags inside a platelet that store proteins and other chemicals that help the platelet work properly

**prothrombin:** A protein (also known as factor II) that helps blood clots to form.

**puberty:** The physical and emotional changes your body goes through on its way to adulthood, usually starting between ages 8 and 13 for girls.

**saturation (saturated):** When something is soaked or absorbed of a substance completely.

**self-esteem:** Feeling and thinking confidently about yourself.

**severity:** Describes the level of seriousness of a disorder, such as with a bleeding disorder.

**sex assignment:** the sex that a person has or is assigned to at birth

**social worker:** A health professional who helps patients find resources to have a healthy lifestyle physically, emotionally and mentally.

**sperm:** The male reproductive cell.

**sweat glands:** Organs under your skin that make you sweat. There are many sweat glands in armpits and feet.

**tampon:** A tube- shaped, absorbent material that can be inserted into the vagina to soak up period blood.

**uterus:** A hollow pear-shaped organ where a baby will grow. The uterus is also called the “womb” When you menstruate, your body sheds the lining of the uterus.

**vagina:** The part of the body where the period blood comes out of the body.

**vaginal discharge:** Thick, clear or white fluid that comes out of the vagina to help maintain a healthy vagina.

**von Willebrand disease (VWD):** A disorder that is caused by a lack of or a problem with the von Willebrand factor (VWF) in the blood.

**von Willebrand factor (VWF):** A clotting protein that helps platelets stick together to stop bleeding; factor VIII is attached to VWF.

**vulva:** The entire area of private parts around your vagina.





Handwriting practice lines consisting of seven horizontal wavy blue lines.

## ACKNOWLEDGMENTS

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**NATIONAL HEMOPHILIA FOUNDATION**

*for all bleeding disorders*

[www.hemophilia.org](http://www.hemophilia.org)



## What do bleeding disorders have to do with all this?

As a caregiver, it's important to recognize there may be additional challenges for girls with bleeding disorders, the most common being the onset of heavy menstrual bleeding. With these challenges come additional conversations for your young person and healthcare providers.

Setting expectations about their puberty experience and discussing a treatment plan with healthcare providers is crucial. Work with them to ensure they have the tools to manage their symptoms and emotions throughout this experience. They should know there is no reason to be ashamed of their bleeding disorder.

Work together to practice having difficult conversations where they are comfortable expressing their symptoms and advocating for their needs with your support.

## Conclusion

Puberty is curious, enlightening, and question-filled time for you and your loved one. With some education, conversation, and little bit of stepping out of the comfort zone you'll both learn and grow through it together.

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## TIME TO TALK PUBERTY: A Guide for Girls with Bleeding Disorders

*Tips for Parents & Caregivers*



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# What Do I Say?

When a child has questions about puberty, it is important to create a safe space for your loved one by listening, respecting their right to privacy, and their right to their feelings. Discussing puberty is a series of conversations over the years. You may be wondering, “What do I say?, How do I start this conversation?” Feeling confident about the subject matter will make these conversations easier.

## You can prepare by:

- Reviewing this book ahead of time.
- Speaking with your child’s healthcare provider privately to get all your questions answered. The healthcare provider can offer advice on how to approach the conversation.
- Use the correct terminology when describing menstruation and body parts.

Knowing the facts can help when talking to your young person. Practice in the mirror, or with a friend, relative or even an older sibling to help get the jitters out.

Your personal values and beliefs can affect the discussion. For example, ask yourself where you stand on debatable topics, such as birth control, relationships and healthy ways to handle emotions. Do they know and understand your values? Can they see you modeling them daily?

## Conversation Tips

Start the conversations early. You may want to wait till they come to ask you questions, but that day may never arrive. It’s perfectly fine for you to initiate these conversations. The key is consistent and open dialogue where both sides should feel they can speak honestly and without judgement. Put yourself in their shoes, and remember puberty isn’t easy or straightforward.

- Try your best to answer each question, but if you don’t know the answer, suggest that you can find the answer together. The most important thing is to listen with compassion and without judgement. Suggest finding out the answer together. Be mindful that putting it off or deflecting could send a message that it’s not okay or important enough to talk about.
- Encourage the young person to talk about their thoughts. An open exchange of ideas can establish the values and beliefs you each hold.
- Don’t be alarmed if they don’t respond or feel uncomfortable with the conversation. Give them time to process the conversation. Remind them that it’s okay to not want to talk about it but you’ll be available when they are.
- Give them a book to read on their own. Discuss it together afterwards.
- Watching tv shows together can sometimes spark conversations.

## Potential questions to ask:

1. Are you noticing any changes in your body?
2. Are you having any new feelings you’re not used to?
3. Are you ever sad sometimes and not sure why?

Remember all the emotions and thoughts that may arise. It’s your role as a caregiver to help guide them through this time. No one expects perfection, but they do expect your best shot!