0 Why specific care for hemophilia carriers?

Interdisciplinary working group
for supporting hemophilia carriers
and their families

ACH Associació Catalana de l'Hemofília · FPCH Fundació Privada Catalana de l'Hemofília · SJD Sant Joan de Déu Barcelona · Hospital · SANT PAU Campus Salut Barcelona · Hospital de la Santa Creu i Sant Pau

Context

Hemophilia is a genetic disorder that affects blood clotting and can cause severe bleeding.

It is linked to the X chromosome, meaning that women are carriers, while men are the ones who typically develop the condition.

As a result, hemophilia and congenital bleeding disorders have traditionally been associated with the males.

Recently, however, the international medical community has begun to recognize that **female carriers** may also experience bleeding and hemorrhages, caused by low levels of clotting factor in the blood.

One in three carriers will develop symptoms at some point and may require treatment. For this reason, they need **specialized care** that considers them in a comprehensive way.

The lack of recognition of their reality has placed many girls, adolescents, and women in a vulnerable situation, as they struggle to find adequate support for their difficulties.

The consequences are not only physical but also emotional, making it essential to consider how to care for them and what kind of **support** they may need throughout different stages of life.

Introduction

The interdisciplinary working group for supporting hemophilia carriers and their families was created with the aim of providing comprehensive care for female carriers, taking their needs into account, with the fundamental goal of humanizing the care they receive.

We want to address several of the **questions** we often receive regarding hemophilia carriers, which can be summarized as follows:

Over the years, women have been regarded as "only" carriers — they were thought to transmit the condition but, supposedly, not to experience symptoms.

1. **Parents** of girls who are carriers and who wonder when to tell them, how to explain it, what to say so that they can understand it, etc.
2. **A female carrier** seeking guidance because she wants to become a mother, wishing to learn about assisted reproduction options, etc.
3. **A pregnant woman** with a family history of hemophilia who wants to confirm whether she is a carrier, the sex of the baby she is expecting, and whether the baby could have hemophilia etc.
4. **A man** with hemophilia who does not take into account that he inevitably passes the carrier condition to all of his daughters
5. **A teenage girl,** who is the sibling of a boy with hemophilia and who wonders: "Could I be a carrier? Where should I go for testing?"

Testimony:

"How can we tell our daughter that she is a carrier? We don't know how she will take it. She is always so attentive when I administer my treatment, and we don't want to worry her even more. But time passes, and eventually we will have to tell her. When is the right moment?

Father of a carrier girl

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Why specific care for hemophilia carriers?

Who are we?

The creation of the group was promoted by the **Advisory Council of the Catalan Hemophilia Private Foundation**, made up of hematologists from the reference hemophilia units at Sant Joan de Déu, Sant Pau and Vall d'Hebron hospitals, members of the Catalan Hemophilia Association, and professionals from the Blood and Tissue Bank.

Currently, the **interdisciplinary working group** is composed of professionals from different fields, including hematology, nursing, psychology, pedagogy, genetics and gynecology from:

- The Associació Catalana de l'Hemofilia.
- The Fundació Privada Catalana de l'Hemofilia.
- The Pediatric Hematology Department of Hospital Sant Joan de Déu from Barcelona and Research institut SJD.
- The Service of Genetic and Molecular Medicine at the Sant Joan de Déu Hospital in Barcelona, Pediatric Institute of Rare Diseases SJD.
- The Thrombosis and Hemostasis Unit, Sant Pau Campus Salut Barcelona.
- The Integrated Hemophilia Unit SJD-HSP. CSUR Coagulopathies and members of Eurobloodnet.

What have we done?

Our working group met several times in order to answer key questions such as:

- Why should we study **carriers**?
- Should all carriers undergo **genetic testing,** and when?
- Should carriers be **monitored?**
- **Which professional disciplines** should be involved?

We understood that being a carrier is a physical condition that may have **different implications throughout life.**

But this physical condition is also accompanied by feelings and thoughts that can cause **concern or discomfort.**

Each girl, each young woman, each adult woman and every member of her family experiences it **in a different way**.

And what do the carriers think?

We presented the group's creation during an update conference organized by the Catalan Hemophilia Association..

Later, we convened **a group meeting** and invited hemophilia carriers to participate. The meeting included: 12 carriers of different ages (from teenagers to grandmothers), 1 man with hemophilia, 1 mother of carriers, and 5 members of the interdisciplinary working group.

Our goal was **to give them a voice** and make them feel heard, to understand what they need, what they feel is missing, and how they would like to be cared for.

"What is not talked about does not exist."

First conclusions and actions

A great deal of information is needed in order to understand everything that being a carrier entails.

There is a clear demand for differentiated, specialized and **approachable care:** a space where issues can be discussed naturally and confidentially, without taboos.

Each stage of life is unique and requires a **different approach.**

For this reason, taking all these aspects into account and as a result of reflection and teamwork, we have **designed a care protocol** to support hemophilia carriers, which will be implemented across the different treatment centers.

In addition, we will also create informational, consultation and support materials.

Any more questions? Any concerns?

The upcoming informational brochures will cover topics related to childhood, adolescence, adulthood, motherhood, and older age.

For any questions, concerns or support needs contact your reference treatment unit or the Association.

We are here to help you.

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Information for families of **girls** who are carriers of hemophilia.

Interdisciplinary working group
for supporting hemophilia carriers
and their families

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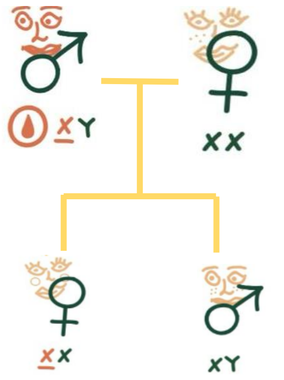
First Contact with the Treatment Unit

If you are reading this, you may be the **parent or relative** of a girl who is a hemophilia carrier. The purpose of this document is to provide you with information that may be helpful as you face this situation.

Hemophilia is a rare bleeding disorder with **X-linked inheritance** (linked to the X chromosome). Depending on clotting factor levels, the condition may be mild, moderate or severe. It may cause bleeding episodes, and its monitoring and treatment should be managed by specialized care units.

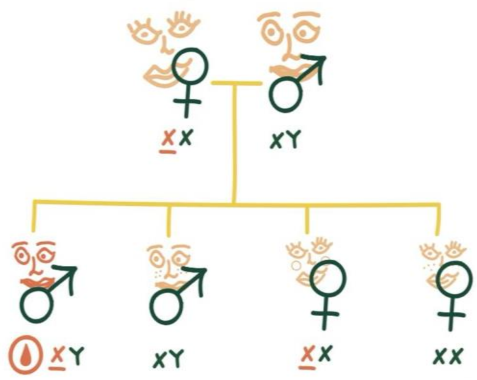
All daughters of a man with hemophilia (XY) are oblígate carriers (XX).

The sons of a man with hemophilia (XY) will never have the condition.



A carrier woman (XX) can pass on the affected X chromosome (X) with each pregnancy.

Half of the sons (50%) may have hemophilia **(XY)** and 50% of the daughters may be carriers **(XX).**



The diagnosis

Obligate Carrier

- Women whose father has hemophilia.
- Women with two or more children with hemophilia.
- Women with one son with hemophilia and at least one other affected relative (such as a grandfather, brother, uncle, nephew, or cousin).
- A genetic study is recommended to identify the specific mutation..

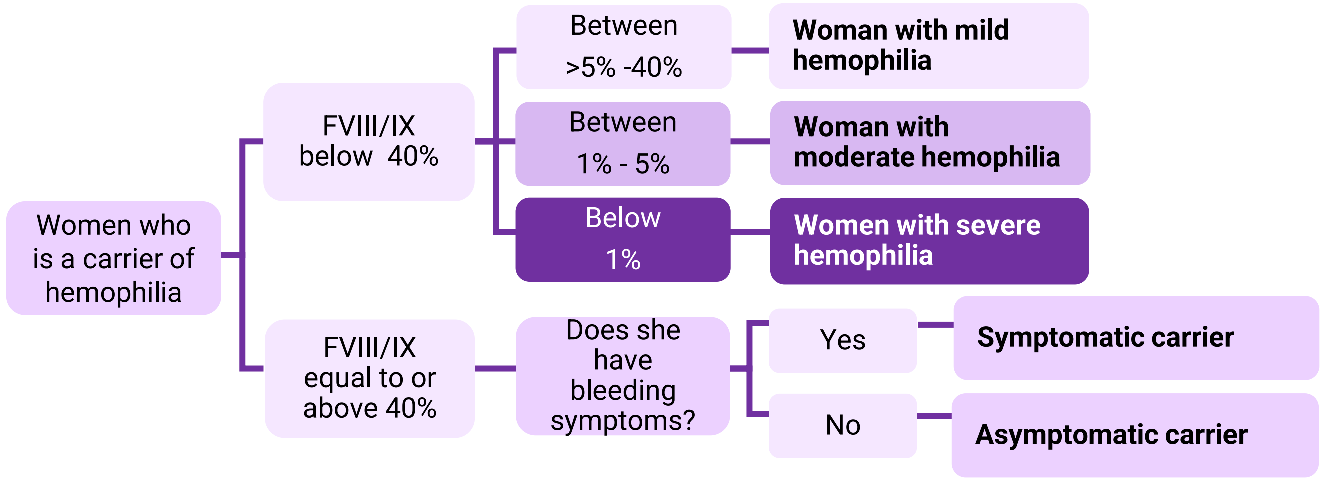
Possible carrier

- Daughters of carrier mothers.
- Mothers of a child with hemophilia but with no known family history.
- Women with a family history of hemophilia but no children with the condition.
- A genetic study is necessary to confirm carrier status.

Carrier status: what should you know?

For many years, only males with hemophilia were believed to have bleeding symptoms. However, carrier women can also **have low factor levels and/or bleeding episodes.**

Today, hemophilia in girls and women is defined according to their **bleeding symptoms and their clotting factor levels.**



Women who is a carrier of hemophilia

FVIII/IX below 40%
- Between >5% -40% → **Woman with mild hemophilia**
- Between 1% - 5% → **Woman with moderate hemophilia**
- Below 1% → **Women with severe hemophilia**

FVIII/IX equal to or above 40%
- Does she have bleeding symptoms?
  - Yes → **Symptomatic carrier**
  - No → **Asymptomatic carrier**

The most common **symptoms** are:
- Bruising easily from minor bumps.
- Prolonged bleeding from cuts.
- Heavy menstrual bleeding, excessive bleeding after childbirth, surgeries, or dental procedures

There are several **treatment** options available. If needed, the healthcare professionals in your treatment unit will explain the different possibilities.

1 Information for families of **girls who are carriers of hemophilia.**

Information for parents

Following **World Federation of Hemophilia** guidance, you should know that, families of girls who are carriers should schedule follow-up from early childhood. If needed, your daughters should receive treatment and care similar to that provided to boys with hemophilia.

Testimonials

Do we need to have a genetic study done?

How do I explain it to my daughter?

When? At what age?

How will the results affect my daughter?

> ***"We need to have acces to the information"***
>
> Mother of a carrier

Is it necessary to know the factor levels?

Girls with hemophilia and symptomatic carriers of hemophilia have **a higher risk of bleeding** after injuries, dental extractions, or surgeries.

It is important to **measure the clotting factor levels** in all carriers (possible or obligate) as early as possible, so that appropriate measures can be taken if the factor concentrations are very low.

A normal factor level does not rule out carrier status.

When should genetic testing be done?

Families often **wonder when the genetic tests should be carried out**. Many ask themselves whether they should be done during childhood, before menstruation begins, or whether they should wait until the girls are adults and can make the decision for themselves.

Knowing her carrier status from childhood can help her live normally with the reality of having hemophilia or being a carrier.

However, every family and every girl has a different life story, and your treatment unit will provide the **best support for your specific situation.**

Your multidisciplinary team will help you **determine the best moment to carry out the genetic study.**

How do we explain it to our daughter

First of all, you should consider whether your daughter **is ready to understand the information**.

It is important to consider **different factors** such as age, emotional maturity, level of understanding, and, above all, **her interest in the information**, the questions she asks you, her curiosity, and so on.

We recommend starting the conversation before adolescence (around ages 9 to 10).

Your care team will accompany you and provide all the support that you and your daughter may need.

Important

Contact your reference treatment center if your daughter is a carrier of hemophilia in any of the following situations:
- A surgical procedure.
- Procedures with a risk of bleeding.
- Dental extractions.
- Accidents or injuries.
- Bleeding episodes.

Remember: there are **different treatments** options for hemophilia carriers.

For more information

You can find more information in the other leaflets and on the website: www.hemofilia.cat .

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2 Information for adolescent hemophilia carriers

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If you are reading this, you are likely a **teenage** carrier of hemophilia. The purpose of this document is to give you information that may be helpful to you at this moment.

You are growing up, and it is time to welcome this new stage of your life, which comes with many changes, one of them is the **start of menstruation.**

Menstruation is a natural and normal process of your body. Even though it may feel new right now, we will give you all the information you need to adapt to this change.

Menstruation and Heavy Menstrual Bleeding (HMB)

The first period (menarche) usually occurs between the ages 10 and 16, most commonly around age 12.

It typically appears about 2-3 years after breast development begins.

What is a normal period like during adolescence?

- Bleeding lasts between **2 to 7 days.**
- Changing pads or tampons **every 2 hours or more.**
- Periods occurring every **21 and 45 days.**
- **No bleeding** between periods.
- **Bleeding volume is less than 80 ml during one period**. For girls who use a menstrual cup, the amount of bleeding in a period can be estimated by knowing the cup's capacity in milliliters.

Being a carrier of hemophilia may mean that you experience **heavy menstrual bleeding (HMB).**

WHAT IS HEAVY MENSTRUAL BLEEDING (HMB)?

- A period lasting **more than 7 days.**
- Needing to change pads or tampons in **under 2 hours.**
- Presence of clots **larger than a 1€ coin.**
- **Interference with** daily activities.

Regardless of your factor level, you may experience heavy menstrual bleeding (HMB).

In this case, we recommend consulting your reference treatment unit, as there are different possible treatment options.

They can help you find the best approach for you and, if needed, refer you to a **Gynecology Department.**

Menstrual pain relief

The best options to help relieve menstrual pain may include:

- Herbal infusions such as Achillea millefolium, guava leaves, or valerian root. These can help improve menstrual pain without increasing the risk of bleeding.
- Local **heat.**
- Regular **physical exercise.**
- Painkillers, **as prescribed by a doctor.**

2 Information for **adolescent hemophilia carriers**

Quality of life

If you feel that your menstrual bleeding is limiting your daily life, consult with your reference coagulation unit; they will help you find a solution

Your period should accompany you, not limit your daily activities in any way. You should be able to do things with your friends, play sports, go to class, and so on.

Other recommendations

A balanced, healthy, and varied diet will provide you with all the nutrients you need for your health.

We recommend foods rich in iron to help compensate for possible anemia or low iron levels due to bleeding.

We also suggest avoiding excessive consumption of dairy products and tea, as they can make iron absorption more difficult.

First sexual intercourse

During the first **sexual encounters**, it is normal for **small tears** to occur in the hymen (the elastic membrane that covers part of the vaginal entrance), which can lead to light vaginal bleeding.

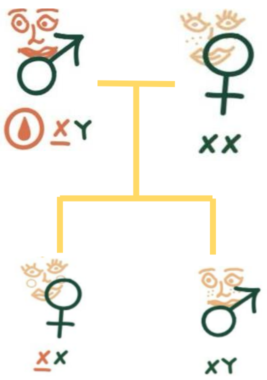
Occasionally, in women who are carriers of hemophilia, this bleeding may be **more prolonged** and/or intense due to the coagulation disorder.

We recommend **seeking medical attention if you experience prolonged and/or intense vaginal bleeding** after your first sexual intercourse.

How hemophilia and carrier status are inherited and passed on

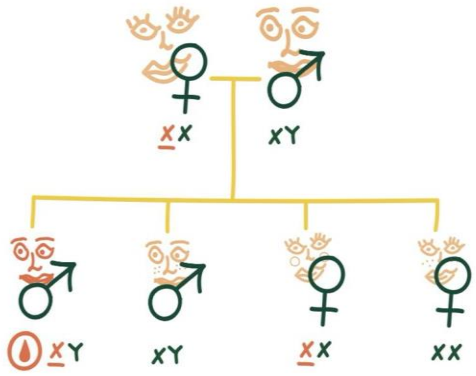
All daughters of a man with hemophilia (XY) are oblígate carriers (XX).

The sons of a man with hemophilia (XY) will never suffer it.



A carrier woman (XX) can pass on the affected X chromosome (X) on each pregnancy.

Half of the sons (50%) may have hemophilia (XY) and 50% of the daughters may be carriers (**XX**).



Important

Contact your reference treatment center in any of the following situations:

• A **surgical procedure**, procedures with a **risk of bleeding**, dental extractions, accidents, **bleeding** episodes (nosebleeds, gum bleeding, gastrointestinal bleeding, vaginal bleeding, etc.).

Heavy menstrual bleeding.

For more information

You can find more information in the other leaflets and on the website: www.hemofilia.cat .

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3 Information for adult **hemophilia carriers**

Interdisciplinary working group
for supporting hemophilia carriers
and their families

JUSTIFICATION

Hemophilia or being a hemophilia carrier has a genetic origin and becomes a lifelong condition.

A carrier woman may experience bleeding symptoms.

One in three carrier women has an increased risk of bleeding. For this reason, it is important to understand the individual effects of hemophilia carrier status and to know how to identify and manage a situation that may involve risk.

How to confirm carrier status? There are two possibilities:

Obligate carrier

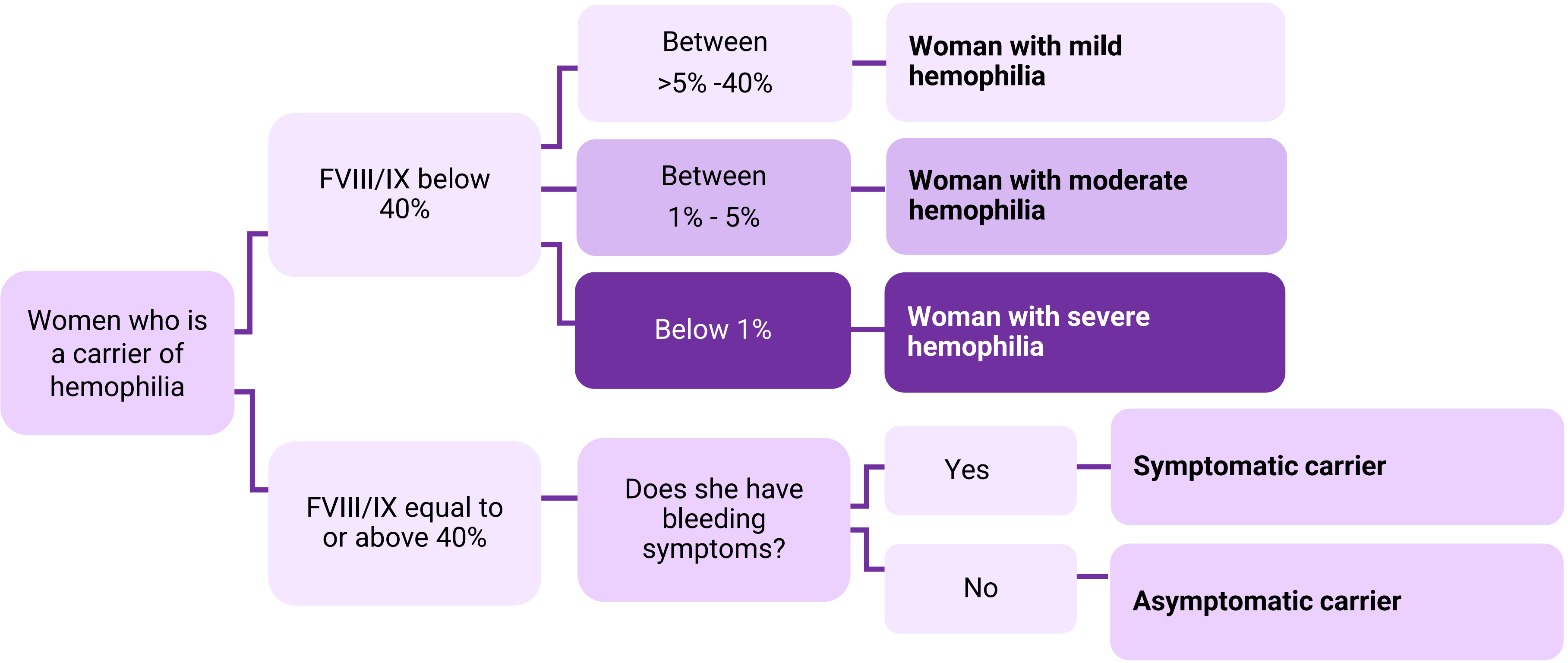
- Daughters of men with hemophilia.
- Women with two or more children with hemophilia.
- Women with one child with hemophilia and at least one other affected relative (such as a grandfather, brother, uncle, nephew, or cousin).
- A genetic study is recommended to identify the mutation.

Possible carrier

- Daughters of carrier mothers.
- Mothers of a child with hemophilia but with no known family history.
- Women with a family history of hemophilia but no children with the condition.
- A genetic study is necessary to confirm carrier status.

Not all carrier women have the same factor level or the same risk of bleeding.

According to the factor level, a carrier woman may be:



Women who is a carrier of hemophilia

- FVIII/IX below 40%
  - Between >5% -40% — **Woman with mild hemophilia**
  - Between 1% - 5% — **Woman with moderate hemophilia**
  - Below 1% — **Woman with severe hemophilia**
- FVIII/IX equal to or above 40%
  - Does she have bleeding symptoms?
    - Yes — **Symptomatic carrier**
    - No — **Asymptomatic carrier**

Information for **adult hemophilia carriers**

RECOMMENDATIONS

1. Women with family members affected by hemophilia, whether children, fathers, or a carrier mother**, should confirm or rule out their carrier status.** This is especially important for possible carriers.
2. Carrier women should **have their factor levels checked** through a blood test at least once in their lifetime. It is recommended to **do so before any surgical procedures** or in the case of significant bleeding complications.
3. Consult your reference treatment center **before any procedure or intervention involving your body**, so that they can anticipate possible complications and provide the appropriate treatment if necessary.
4. Consult your reference treatment center **if you have any concerns or experience any type of bleeding..**

HEAVY MENSTRUAL BLEEDING

A carrier woman **may experience heavy menstrual bleeding** from the first period to the last. This condition **can be treated**, and it is not necessary to live with it throughout life.

There **are different treatment options that should be individualized according to each woman's preferences**, her needs, and any other medical conditions she may have. These options include various hormonal treatments, intrauterine devices (IUDs), or medications that reduce bleeding, such as antifibrinolytics (Amchafibrin®).

DENTAL PROCEDURES

Between 27% and 72% of carrier women with factor levels below 60% **may experience prolonged bleeding**, lasting more than 3 hours, after dental extractions.

There are various **measures to minimize bleeding** during dental cleanings or tooth extractions. These measures are always **individualized, and take into account factor levels**, each woman's the bleeding tendency, and the type of dental procedure. You can contact **specialized dental services** that coordinate with hemophilia treatment units.

SURGICAL PROCEDURES

Not all surgeries, nor all women, carry the same risk of bleeding.

However, between 29% and 48% of carriers with factor levels below 40% may experience bleeding complications during surgical procedures, including bleeding lasting more than 3 hours. **They may require treatments to improve coagulation** or even blood transfusions.

Again, treatment **must be individualized** in order to start the most appropriate management for each case.

TRAUMA AND SPONTANEOUS BLEEDING

The same injury can have different consequences for carrier women, leading to a larger or smaller bruise depending, once again, **on factor levels and each woman's individual bleeding tendency.**

The same can happen with bleeding that occurs without any apparent cause, such as nosebleeds (epistaxis), which may be more frequent in women with **low factor levels** and much less common in those with higher levels.

Testimonials

I don't know what my factor level is

My bleeding has become "normal" to me

How does it really affect me?

When should I say that I am a hemophilia carrier?

There used to be a lot of secrecy within families affected by hemophilia

For more information:

You can find more information at:
https://www1.wfh.org/publications/files/pdf-2342.pdf
If you are considering becoming a mother, there is another specific leaflet about maternity for hemophilia carriers.
For any questions, concerns or support needs contact your reference treatment unit or the Association.

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Information for hemophilia carriers: What if I want to become a mother?

Interdisciplinary working group
for supporting hemophilia carriers
and their families

Motherhood is a personal choice that each woman may or may not consider. Today, scientific advances offer different possibilities for women who are hemophilia carriers. Making a choice is not always easy.

If a woman decides she wants to become a mother, **before pregnancy she should receive appropriate information** about the genetic implications of hemophilia, the available reproductive options, and the diagnostic possibilities.

This will allow for **pregnancy to be planned**, including how it will be monitored, what the delivery might be like, and which medications are most appropriate for her care, among other considerations..

Before pregnancy, what should you know? Genetic counseling

It is advisable to get informed when you have the desire to become a mother, so that you can make decisions about all the available options and plan the pregnancy. **Your treatment unit** can put you in contact with the **genetics department** so that you can receive genetic counseling.

In addition, you can take some time to think about the different options and, if you or your partner wish, you can also consult with the **psychology service**.

Natural Pregnancy

It is important to have a good understanding of how hemophilia is inherited.

If the chosen option is a natural pregnancy, it is essential to have information about the **prenatal diagnostic options** that are recommended in this situation.

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Pregnancy with assisted reproductive techniques

Hemophilia carriers may choose assisted reproductive techniques to achieve a pregnancy with a baby who does not carry the mutation that causes hemophilia.

These techniques may include **in vitro fertilization** with:

- selected embryos without the mutation, or
- donor eggs.

IN CASE OF A PREGNANCY: PRENATAL DIAGNOSIS

In the case of a natural pregnancy (when no embryo selection has been made), we do not know whether the baby will be a boy with or without hemophilia, or a girl who is or is not a carrier (remember that girls are obligate carriers only if the father has hemophilia, and possible carriers if the mother is a carrier). It is advisable, first of all, **to determine the sex of the baby**. If the fetus is male, it is possible to find out whether he carries the hemophilia gene.

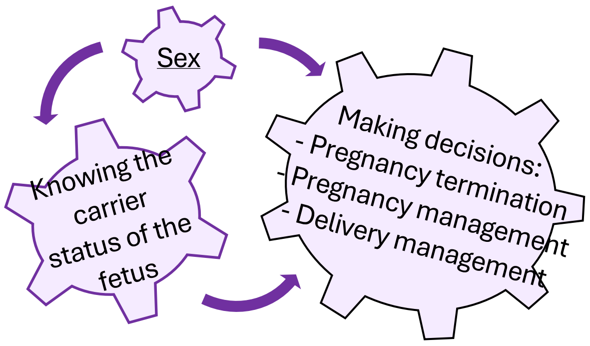
Whether it is a natural pregnancy or a pregnancy conceived through assisted reproductive techniques, prenatal diagnosis is recommended.

There are **different procedures** to determine the sex of the fetus and whether it carries the hemophilia mutation:
- By analyzing cell-free fetal DNA in maternal blood, the fetal sex can be identified during the early weeks of pregnancy (7-9 weeks).
- Though chorionic villus sampling (week 10-13) or amniocentesis (14-16 weeks), a genetic study of the future baby can be performed.
It is important to be informed about the risks associated with invasive techniques (chorionic villus sampling/amniocentesis).

If it is known that the fetus is a boy affected by hemophilia, it is important to **take some time to think and evaluate the different options.**

These are always **difficult decisions**. You can consult your multidisciplinary team and request psychological support.

If the decision is to proceed with a termination of pregnancy, this must be carefully planned.


Sex

Making decisions:
- Pregnancy termination
- Pregnancy management
- Delivery management

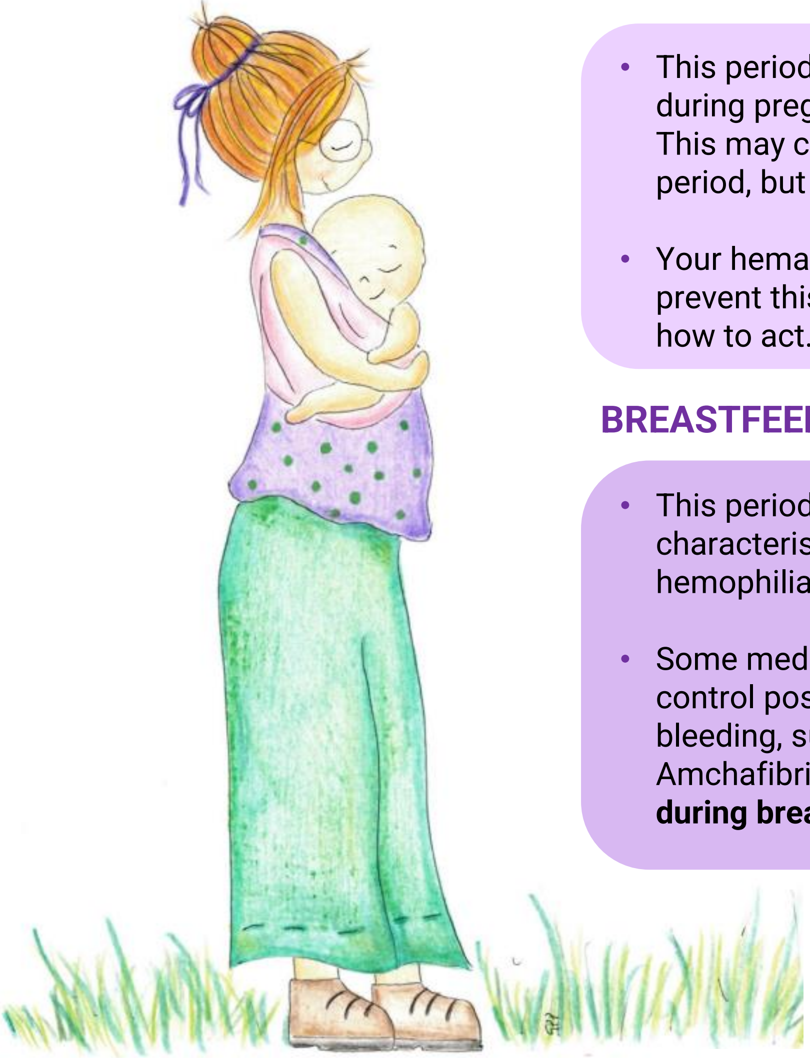
Knowing the carrier status of the fetus

PREGNANCY FOLLOW-UP

- In hemophilia carriers, **factor VIII, and to a lesser extent factor IX, increases during pregnancy**. In most cases, by the end of pregnancy these levels reach optimal and safe values for delivery.
- Your hematologist will **carry out the appropriate monitoring** during pregnancy, especially if any procedure with a risk of bleeding is needed, such as an amniocentesis, but also in the event of any bleeding complication and just before the expected delivery date.
- In general, during pregnancy, bleeding complications **are related to pregnancy itself** and not to the fact of being a hemophilia carrier.

DELIVERY

- It is recommended that the delivery take place in a **specialized center** with obstetricians experienced in hemophilia and other bleeding disorders, and, if possible, with a **hematologist available** at all times.
- Your team of doctors and nurses, will need to **prepare a "Plan"** for this moment. The aspects that require the most attention are the type of anesthesia and its management, the model of delivery (cesarean section, vaginal delivery, induction, etc.), as well as the need for any treatment to improve your hemostasis in case your factor level has not reached a sufficient value.
- This "Plan" will also include measures to ensure the **well-being of the baby**, especially if the baby has hemophilia. For example, efforts will be made to ensure a minimally invasive delivery and to reduce the use of instruments such as forceps.
- This "Plan" is coordinated among the **Hematology Department, the Gynecology Department, the Anesthesiology Department, and the Pediatrics Department.**



POSTPARTUM (PUERPERIUM)

- This period begins **after the birth of the baby**. **The factor level** that increased during pregnancy, often reaching normal levels, begins to **decrease again**. This may cause vaginal bleeding a few days after delivery, similar to menstrual period, but heavier than expected.
- Your hematologist will have given you **treatment and instructions** either to prevent this from happening or to help you recognize warning signs and know how to act.

BREASTFEEDING

- This period has no special characteristics for a hemophilia carrier.
- Some medications used to control postpartum bleeding, such as Amchafibrin®, are **safe during breastfeeding.**

For more information

You can find more information at: https://www1.wfh.org/publications/files/pdf-2342.pdf

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5 Information for older hemophilia carriers

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JUSTIFICATION

Hemophilia is a genetic condition that accompanies us throughout lives. It is important to remember that carrier women can experience bleeding and hemorrhages.

Life can be divided into different stages, each of them very distinct, with the last one being older adulthood.. **Aging** is a natural process of life, and it is advisable to reach it in an active and healthy way.

As a hemophilia carrier, during your reproductive years you may have experienced heavy menstrual bleeding or postpartum bleeding if you have been a mother. In this stage of life, however, you may face **other challenges**.

CHALLENGES OF AGING

Physical activity

Several studies have shown that carrier women have more **joint problems** than women of the same age who are not carriers.

Being **physically active** helps slow down, alleviate, and even reverse many effects of aging.

For this reason, it is advisable to incorporate **thirty minutes** of physical activity into your daily life: walking to get around, taking the stairs, walking the dog, joining a gym or swimming pool, etc.

Prevention of accidents and injuries

Falls can occur at any age, but as the years go by, the likelihood increases, and the consequences can significantly impact quality of life and independence.

With aging, balance **or memory problems** may appear, and certain medical conditions can cause **muscle weakness**, all of which may lead to falls. In addition, wearing inappropriate footwear or taking medications that cause drowsiness or dizziness can further increase the risk.

To reduce the risk of falls, you can:
- Perform exercises to improve strength and balance.
- Use walking sticks or mobility aids,.
- Have regular eye check-ups.
- Increase home safety with measures such as installing grab bars in the bathroom or shower, removing rugs, or improving lighting.

In a carrier woman, a fall may cause a larger bruise than in a non-carrier woman, take longer to heal, or require medical intervention. Similarly, if an injury results in a fracture requiring surgery, even with the appropriate precautions to ensure effective hemostasis, the **risk of bleeding is always greater** than in someone without hemophilia carrier status.

5 Information for **older hemophilia carriers**

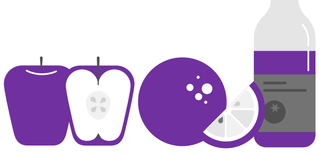
Nutrition

Most older adults need **less energy** than they did at other stages of life, but it is essential to eat a bit of everything. Diet should be **balanced, varied, and sufficient.**

As a carrier woman, **obesity** can affect the joints and accelerate bone wear. This could lead to the need for certain interventions in a shorter period of time than usual, with the associated risk of bleeding.

In addition, obesity increases the risk of **other conditions**, such as hypertension, diabetes, and cardiovascular diseases, including heart attacks.

As a carrier woman, it is important to take care of **cardiovascular health**, and diet is a key factor.
The treatment of a cardiovascular condition may involve medications that increase the risk of bleeding.



DENTAL PROCEDURES

Between 27% and 72% of carrier women with factor levels below 60% may experience prolonged bleeding lasting more than 3 hours after dental extractions.

There are **different measures** to minimize bleeding during dental cleanings or tooth extractions. These measures are always **individualized** and take into account factor levels, each woman's bleeding tendency, and the type of dental procedure. You can contact **specialized dental services** that coordinate closely with hemophilia treatment units.

SURGICAL PROCEDURES

Not all surgeries, nor all women, have the same risk of bleeding.

However, between 29% and 48% of carriers with factor levels below 40% may experience bleeding complications during **surgical procedures**, including bleeding lasting more than 3 hours. They may require treatments to improve coagulation or even blood transfusions.

Again, management must be **individualized** in order to begin the most appropriate treatment for each case.

TRAUMA AND SPONTANEOUS BLEEDING

The same injury can have different consequences in carrier women, leading to a larger or smaller bruise depending, once again, on the **factor levels** and on each woman's individual bleeding tendency.

The same can occur with bleeding that appears without any apparent cause, such as nosebleeds (epistaxis), which may be more frequent in women with low factor levels and only occasional in those with higher levels.

RECOMENDATIONS

1. Aging is a stage of life that we should reach in an active and healthy way.
2. Carrier women must face the challenges of aging by maintaining good physical activity, following a healthy diet, and preventing or minimizing, as much as possible, the risk of falls and injuries.
3. Consult your reference hematologist with any questions related to medical procedures or bleeding, so that possible complications can be anticipated and the appropriate treatment provided if necessary.

For more information

For any questions, concerns or support needs contact your reference treatment unit or the Association.

We are here to help you.

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