

LET'S TALK WOMEN AFFECTED BY HEMOPHILIA

There are different ways to be affected.

Women or Girl with Hemophilia

FVIII/FIX level <40%

Symptomatic Hemophilia Carrier

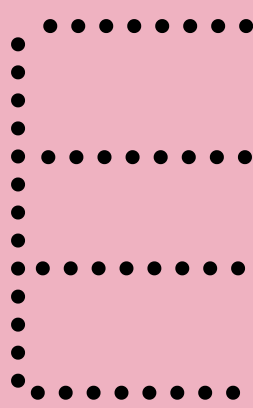
FVIII/FIX level >40% and abnormal bleeding

Asymptomatic Hemophilia Carrier

FVIII/FIX level >40% and no abnormal bleeding

They are underdiagnosed.

FOR EVERY
MALE
WITH
HEMOPHILIA



THERE ARE
FOUR
FEMALE
HEMOPHILIA
CARRIERS

Many Hemophilia Carriers are **unaware of their status**

They can experience abnormal bleeding.

Heavy Menstrual Bleeding



- Longer than 7 days
- Changing protection every 1-2 hours
- Clots larger than a quarter
- Using 1+ pad/tampon at a time

Prolonged bleeding after dental and surgical procedures



Nose bleeds that last longer than 15 minutes.



Postpartum hemorrhage



Joint Bleeding



Easy Bruising



can lead to...

- iron-deficiency anemia
- reduced quality of life
- hospitalizations or blood transfusions

They have treatment options.

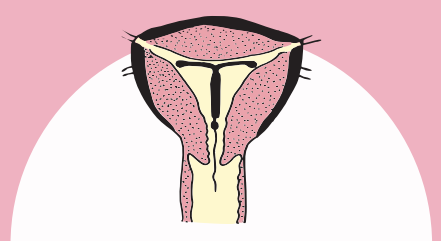
DIFFERENT TREATMENTS EXIST DEPENDING ON THE BLEEDING SYMPTOM AND SEVERITY.



Talk to your family doctor, gynecologist or hematologist about what can be done to treat YOUR abnormal bleeding symptoms!



Tranexamic Acid can be used to treat many bleeding symptoms like nosebleeds, heavy menstrual bleeding, and bleeding after dental and surgical procedures.



Heavy Menstrual Bleeding can be treated with various types of hormone therapy (ex. oral contraceptives, IUD) and other surgical options (ex. endometrial ablation).

Different women bleed differently.



On average, Hemophilia carriers have **LOWER**



factor levels than average.

Knowing your factor level is an important step in determining your bleeding risk, but even Carriers with **normal factor levels** can have abnormal symptoms.

Sound like you?

Take the **Self- Administered Bleeding Assessment Tool (Self-BAT)** and see if your bleeding is normal.

<https://letstalkperiod.ca/>



FREQUENTLY ASKED QUESTIONS

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Where can I get more information on hemophilia?

Let's Talk Period has great resources to help you identify symptoms and understand hemophilia. The World Federation of Hemophilia and The Canadian Hemophilia Society are also great resources.

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I have a family history but I don't know if I'm a carrier or not, where do I start?

Depending on your family history, you could be an obligate or potential carrier or not a carrier at all! Either factor level or genetic testing may be needed to determine your carrier status. Start by talking to your primary care provider who can refer you to a hematologist if needed.

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Does my carrier status affect future pregnancies?

There are implications both for yourself during or after the delivery of your child, as well as a chance that your child may be affected by hemophilia. It is important for every hemophilia carrier to discuss this with their obstetrician or family doctor, even if you are unsure of your carrier status but have a family history of hemophilia.

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What supports can I get to manage the impact that my bleeding symptoms have on my daily life?

Many women with undiagnosed and untreated bleeding symptoms related to their carrier status recount challenging experiences and similar struggles. Speak to your primary care provider or hematologist about treatment for your abnormal bleeding symptoms! Additionally, look into if your local hemophilia society offers carrier-specific programming to connect with other women and share stories of support.

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What do I do when my healthcare provider thinks hemophilia only affects men and doesn't believe carriers can experience abnormal bleeding symptoms?

Research on abnormal bleeding in carriers is fairly new, and some healthcare providers are not aware of the updates. Self-advocacy can be challenging, but there are many updated materials on bleeding in carriers available on the WFH website to help you out! Additionally, you can look at our Healthcare Provider Infographic on Hemophilia Carriers to give to your healthcare provider. It is available on the Let's Talk Period website under resources.

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How do I know if I have abnormal bleeding?

A great place to start is taking the Self-BAT, available on www.letstalkperiod.ca. The Self-BAT will ask you questions about some of the most common bleeding symptoms and give you a bleeding score at the end. An abnormal bleeding score of 6 or greater for a female 18+ and 3 or greater for a female under 18 is a strong indicator that you have a bleeding tendency. If you have these scores, you should speak to your healthcare provider about treatment options for your symptoms.

