

# TIME TO TALK

## Period

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A guide for young girls  
with a bleeding disorder

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# OPEN

START  
READING!

We would like to acknowledge the National Bleeding Disorders Foundation who provided the base document from which this resource is derived.

You can find more information about the National Bleeding Disorders Foundation and the original booklet at [www.bleeding.org](http://www.bleeding.org).



Scan the QR Code to  
visit NBD website!

This booklet, developed by the EAHAD Women and Girls+ with Bleeding Disorders (WG+BD) Working Group, is for informational purposes only and should not be used for healthcare management or treatment decisions. It is intended for girls who have just started or will soon start their periods. Some of the information may be new, while some may be familiar, and that's perfectly fine. It can also be informative for your family. While the booklet is primarily targeted towards women and girls, people with the ability to menstruate are, of course, taken into account and part of the conversation.

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# TIME TO TALK PERIODS

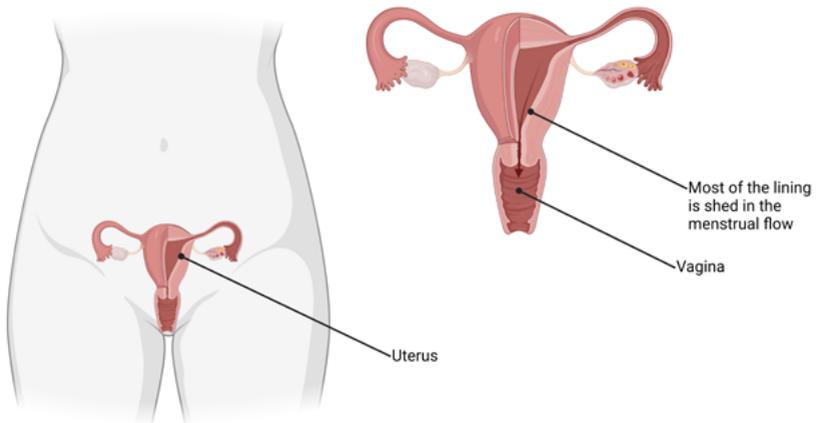
Period (also known as menstruation, starting to menstruate, 'that time of the month', 'surfing on the red sea') is a **release of blood from a girl's uterus through her vagina**. It is a natural and healthy sign of your body preparing to be able to have children.

## What is a period?

A period is one phase of the menstrual (MEN-strə-l) cycle, but it's not the first. Let's begin with the basics: eggs. Not the kind you find in a store, but the ones women and girls naturally have. They possess two ovaries, located in the lower abdomen, and each ovary contains thousands of tiny eggs—each no larger than the tip of a pin. These ovaries are connected to the uterus by tubes, and the uterus opens to the outside of the body through the vagina.

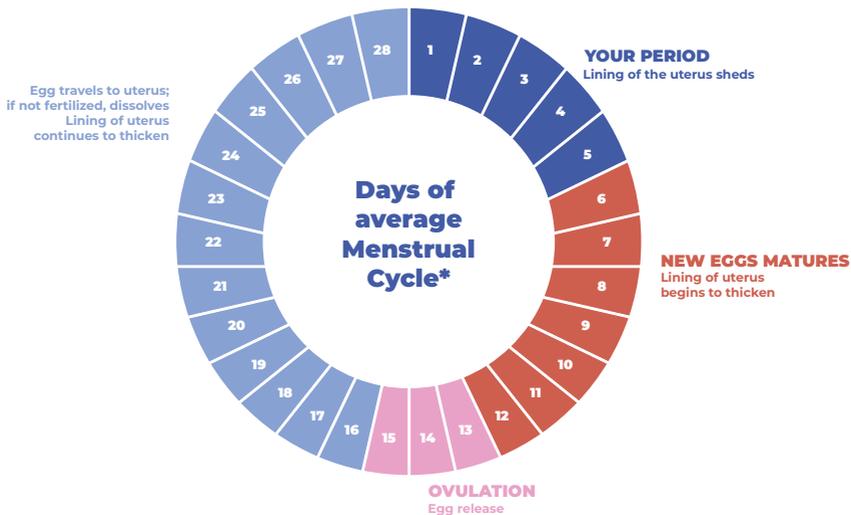
A period occurs due to hormonal changes. Hormones act as chemical messengers. The ovaries release the female hormones estrogen and progesterone, which cause the uterine lining to thicken. An egg is then released from one of the ovaries and makes its way to the uterus. The thickened lining prepares to support a fertilized egg, allowing it to attach and grow. If no fertilized egg is present, the uterus sheds its lining as blood, which exits the body through the vagina. This process is what we call a period.

Then the same process happens all over again. It usually takes about a month for the lining to build up, then break down. That is why most girls and women get their periods around once a month but it can be more irregular at the start or between 21 to 45 days in some girls so your cycle may not match up exactly with the months on the calendar.



## When will I get my period?

We can't predict exactly when, but a person's first menstrual period usually occurs between the ages of 11 and 14. Sometimes your friends might get their period before you and you might feel left out. Don't worry, everyone starts their period at different ages and this is normal. Some girls start as early as age 8 and others as late as 16. When a girl gets her first period, she may notice a reddish-brown discharge in her underwear, which is caused by menstrual blood.



## How does this fit in with my bleeding disorder?

Having a bleeding disorder or heavy periods does not affect your chances of having children in the future. It is important to understand about periods if you have a bleeding disorder as you may experience heavier periods than some of your friends. There are lots of ways to manage this and treatments that can help improve your period. The most important thing is that you understand and recognise when your periods are heavy, so you talk to your doctor and can get the best treatment for you. This booklet is here to help inform you about periods, your bleeding disorder and the options available to you.

## If I have a bleeding disorder, will that affect my periods?

For most girls and women, heavy menstrual bleeding (HMB) is very common. One study found that 78% of women and girls+ with bleeding disorders have HMB. If you get a heavy period, you are NOT alone!

## How long and how much?

In a normal period, the bleeding usually lasts between 3-7 days. Most girls lose 20-80 ml, during the whole period, but it can look like a lot more. Most girls need to change their pad, tampon, or menstrual cup about 3–6 times a day. But, if you have a bleeding disorder, you may experience:

- Bleeding that lasts seven days or longer
- Needing to change tampons or pads every 2-hours or more frequently
- Passing blood clots larger than a 1 euro coin
- Feeling tired or short of breath due to blood loss
- Anemia or low iron levels

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. If your periods are heavy, you may lose more than 80 ml of blood and your iron levels may start to fall. This can make you feel tired or to become anaemic.

## How can I understand my menstrual cycle?

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 the 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.

## Will my period hurt?

Having a bleeding disorder doesn't necessarily mean your periods will be more painful than other girls' or painful at all. Since blood is often linked to pain, it's understandable why some girls wonder if their period will hurt. The truth is, your period might not cause any pain. Some girls experience cramps (dull aches in the stomach, back, or legs) while the uterine lining is being shed. Cramps can even start before the period begins, but the intensity and occurrence differ from person to person. Over time, cramps can also change or even disappear for some. If cramps are interfering with your daily routine or social life, it's a good idea to consult your doctor or nurse.

## Your body, your period

You might also hear things like, "We all have really heavy periods in our family. That is just how it is." Most likely, your bleeding disorder came from one or both of your parents when they passed their genes on to you. It is possible for both a mum and her child 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 interfering with school and your social life, you should talk to an adult about checking with a doctor.

## The 7, 2, 1 rule



If your periods last for 7 days or more



Needing to change your pads/tampons more frequently than every 2 hours



Passing clots of blood larger than a €1 coin

from [www.knowyourflow.ie](http://www.knowyourflow.ie)

These are all signs that your period are longer or heavier than expected. Talk your doctor about the different options available to help improve your period and reduce the flow.

## 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.

What helps with your cramps can be very individual. **Perhaps you can see if any of these will help you?** Exercise, perhaps go for a walk or do an easy yoga class, rest or take a nap, soak in a warm bath, put a heating pad over your lower belly.

If you have a bleeding disorder it is better to use paracetamol based pain relief rather than anti-inflammatory medications. Ask your pharmacist or doctor if you are not sure.

# TIME TO TALK PERIODS

## Pad

A pad is a soft, rectangular material worn inside underwear during a period to absorb blood. Some pads have wings to prevent leaks by securing the pad in place. Most pads are disposable, but washable, reusable options exist. They come in various lengths and sizes for different levels of protection.

## Tampons

A tampon is a small, tube-shaped absorbent material inserted into the vagina to soak up menstrual blood. Available in various sizes, tampons often come with applicators for easier insertion. They should be changed every eight hours or sooner if full. Tampons are popular for activities like sports or swimming and should be comfortable when properly inserted.

## Panty liners

Panty liners are a bit like pads, but they're much thinner because they don't soak up as much blood. Some girls use them on days when their period flow is lighter, or as an extra layer of protection alongside tampons.

## Menstrual cups

A menstrual cup is a small, flexible device inserted into the vagina to collect menstrual blood. It creates a seal to prevent leakage, unlike

pads or tampons. When it's time to change, you dump the blood in the toilet, give it a wash, and put it back in. After your period is done, you can clean the cup by boiling it in water making it ready for use next month.

## Period underwear

Period underwear is made of a special material that soaks up blood, and you wear it just like regular underwear. Depending on how heavy your flow is, it can last most or all day, or you can use it as a backup with a tampon. At the end of the day, you rinse them out, usually by hand, and then toss them in the wash. You might need more than one pair to get through your period, but the good thing is you can use them again and again each month.

## Useful tips

- Having various menstrual products is beneficial, as different options can suit different needs. You might use tampons on heavy days, pads on lighter days, or a menstrual cup. It's a personal choice and can change over time. Take your time exploring the "feminine hygiene" aisle and consider trying different products to find what works best for you.
- Track both your period length and the amount you bleed. For heavy periods, aim to reduce the flow by noting the number and saturation of pads/tampons used daily. Sharing these details with your doctor or nurse helps them better understand your experience. Use the period diary at the back for this tracking.

# EXPERIENCES

“

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.

“

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

“

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

“

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

“

I struggled with limited mobility while using pads, especially during dance classes, as they would shift and require constant checking. Concerned, I talked to my dad and switched to tampons.

“

On my heaviest days, I set nighttime alarms to change my pads to avoid leaking, but I felt safer once I switched to tampons.

”

When I'm out and active during my period, I carry at least 2 extra pairs of panties, an extra pair of pants, and a sweater or jacket to tie around my waist in case of accidents.

“

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.

# YOUR SUPPORT NETWORK

Treating girls with bleeding disorders requires a team of specialists. You, your gynaecologist and your haematologist can all work together to reduce your period, even if the two doctors are not in the same hospital or clinic.

- **Haematologists** are doctors who focus on how your blood clots and what medicine to take.
- **Gynaecologists** are doctors who focus on the reproductive system and know a lot about heavy periods.
- **Nurses** can teach you about your symptoms and how to take care of yourself and might take your blood tests.

## 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. If you're nervous, write down your questions and symptoms for your doctor or nurse. Bringing your menstrual app or diary can help them understand your experience. You can ask for a parent or guardian to join you, or request privacy, and **your concerns will remain confidential.**

## Being period ready

Before your period starts, discuss any questions with your treatment team and know how to contact them if you experience heavy bleeding or have concerns. It's best to call them or have a parent call if you're unsure. **Your team is there to support you!**

# TREATMENT

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, treatment may mean that you take a pill or liquid, inject the medicine into your vein using a needle, or use a nasal spray. Your doctor will go through the different options and find a good plan, and then train you, so **you can manage the treatment yourself**.

## Tranexamic acid (TXA)

Tranexamic acid works by blocking the breakdown of fibrin, which is a protein in your blood that helps to keep the blood clot in place and prevent bleeding. This medication can be used to treat a variety of bleeding disorders, including heavy menstrual bleeding, nosebleeds, and bleeding after surgery.

## Hormonal treatment

Hormonal therapy is a safe and important treatment that can improve heavy menstruation by regulating the hormones that control the menstrual cycle. These therapies can help reduce the amount and duration of the bleeding, as well as ease other menstrual symptoms like cramping.

One type of hormonal therapy is contraceptive pills. These pills contain synthetic versions of the hormones estrogen and progesterone, and you need to take the pill for 21 days each month or every day to regulate the menstrual cycle.

Other hormonal options include patches, injections, and IUDs, a small T-shaped device placed in the uterus to make periods lighter. This is not to be mistaken for the copper coil, which does not contain hormones and is not a treatment for heavy periods.

## Desmopressin

Desmopressin is a synthetic hormone that boosts the levels of some clotting factors. You usually need to take it once or twice per period, and you can either take it as a nose spray (in certain countries), through an injection under the skin or into the vein.

## Iron (Fe)

Iron deficiency is a condition where the body doesn't have enough iron, a mineral that is important for making haemoglobin - a protein found in red blood cells that helps carry oxygen to different parts of the body. When a person doesn't have enough iron and cannot produce enough haemoglobin, they can feel a variety of symptoms, including tiredness, weakness, shortness of breath, dizziness, headaches, and can look pale. It can also affect cognitive function, causing poor concentration, memory problems, and difficulty in learning.

Iron deficiency can be treated with iron supplements as tablets or through a drop into your vein. It is important that your doctor check your iron level and haemoglobin regularly to see if you need iron supplements.

## Factor replacement

Factor concentrates are medicinal products containing the missing factor that some people with bleeding disorders miss. By infusing the factor into the bloodstream, the clotting process normalises, and that can stop bleeding. The effect of the factor will last for some hours or days, and it can be necessary to get one to three doses on separate days during your period for it to work.

Dear Doctor,

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 haematologist and then an adolescent gynaecologist. We decided it was best for me to take hormonal treatment 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

“Hormones can be used for many reasons. Remember, you know yourself better than anyone else why you're taking hormonal treatment. 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. Treatment options vary from person to person. You may only have one type of medicine, while others may have more than one medicine. When you, together with your medical team, find a good treatment nothing should stop you from going to school, having fun with your friends and doing exercise just like on the days you don't have your period.”



# 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 is a part of who you are. It can be good to share it with friends for them to support you when you need it. Here are a few tips to talk to your friends and classmates:

- Before sharing with friends, learn about your bleeding disorder with help from your parents or doctor.
- If you're comfortable, ask your teacher to share or let you talk about your bleeding disorder in class. You can explain that your blood doesn't clot properly, leading to easy bruising and occasional nosebleeds. You might also mention that you take medicine to help with clotting.
- If you don't feel comfortable talking to the whole class or having the whole class know, you can 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.
- You can meet others with a bleeding disorder just like you at the National Member Organisations. There is one in every country and it is a meeting place for those with bleeding disorders.

## 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! While they may not have a bleeding disorder, they do understand what it's like to be your age. Before the conversation, you could write down a few questions or points you want to talk about. 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!



# RESOURCES

## Period Talk Toolkit

A collaborative effort between the WGBD LAN Education & Advocacy and Clinical Care Subcommittees, the Period Talk Toolkit is a resource to assist providers in proactively engaging in conversation about menstruation, as well as the signs of heavy menstrual bleeding.

[Discover the toolkit](#)

## Foundation for Women and Girls + with Blood Disorders Podcast

- [Episode 1: Normal vs. Heavy Menstrual Bleeding](#)
- [Episode 2: Demystifying IUDs \(Part I\)](#)
- [Episode 3: Demystifying IUDs \(Part II\)](#)
- [Episode 4: Destigmatizing the Pill](#)

## Other resources

- [Navigating Puberty with a Bleeding Disorder | Steps For Living](#)
- [Normal and Abnormal Periods | Steps For Living](#)
- [MASAC For You \(MFY\) | National Bleeding Disorders Foundation](#)

# Period Diary Template

For each day of your period you can use a chart like this to record your flow. This can help when you go back to your appointment to discuss with your nurse and doctor. Mark a line for each pad or tampon you need each day depending on how soaked they are when you change them. you can also record pain by marking a "x" on the line depending on how you are feeling that day between having no pain or really bad pain. If the bleeding is longer than 7 days consider talking to your doctor!

	Tampon			Pad			Menstrual Cup			Clots <small>(lumps of blood larger than 1c or 1g)</small>	Flooding <small>(bath or blood when you stand up)</small>	Pain
												
Example												No Pain  -----  Pain

Day 1												No Pain  -----  Pain
Day 2												No Pain  -----  Pain
Day 3												No Pain  -----  Pain
Day 4												No Pain  -----  Pain
Day 5												No Pain  -----  Pain
Day 6												No Pain  -----  Pain
Day 7												No Pain  -----  Pain
Day 8												No Pain  -----  Pain
Day 9												No Pain  -----  Pain
Day 10												No Pain  -----  Pain

## EAHAD Women and Girls + with Bleeding Disorders Working Group

Formed in September 2018, this group aims to share knowledge on diagnosing and treating women-specific bleeding symptoms in inherited bleeding disorders, set research priorities, and reduce misdiagnosis and undertreatment of women in Europe.

[Discover our projects](#)

## Acknowledgments

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