know your flow



a guide to periods when you have a bleeding disorder

table of contents



Visit mydatch.com for additional resources!

As you'll see in this booklet, there is a lot to learn about periods. If you or your family members have a bleeding disorder, things can get a little more complicated. And maybe a bit messy — but everything will be okay! Periods are a normal part of your health and wellbeing.

You might be excited, scared, or nervous. You might not have even thought about your period yet!

Whatever your situation, this guide will help you prepare for and feel confident about your period.

what is a period?

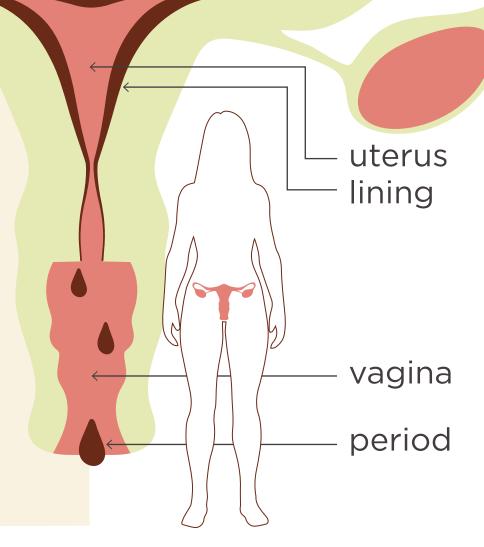
In your body, different chemicals called **hormones** help you digest food, manage your temperature, and help you grow. Hormones also turn periods on and off.

A period is a natural bleed that comes out of the vagina. It's also known as menstruation or a menstrual period.

Every month or so, your **uterus** will shed its **lining**. This lining comes out of your body as blood. This is your period! Your body then makes a fresh lining again the next month (see page 3).

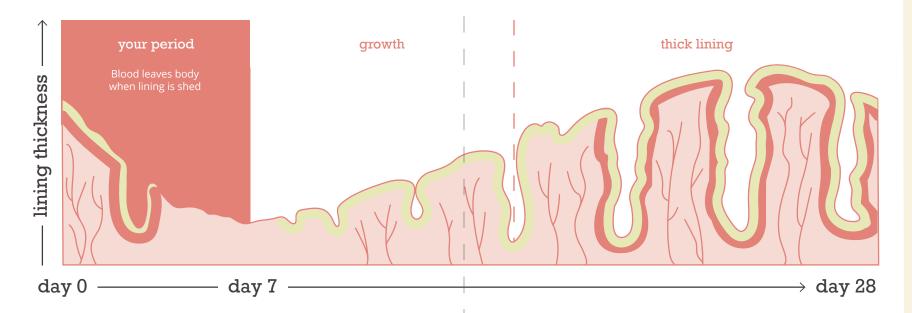
How long does it last?

Everybody's body is different, which makes their periods different, too. For most people, bleeding lasts around 3-7 days. Once your periods start, you keep having them until you're around 45-55 years old. Periods don't come at exactly the same time every month but they do happen in a **cycle**. A cycle counts the number of days between the first day of one period to the first day of the next period. For teenagers, a cycle can start between 21-45 days but usually finds its own pattern as you get older.



The lining of the uterus changes during your cycle

A cycle starts with the uterus shedding its lining as period blood. After that, the lining grows back and thickens for your next period!



what's "normal"?

Everyone's periods are different but in general:

- People typically start getting their periods around the **age of 11-14**, but they can start earlier or later for some people (from 7 to 16 years old)
- The time between periods (cycle) is **around 28 days**
- Bleeding can last between **3 to 7 days**
- On average, normal bleeding is losing between
 2 to 5 tablespoons over the week
- People use around **3 to 5 pads** or **tampons** in a day

hello flow: some facts about periods

Flow is how much blood comes

out. Your flow can be light, moderate or heavy and can change over time. The first few days of your period are usually your heaviest flow days.

The colour of blood changes.

Periods can be light pink, bright red, dark red, dark brown, and even blackish. It's not unusual that your period starts brown then changes to red then back to brown.

Emotional changes may happen

before and during your period. You might feel grumpy, get angry, or want to cry without being exactly sure why. Don't worry, you're not the only one going through this.

What does it look like?

spotting

<mark>fresh</mark> blood

end of period

Cramping! When people have pain during their period, they are usually talking about cramps (see page 25). Cramps happen when your uterus squeezes and then relaxes. This squeezing helps push blood out of your body.

Period blood can come out as a jelly-like blob. It can

feel like a small gush coming out of you. These are menstrual clots.

period products

As you may have guessed, periods can get messy. This is where period products come in. There are a lot of options available. The products that you decide to use might change over time and might be different from your friends and family. Here are some of the pros and cons of each product to help you decide which product is right for you.

pads

7

Padding that you stick to the inside of your underwear to soak up your period. When the pad looks full of blood, roll it up, wrap it in some toilet paper, and throw it away in the trash. Pads come in different shapes and sizes. Some are even washable so you can wear them again.

PROS

Easy, especially for beginners Can be worn while you sleep Help you to see what's going on

Easy to buy at the store

CONS

Might feel wet, itchy, or bulky in your underwear

Might smell

Cannot be used for swimming

Can sometimes move out of place

The heavier your flow, the more often you may need to change your period product.

Your period might leak out of one product so you might want to have extra backup ready.

tampons

Small tube that absorbs your period. A tampon is put in the vagina and then pulled out when full. You might need help learning how to put one in the first time, but it gets easier! Like pads, tampons cannot be flushed down the toilet. When you take it out, just wrap the tampon in toilet paper and throw it in the trash.

PROS

Can't see or smell it

Should not feel it

Good for swimming, sports, and sleeping

Easy to buy at the store

CONS

Takes practice to put in at first

May need to also wear a pad to protect against leaks

Needs to be changed every 4 – 8 hours

products you buy once and can use over and over again

menstrual cups

A small, flexible cup

that is put inside the vagina to catch your period before it comes out. When you take it out, you empty the blood in the toilet, sink, or while you shower. One cup lasts a long time. To keep it clean, it has to be put in boiling water once your period is over.

PROS

Can wear up to 12 hours Can be worn while you sleep Should not feel it Good for swimming

Can measure how much blood

period underwear

Special underwear that can absorb your period but looks like regular underwear. If you have a heavy period, you can use this as a backup option to catch any leaks.

PROS

CONS

Easy

Wash, dry, re-use

Comfortable and doesn't move around

Good for travel, sports, and sleeping

Great with other products as extra protection against leaks May need to wear with other products on heavy days

Expensive at first, but cheaper in the long run

Need many pairs for an entire period

Might need to change every 10 hours

Can't put in a dryer

CONS

Takes practice to put in and take out, but gets easier

Needs to be washed after each use before putting back in

Can be messy to empty

Needs to be boiled at the end of your period

how can a bleeding disorder

A lot of people don't know they have a bleeding disorder. About 1 in 3 people who see their doctor about heavy periods find out they actually have a bleeding disorder they didn't even know about!

11

When we bleed, our blood forms a clot (or "plug") to slow and stop the bleeding. When you have a bleeding disorder, your blood doesn't always clot, which means it can take longer for the bleeding to stop.

During a period, there are tiny blood vessels in the uterus that leak blood while the lining is shed. Sometimes, this means that periods might be longer or heavier in people with a bleeding disorder.

the clotting process

Legend

a: red blood cell b: platelet c: fibrin d: clot

Step 1 Bleeding starts

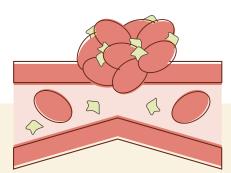
Blood moves through the body in veins and small blood vessels. A tear or hole happens when you get a cut (or as the lining sheds during a period). Parts of your blood then work together to make a clot.

b

Ý

Over 11,000 people in Canada

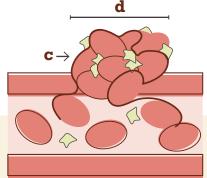
have a bleeding disorder, too! This includes people who have clotting factor deficiencies, hemophilia and hemophilia carriers, von Willebrand, and platelet function disorders like Glanzmann thrombasthenia and Bernard-Soulier.



affect

ur

period?



Step 2 Making the plug

Platelets are parts of the blood that start gathering at the hole to stop bleeding. The blood vessel also gets tighter.

Step 3

Clots stop bleeding Many different clotting factors work together with your blood to keep the plug in place, making a clot. If everything isn't working perfectly, this might take longer.

everyone's experience is unique

your periods may not be the same as your friends' and family's

Periods are different for everyone and **bleeding disorders are different** for everyone. For some people with bleeding disorders, periods can be easy to manage, but for others, their periods can be complicated or difficult. Periods can also tell you a lot about your overall health. This is why it's important to keep an eye on your periods and your whole body, and learn what a typical period looks like for YOU.

The good news is that there are lots of things that can help you during your periods, so that you can (and SHOULD) enjoy the same activities that you do when you're not on your period.

"Just because I have a bleeding disorder doesn't mean that I WILL have a heavier period, just that there's a chance...I spoke with my doctor because my family wanted me to know there are ways to help if my periods became unmanageable."

> *– "Snapdragon" Carrier of hemophilia A*

Your family members might not recognize how difficult heavy periods can be *even if* they've lived with heavy periods or bleeding disorders, too. But that shouldn't stop you (or them!) from getting help if your periods are too heavy.

Everyone deserves a life where periods are *not* a problem.

visten to Your b

are periods getting in the way of you living

how do y<mark>ou know</mark> if your periods are *too* heavy?

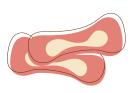
Although everyone's "normal" is different, there are some signs that your period might be too heavy:



Bleeding for more than 7 days



Menstrual clots bigger than a quarter



Soaking through more than one pad in 2 hours

If your bleeding is so heavy or long that it's getting in the way of studying, hobbies, activities, or having fun, this is a big sign that you should check in with an adult and your healthcare team.

your best life?

Heavy periods that need a change of product more than every 1 - 2 hours, for 3 hours or more in a row, requires urgent medical attention at your nearest Emergency Department.

Other warning signs:

- lightheadedness
- passing out
- shortness of breath
- racing heartbeat



Needing to wear more than one product at a time to prevent leaks

Changing products at night when you should be asleep

47

There is **no wrong time** to talk to your healthcare team if your periods, or anything else, are bothering you!

what happens if you lose

Iron deficiency anemia is serious and might impact how you grow or how you focus and learn in school. **Losing too much blood** can lead to a problem known as iron deficiency anemia where there isn't enough iron in the body.

Iron is needed for your muscles and brain to work to their fullest potential.

At first, people might not notice that they have iron deficiency. It can make you:



Feel very tired or weak, or even lead to fainting



Feel dizzy, light headed, have a hard time concentrating, or experience changes in mood

Have pale skin or cold hands and feet

too much blood?

heavy

period

People with heavy periods can **lose five to six times more iron** per cycle than people with lighter periods!

iron

Call your doctor ASAP if you start feeling this

way-it may be a sign that your periods are too heavy. Your healthcare team can prescribe iron pills to bring your iron level back to where it should be. light

period

but how much blood is too much?

A heavy period is losing **more than 80 mL** of blood in one period. This is about the same as **6 tablespoons.**

Measuring how much blood you lose during a period is not easy. You can keep track of your flow by counting how many pads or tampons you use a day or using the measuring lines on your menstrual cup. Make notes in an app or period calendar and pay attention to how you feel. Specific details will help your healthcare team understand your experience.

Your healthcare team might ask questions like "how many days does your period last?" or "how many products do you use on your heaviest days?" to try and figure out how much blood is leaving your body. If your healthcare team has never asked you these questions, it's a good idea to tell them yourself!



Lots of apps are available to help you keep track of the your periods and help predict when your next period is coming (so you can wear a pad, just in case).

Popular apps are "Flo", "Clue", and "Period Tracker". **WeThrive** is a new app made in Canada!







Periods happen to people with and without bleeding disorders so you are not alone! Here's their advice:

\rightarrow be prepared

Your period is not interested in your schedule and might show up without warning. Luckily, you CAN plan ahead:

- **Carry a zip bag** with you that has period products, pain medication (talk to your doctor first!), backup underwear, travel stain remover, and medication that you take for your bleeding disorder
- Keep extra clothes in your bag or locker. A sweater or jacket can be tied around your waist if you need it
- **Plan what you're going wear** like dark colored clothing and underwear that can hide stains and leaks
- Sleep on a dark towel
- Wear shorts that keep pads close to your body while you sleep or when you travel



Leaks will probably happen.

These supplies can all help remove blood stains from clothing or bed sheets. Be sure to get the stain out before putting the item in the dryer (which can make stains permanent).





experiment with different period products

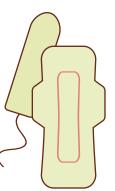
Don't be afraid to explore different period products to find what works best for your body and flow.

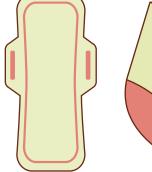
DOUBLE UP!

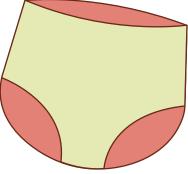
You can combine different products, too. This could be:

- two pads (end to end)
- a tampon plus a pad as backup
- a menstrual cup with a pad or period underwear

Some products are designed for extra protection against leaking:







maxi/super

the highest absorbency level for pads or tampons long /extra-long/ overnight

provides extra coverage. Overnight pads can be used during the day, too! adult diapers

can give even more protection but might feel a bit big and bulky.

"There was a huge learning curve for me with the menstrual cup. It took me about 6 months to be really comfortable with it, but once I figured it out **it changed things so much.** I empty it first thing in the morning and before I go to bed. I often forget that I am even on my period."

> – "Lavender" Carrier of hemophilia A

tips from the pros

→ dealing with cramps

Cramping during your period is pretty common. A lot of people have mild pain but for some, it really hurts and can be really uncomfortable. There are a few ways to deal with cramps:

- **Get warm:** Try a warm bath or put a heating pad, warm towel, or hot water bottle on your lower belly
- **Exercise:** Trust us! Activities like walking, jogging, dancing, or swimming can ease cramps
- **Relax:** Stress can make cramps worse. Try taking slow, deep breaths, meditation, or even doing yoga
- **Pain relievers:** Always check with your doctor about which medicine will work best for you

tips from the pros

Sometimes cramps can feel bad. Really bad. If the pain is so intense that you have to skip activities or school (or can't even walk!), it could be a sign of other problems. Think about if it feels a lot worse this month vs. last month. If it's bad, call your healthcare team for help!

4

27



stay active

Although it can be tempting to skip exercise while on your period, being active can be really helpful. Exercise can help with cramps and it releases endorphins, which are chemicals in the body that make you feel good. The key is to not push yourself and listen to your body.

Talk to your coach or teacher about any barriers to participating in sports or activities that you love.

tips from the pros

"Start with something you feel really confident doing - either because it makes you feel great, or you feel secure and won't leak. Then, try something that is a little less comfortable. Continue to increase. The more experiences you have, the more you see that the "**worst case scenario**" **often doesn't happen!**"

> –"Daisy" Has von Willebrand disease



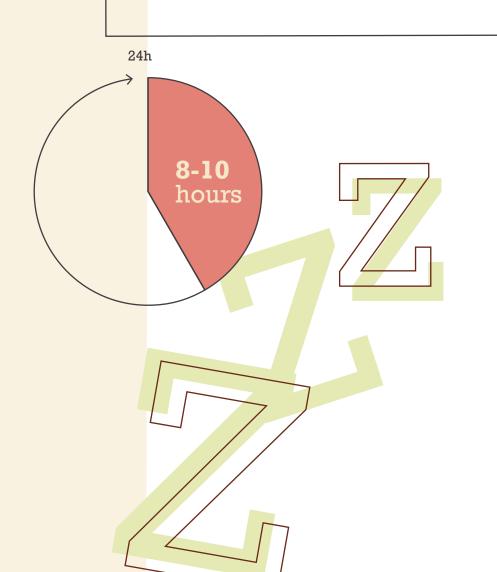
→ how to deal with feeling tired

It is not uncommon to feel tired or sluggish before and during your period. You might not feel like doing sports or hanging out with your friends and that's fine. But if you feel like you're missing out or too tired to concentrate on your schoolwork, be sure to tell someone.

Self-help tips:

- Get 8-10 hours of sleep as a part of a healthy lifestyle
- Drink plenty of water
- Remember, if you start to feel extreme tiredness, weakness and shortness of breath, this might be iron deficiency

There are all sorts of new period products that you can use while you sleep like **period shorts** and **period blankets**.



tips from the pros

→ lean on friends and family

To start the conversation. try something as simple as "I got my period and I need some supplies," or try talking about something funny that happened during your last period, and ask if the same thing has ever happened to them.

Periods are natural and normal so don't be shy to talk to your family and friends about your periods. You may even find that you feel closer with them once you start talking about it.

Your parents or trusted adults can help buy period products for you, so it's important that they know when your periods have started, too. They're probably familiar with periods and can share more advice.

Remember: half of all people on earth have periods, and it's just a part of their lives. It's not weird, gross, or anything to hide. It's totally normal. At the same time, don't feel pressure to celebrate OR defend your period if you don't want to. You can say that periods are funny, annoying, awesome, or anything in between! Do whatever feels right for you. Cultures and religions around the world view periods and period products in different ways. It's important for you to figure out how you want to deal with your period.

In some Indigenous cultures, your period or "moon time" is considered a sacred and powerful time. In Islam, you might skip fasting during your period.

"Find someone you can talk to about your periods. That way, you can ask about their experience, and you don't end up ignoring heavy bleeding because you think it's normal."

> – **"Sunflower"** Has von Willebrand disease

32

tips from the pros_

when should I talk to my healthcare team?



If traveling to a clinic is a problem, check to see if your clinic has a **telehealth** option, or if you can talk to your healthcare provider on the phone. Some clinics may also offer after-hours appointments.

talk to your healthcare team if your period impacts:



School

Missing classes, or missing whole days because of your period or cramping



Sports

When your bleeding or symptoms get in the way of doing the things you love Social time

If your period keeps you from interacting with friends or joining in activities



If your sleep is interrupted by leaking or cramps

For people with bleeding disorders, it's also a good idea to be monitored by your healthcare team once your periods start. The earlier your healthcare team knows about your periods, the better!

self-reflection checkpoint

what's your plan?

Who will you tell when your periods start?

What **products** do you have ready for your period?

Do you know the **warning signs** of when to go to the Emergency Department?

Hint: see page 16

prepping for the talk with your healthcare team

Periods are a part of your health so it's a good idea to keep track of them.

35

Write down any questions or concerns and bring the list with you to your appointment (see page 49). This will help you remember everything you need to ask, since appointments can go by fast.

Be honest and open about your bleeds (periods or otherwise) with your healthcare team. Period apps can be extra helpful for sharing details that you might have forgotten. If you think changes in your body are serious, say so. If your usual healthcare team isn't that familiar with bleeding disorders, a gynecologist and the team at your local hemophilia and bleeding disorders treatment centers (HTC) are experts in both periods AND bleeding disorders.

> Did you know that a **medical interpreter** can help communicate information between you and your healthcare team if English or French is not your first language?

Have this information ready to share with your healthcare team, even if they don't ask you first:

- How many days do your periods last?
- How many pads/tampons do you use on your heaviest days OR how many times do you empty and re-insert your menstrual cup in a day?
- How big are your period clots and how often do you see them?
- Do you have any changes in cramping or pain with your periods or other bleeds?
- How many times have you missed school or social activities because of your period?
- Do you wake up at night to change your period product or does your period overflow onto your pajamas and bed sheets?
- Do you have joint pain, nosebleeds, bruising, or other bleeding events, either without anything happening or after going to the dentist?
- Has anyone else in your family experienced heavy periods or has a bleeding disorder?

Be specific! The more details you can share, the easier it will be for you to get the help that you need.

medications to help with your blood flow

There are lots of medicines to help with periods and even make periods stop altogether (!). You and your healthcare team can work together to figure out what's best for you. Here is some more information to help you learn about the different options.

non-hormonal medications

If you have heavy periods and your healthcare team hasn't given you an official bleeding disorder diagnosis yet, there are options for you even while you wait for your results!

Tranexamic Acid (TXA)

TXA can help stop or control different types of bleeding. When you bleed, your natural blood clotting system makes a clot to stop blood flow. TXA helps to keep the blood clot in place instead of breaking down.

TXA is taken by mouth, as pills or mouthwash. TXA can be used with other medications or alone.

TXA

"I remember being so happy when I started my medicine. The amount of blood reduced dramatically and no globby clots!"

– "Lily" Carrier of hemophilia A

hormonal medications

Hormones are chemicals in the body that control the menstrual cycle, so hormonal medications can be used to help manage periods, period-related symptoms, and even other hormonerelated aspects of health (hello, pimples!). The different hormonal medications act like natural hormones and tell the uterus not to make a thick lining each month. They are sometimes called "birth control" because they can prevent pregnancy but they can also be used to treat heavy periods or very bad cramping.

IUD

Depot medroxyprogesterone (DMPA) Injection The 'Shot'

The Shot is an injection of hormones provided by your healthcare team every 3 months.

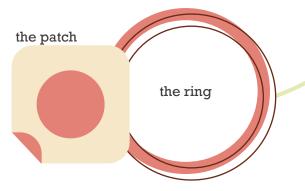
Intrauterine Device (IUD)

An IUD is a small T shaped device that is placed inside the uterus and slowly releases a hormone to control the menstrual cycle. The IUD is implanted by a doctor. It works for 5 years, then needs to be removed and replaced.

Combined Hormonal Contraceptives (CHCs): 'The Pill', 'The Patch', or 'The Ring'

CHCs can come in the form of a **pill** taken by mouth every day at the same time of day, a **patch** or sticker placed on the skin every week, or a **ring** inserted into the vagina like a tampon and changed every month.

CHCs can reduce bleeding, cramping, and allow you to turn off or control when you have your periods. Some **breakthrough** bleeding (which is unexpected bleeding) can still happen.



he pill

Hormonal medications can be used to turn off periods for months at a time so you can have your period when it's convenient for you. Talk to your doctor about the best option for you!

The Shot

other treatments

41

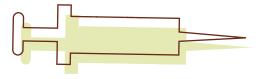
Desmopressin

Desmopressin (also known as DDAVP) can be used to help control bleeding in people with von Willebrand disease or types of hemophilia A. DDAVP increases the clotting factors von Willebrand factor and factor VIII, which helps to stop bleeding. It can be taken as a spray in the nose or an injection. Other treatments may be available depending on the type of bleeding disorder you have. Your healthcare team might have already suggested these for nose bleeds or other types of bleeds.

Clotting Factor Concentrates (Factor)

Clotting factor concentrates or Factor help control or prevent bleeding by making sure that your body has everything it needs to stop a bleed.

Each bleeding disorder has a different type of Factor treatment. Factor is given as an injection into a vein to protect the whole body from any bleeding that might occur (prophylaxis) or can be used to control bleeding that has just happened (on demand).



questions to think about

Period history

- Have your periods started? What has it been like?
- Does anyone in your family have heavy periods?
- Do you know when your next period is coming? (Hint: have you downloaded an app or checked your calendar?)
- How often do you have to change your product on your heaviest day?

How do your periods impact your life?

- Are you bothered by your periods?
- Have you missed school, work, or activities due to your periods?
- Do you make up excuses not to do things because you are worried about bleeding or leaking?

Bleeding symptoms and medication

- Do you ever feel tired or weak during your period?
- How bad are your cramps?
- Do you have treatment for bleeding events that might occur?
- Are your bleeds under control (periods, joints, nosebleeds, bruising, dentist visits, or anything else)?
- Have you met with a hematologist yet? What about a gynecologist?

Other

()

- Do you have an older go-to person who you can talk to about periods?
- Do ALL of your doctors know about your bleeding disorder?
- Do you have any worries or questions about your body that your healthcare provider can help with?
- Do you feel like your healthcare team is listening to you?
- Have you ever gone to a bleeding disorders camp to meet other kids and teens with bleeding disorders?

[O]

Let's Talk Period: <u>letstalkperiod.ca</u> Self-BAT test. An online quiz to help think about your bleeding: <u>letstalkperiod ca/celf.bat</u>

Know your flow: <u>knowyourflow.ie</u> Center for Young Women's Health: <u>youngwomenshealth.org</u>

Canadian Hemophilia Society (CHS) and local chapters (not just for people with hemophilia!): hemophilia.ca/provincial-chapters

Code Rouge: coderougewomen.ca

Your Period: yourperiod.ca

heavymenstrualbleeding.com

The North American Society for Pediatric and Adolescent Gynecology (NASPAG): naspag.org

World Federation for Hemophilia. (WFH): wfh.org/en/home Period Tracking app **MyCBDR or iCHIP (BC only):** two apps that are the best way to report treatments and bleeds to your healthcare team.

For Teens Period: @for.teens.period

other helpful resources

preparing for menstruation

If you care for a

child with a bleeding disorder, you may be wondering what you can do to prepare your child for menstruation. Here are some ideas on talking with your child and their healthcare team, and for even thinking about yourself.

start early

Preparing your child before their periods start will help make the transition smoother. Introduce the topic gradually over time so that it's part of a normal conversation. Encourage open and honest communication. The more comfortable your child becomes with discussing periods, the easier it will be for them to advocate for the help and support they need. Early recognition and treatment for heavy periods has a **huge impact** in the long-term.

for adults, parents, and caregivers

share your experience

Even though your experience may not be the same as your child's, talk about your experiences with periods and what your child might expect in terms of the flow and length of their period. Setting expectations will help your child feel more comfortable when their period arrives.

support your child's mental health

During this transition, your child's mental health is just as important as their physical health. Encourage your child to talk about their feelings and watch for signs that they may be struggling. There will likely be times when your child feels sad, anxious, or overwhelmed, but if these feelings start to interrupt school or their activities, it could be a flag that they need additional support.

Everyone deserves support and to

have their experiences taken seriously. Discussing menstruation with all siblings and family members can help make sure everyone knows that periods are normal, healthy, and nothing to be ashamed of.

talk to the healthcare team

In addition to providing medical care, your healthcare providers are a valuable resource for guidance. Talk to them about how and when to seek care, what treatments are available to control bleeding, and what advice is unique to your child's situation. Call your doctor when your child gets their first period so that they are ready to help, if needed.

speak with your child's school about support

Let your child's teacher, coach, or school nurse know about your child's bleeding disorder (and if it impacts their periods). They may be able to make accommodations if your child needs to miss class, take more visits to the washroom, take their medicine, or adapt training schedules so that your child can still participate in their favorite activities.

be open and ready to discuss hormonal treatments to manage periods or new-to-you period products

Some adults may be concerned about their child using "birth control" medication or certain period products. Hormonal medications are used as contraceptives, but they can also help to reduce heavy periods and make periods more regular. Your child may also prefer certain period products that you're not used to. Keep an open mind and be ready to discuss topics like relationships, sexual behaviour, and birth control if questions arise.

support independence

Provide a safe space in the clinic for private conversations between the clinic and your child by leaving the room if you need to. They might be embarrassed to talk about their problems in front of you and that's okay.

for adults, parents, and caregivers

build a network

Build a network of friends, family, and other parents or caregivers who you can chat with for support. Connect with your local hemophilia society, which supports anyone with a bleeding disorder. Register yourself at your local hemophilia treatment centre too, to **make sure you're also** getting the best care.

questions for my healthcare team

49

This book has been developed by healthcare professionals, people living with bleeding disorders, and caregivers to people living with bleeding disorders across Canada. They contributed their expertise in living with and/or managing a bleeding disorder. A special thank you to all those individuals who shared their advice and who reviewed drafts of this booklet.

This booklet is intended for informational purposes only. It is not intended to be used to make healthcare coverage or treatment determinations. Always seek the advice of your physician or health provider with any questions you may have.

This project was led by Dr. Anthony Chan and Casey Li at Hamilton Health Sciences as a part of DATCH: Developmentally Appropriate Tools for Children with Hemophilia.

This project was sponsored by Novo Nordisk Canada Inc.