

# Frequently asked Questions



## Question

I have a bleeding disorder and I'm really scared by the amount of blood I lose in a period. Last time I went through 6 super tampons and pads in a day and I felt like I was going to be sick and I was really dizzy and tired.

When should I go to the emergency department in my hospital? When would I need a blood transfusion?

## Answer

Having a very heavy period can be troubling and frustrating. It can be hard to manage the amount of bleeding, particularly if you have to change your tampons or pads very often or have flooding for days and you are not feeling well.

Understanding what is happening is important so that you know what to expect and when you should talk to your Haemophilia Treatment Centre or seek medical assistance.

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## What is heavy bleeding?

- Soaking through a tampon and a pad around every two hours or more often, or needing to change protection during the night.
- Periods for longer than normal (longer than 8 days)
- Bleeding with clots bigger than a 50 cent piece
- Bleeding or spotting between periods.

Spotting can sometimes happen mid-cycle, at the same time every month, but in women with a bleeding disorder this can sometimes last several days and require pads or tampons. Keep a diary. It is also worthwhile having this checked by your local doctor. Sometimes there can be other causes that need to be checked and they may need to refer you to a gynaecologist.

- Flooding (soaking through tampon or pad through clothes or onto bedsheets)



## Why am I feeling like this?

During your period, your hormone levels change and the prostaglandins and other special chemicals that tell your body to peel off the lining of your uterus and start the bleeding can affect how you feel. They can make you feel dizzy and faint, they can cause nausea (feeling like you are going to be sick), vomiting and diarrhoea, give you cramping pain, and make you feel like you don't have any energy and make you look pale.

It is unusual for a single heavy period to cause anaemia - usually it happens over months to years. If you often have heavy periods, the iron levels in your blood can gradually drop. This causes anaemia which in turn can make you look pale and feel really tired and dizzy and breathless, particularly if you are doing something a little bit strenuous like walking up stairs. It is very important to visit your GP - to have your blood and iron levels checked and to

replace the iron in your body. You also need to deal with the heavy menstrual bleeding which is causing your low iron levels.

You might be feeling alarmed at the amount of blood you are losing during a single heavy period but your body is able to quickly replace it. Throughout one heavy period, you could easily lose more than 80ml of blood (around a third of a cup)<sup>3</sup> and sometimes much more over several days. That might seem like a lot but, if you are around 50-65kg, your body has around 4.5 - 5.5 litres of blood<sup>4</sup> which it constantly replaces. By comparison, a blood donation usually takes about 10% of the donor's blood, or around 450 – 550 ml in one day.<sup>5</sup>



## When should I seek help?

**If you have very heavy bleeding, and ongoing and very noticeable symptoms of dizziness or extreme tiredness or breathlessness then it is important to seek medical help urgently.**

Medical staff need to check for and treat anaemia and start medical treatment to slow the bleeding. You should seek advice from your Haemophilia Treatment Centre about the best place to go (such as which hospital) depending on your individual situation and where you live.

In some situations, this may need to be the Emergency Department. This is so that a quick medical assessment and blood tests can be done and treatment can be started in consultation with the Gynaecology and Haematology specialty doctors on call for the hospital. If you do need emergency treatment for extremely heavy periods it is important to let the Emergency Department doctor know about your bleeding

disorder and show them your ABDR treatment card so your haematologist is contacted for advice.

Most of the time however, heavy periods are not an emergency and can be managed at home. If you are feeling nauseous, fatigued or have cramping pain during your heavy period, it is important to look after yourself. Take the time to rest, drink plenty of water and take pain relief if you need it to feel more comfortable. Sometimes a hot water bottle can provide comfort for cramping pains.

If you are still bleeding heavily after 8 days, or if you are still feeling faint and dizzy or have no energy to the point where you can't do your normal daily activities (such as go to work or to school), and are still worried make an appointment with your GP. If you do faint and hit your head, make sure you are taken to hospital right away to check if there is bleeding inside your head that can put pressure on your brain.

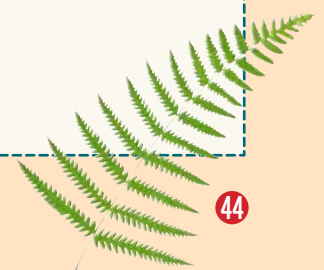
## Who should I talk to?

Seeing your GP can be a good place to start. They can take care of other aspects of your health including doing a general Women's Health check. If you are not already being managed by your Haemophilia Treatment Centre for heavy bleeding, talk to your doctor about making an appointment with them when you feel better.

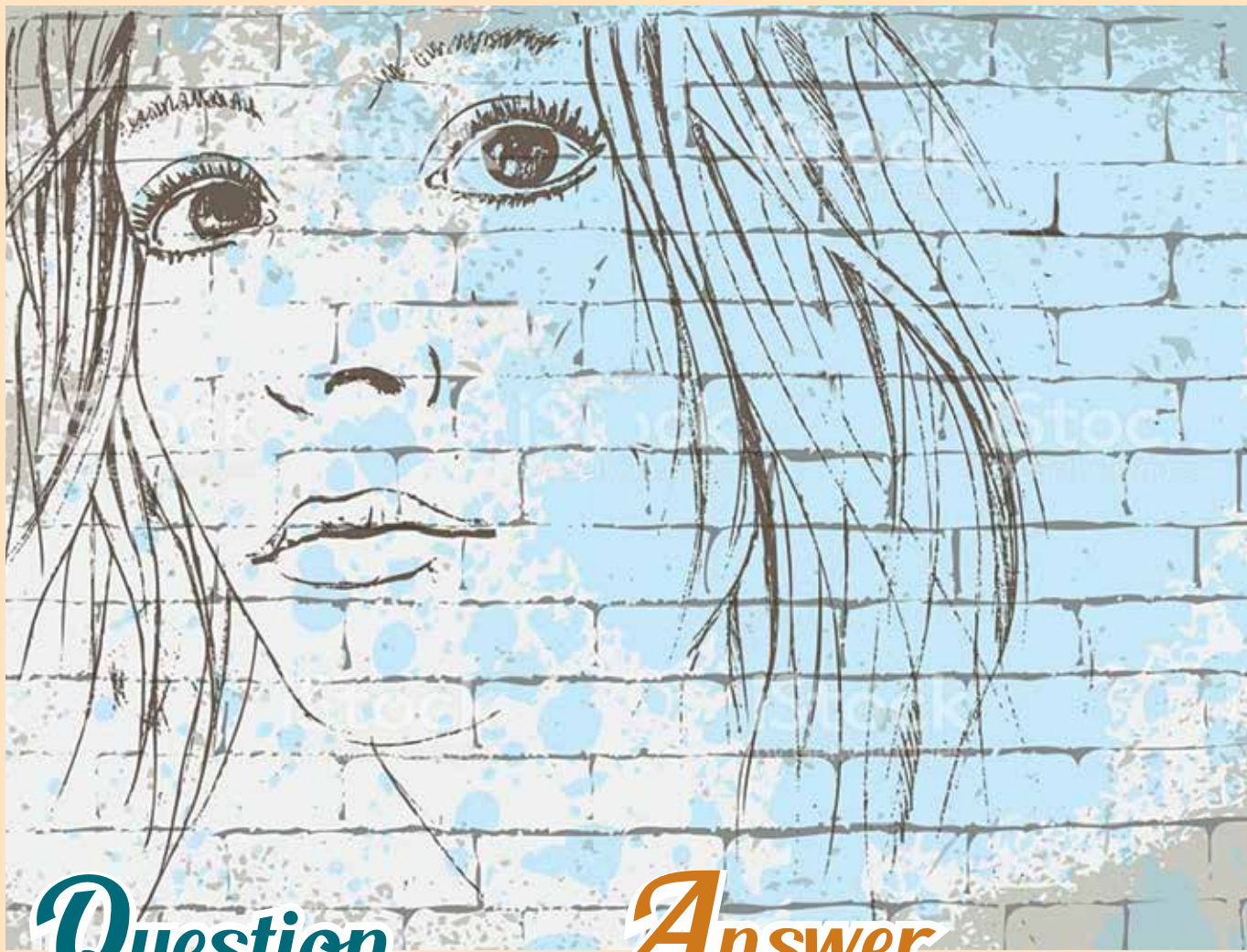
Your Haemophilia Treatment Centre will discuss the bleeding symptoms with you, and may also want to test your blood to check your iron levels. If needed they can put some management strategies in place and may want to refer you to a gynaecologist for specialist care. Your gynaecologist will be part of your medical care team, and will work together with you and your haemophilia team to understand and manage your bleeding symptoms. Not all gynaecologists are familiar with treating people with mild bleeding disorders and sometimes it is necessary to change doctors to find one who will listen to your concerns.

## Would I need a blood transfusion?

It is quite unusual to need a blood transfusion for heavy periods. Very occasionally it may be needed when girls with bleeding disorders start their periods for the first time (known as *the menarche*) or during the first 6 months after this. A transfusion might be given when a girl's menstrual bleeding (period) is extremely and persistently heavy, leading to very low red blood cell counts (low haemoglobin), and when it takes a while for the first line medical and hormonal treatment to stop the bleeding. Usually if a girl has anaemia due to low iron as a result of heavy periods, it is safely managed through treatment with iron replacement rather than a blood transfusion.







## Question

**I have read on the internet that my only option to control my bleeding issues is a hysterectomy. I don't want to do that, because I might want children one day. What are my other options? Who can I talk to?**

## Answer

Although there is some good information on the internet, there is also a lot of information that does not apply to young women with bleeding problems, is incorrect, or might not be relevant to your situation. It can often be hard to separate the good information from the not so good. It is important to talk to your haemophilia nurse or doctor at your Haemophilia Treatment Centre. They will be able to talk with you about your individual situation, tell you where to get the most up to date and accurate information and discuss the best treatment options for you.

Sometimes heavy periods can be a sign of a gynaecological (women's health) disorder. This may not be related to the bleeding disorder, but the bleeding disorder might make the heavy periods worse. With diagnosis and appropriate treatment, these bleeding problems can usually be reduced or managed. It is important that your gynaecological care is managed in a team, where the gynaecologist and your Haemophilia Treatment Centre discuss the treatment options with you.

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## *What options are there?*

These days there are many treatment options available such as the simple non-hormonal method of tranexamic acid.

It is now known that there are no problems with using female hormones (either the combined contraceptive pill or other progesterone medications such as provera, or norethisterone) in a continuous way, to skip periods altogether. There is a hormone releasing IUD (interuterine device that is placed inside the womb) that works well to reduce heavy bleeding and is often offered to young women once their body has matured. If you are concerned about skipping periods keep in mind that at certain times it is quite normal for women to go for many months without getting their period, such as during pregnancy and breastfeeding. In previous generations women who had 10 or 15 babies and who breastfed them all would have had less than 50 periods in their lifetime!

Generally, your medical care team will suggest trying all of the medication options before considering surgery such as hysterectomy (surgical removal of the uterus), or procedures such as endometrial ablation, where the lining of the uterus is removed to reduce heavy bleeding. After these kinds of procedures you will not be able to have children and these procedures are not usually recommended for young women who might want to have children in the future. It is also worth remembering that all operations, including hysterectomy, carry risks of bleeding complications.

## *Endometriosis*

Girls and women with bleeding disorders have an increased chance of having a condition called endometriosis, where tissue similar to the lining of the uterus (womb) grows in the pelvis outside the uterus and can bleed during menstrual periods. Endometriosis can cause pain and period problems.

For more information about endometriosis, see page 7.

## *Do I need an operation?*

Just because you have pain does not mean you need an operation. Most, if not all endometriosis can be prevented by reducing or stopping the bleeding altogether through effective treatment. Reducing the bleeding also gives your body the chance to absorb any bleeding outside the uterus (just like a bruise on your arm will be reabsorbed).

If reducing or stopping the bleeding results in the pain disappearing, you can avoid surgery and the risks with having an operation.

## *Having children*

If you want to discuss your questions about having children, talk to your Haemophilia Treatment Centre team and your gynaecologist. They will also discuss with you if they believe you might benefit from seeing other specialists. You may also find it valuable to talk to a social worker, counsellor or psychologist at your HTC about your situation and your future plans. Your HTC can also refer you to a counsellor in the community if you prefer.

For more information visit [factoredin.org.au](http://factoredin.org.au)

**Important Note:** This booklet was developed by Haemophilia Foundation Australia for education and information purposes only and does not replace advice from a treating health professional. Always see your health care provider for assessment and advice about your individual health before taking action or relying on published information. © Haemophilia Foundation Australia, October 2018. [www.haemophilia.org.au](http://www.haemophilia.org.au)

# More Information

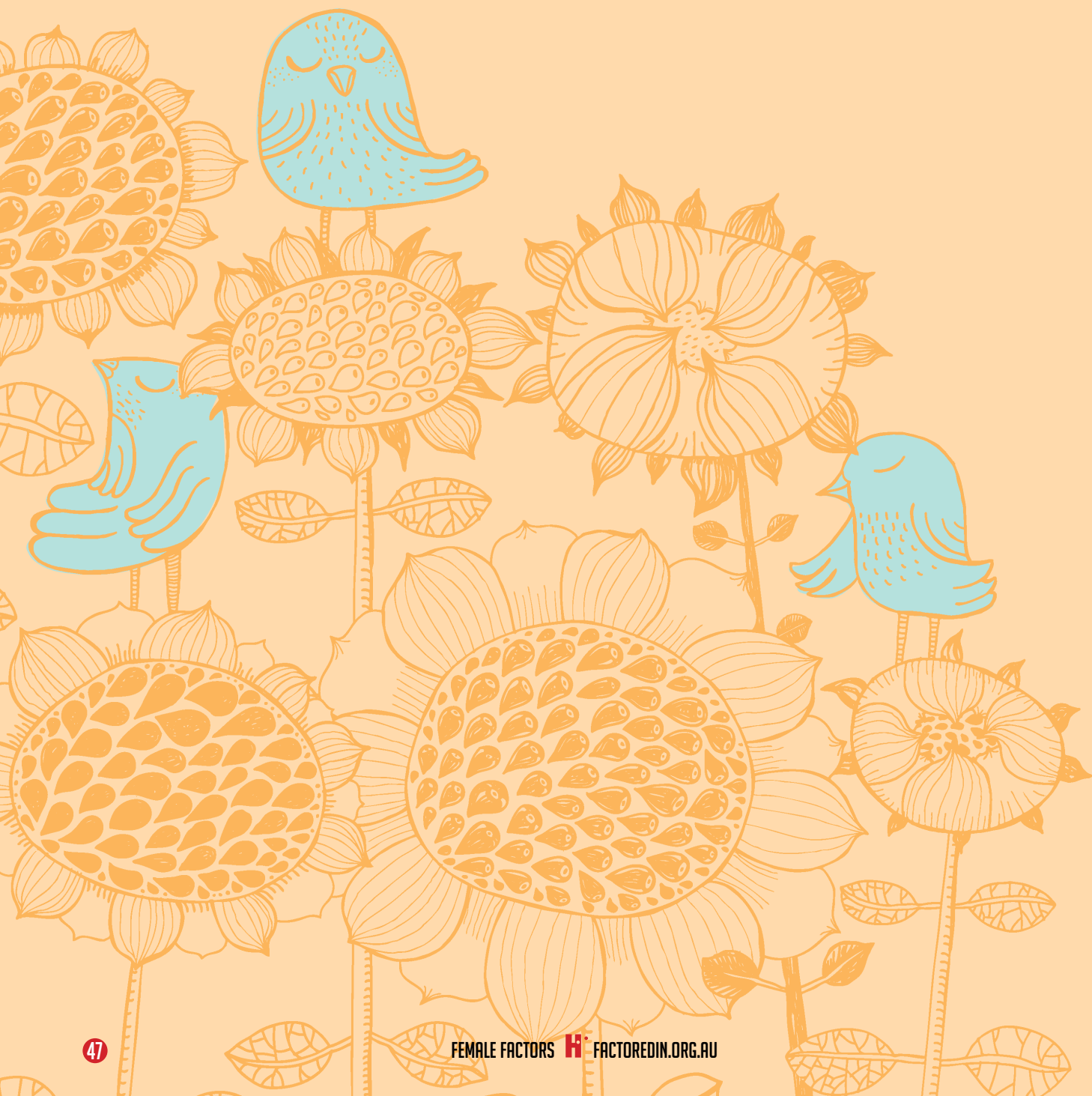
For more information about bleeding disorders, or to find out how to get in touch with your local Haemophilia Foundation or a specialist Haemophilia Treatment Centre, contact:

**Haemophilia Foundation Australia**

**P: 1800 807 173**

**E: [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au)**

**W: [www.haemophilia.org.au](http://www.haemophilia.org.au)**





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## Other sources

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# About this booklet

This booklet is an introduction to bleeding disorders in females designed for young women. It aims to explain bleeding disorders in detail in a way that is easy to understand for you, your family, partner or friends.

Bleeding disorders covered in this booklet include:

- Haemophilia A and haemophilia B
- Carrying the gene for haemophilia A and haemophilia B
- Von Willebrand disease
- Rare clotting factor deficiencies including platelet function disorders.

Treatment is only described briefly in this resource, and will be covered in more depth in a separate booklet.

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This resource may be printed or photocopied for education purposes.

## Acknowledgements

We would like to thank the organisations and the many people who made valuable contributions to this booklet.

The menstrual cycle diagram was originally published by Jean Hailes ([jeanhailes.org.au](http://jeanhailes.org.au)) and has been reproduced and adapted with permission.

**Quotes and personal stories** in this booklet were contributed by young Australian women with bleeding disorders or who carry the gene.

We thank them for their generosity in sharing their experiences.

## Reviewers

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**Note:** Apart from the photograph of Jade with Jade's Story, all photographs used in this booklet are stock images for illustration only.