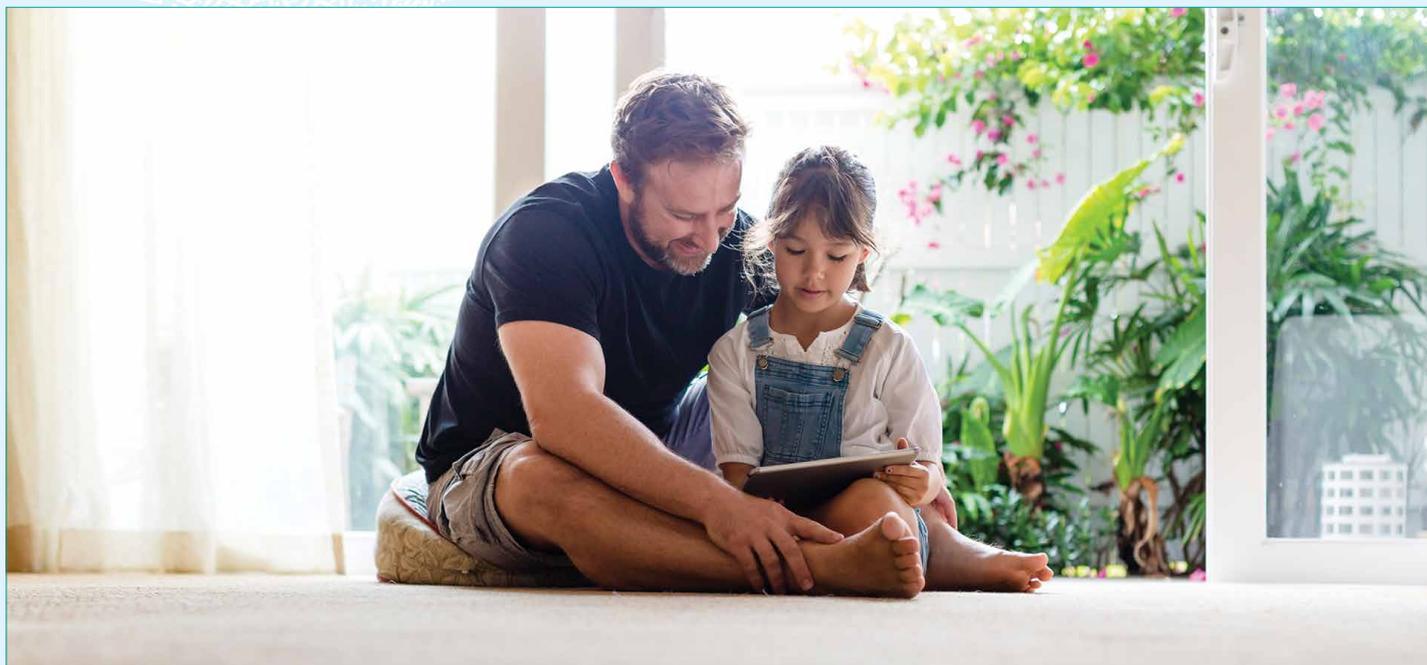


Telling daughters



Telling daughters - key points

- If your daughter might have a bleeding disorder or carry the gene, she will need to be told about this at some stage
- She may need to have clotting factor level testing or other testing early in life, or as soon as she seems to have bleeding problems, to see if she has a bleeding tendency
- It's a good idea to tell your daughter before she gets her first period. Heavy periods can be a symptom of a bleeding disorder, which can be quite distressing if she doesn't know beforehand and can be hard to manage and cause anaemia (low iron).
- If you are both prepared, you can act quickly if she does have heavy periods or other bleeding problems so that she gets a medical management plan to control or prevent bleeding and pain
- A common time for girls to have genetic testing for haemophilia is when they have reached childbearing age
- It is also important your daughter knows about her bleeding disorder to help her with any family planning decisions in the future
- Your Haemophilia Treatment Centre (HTC) can help you prepare for these discussions.

If you have a daughter who may have a bleeding disorder or carry the gene, she will need to be told about this possibility at some point.

If her father or other family members have a bleeding disorder, there may have already been family discussions. How much it was discussed might depend on the family member's symptoms and the

impact of the bleeding disorder on them. It might also depend on whether her father has haemophilia, in which case all of his daughters will be **obligate carriers** and will definitely carry the gene. Each family also communicates in its own way. In Zev's story, Zev as the father took the lead and the family were used to talking openly.

Zev's story



Zev and his daughter today

'Make it a family conversation'. This is the advice Zev, a man with severe haemophilia, would like to give to families affected by haemophilia. Zev has two sons, neither of whom have haemophilia, and one daughter whom he realised at an early age would carry his altered gene.

'My kids knew I had haemophilia. We were very open. There were lots of signs because of the bleeds I had before I started prophylaxis [preventive] factor treatment. But they also saw I was ok, that I was working, active, involved in everything.'

'When my daughter was 12 years old we went through a particularly difficult time. My wife passed away. Before then we hadn't discussed with our daughter how she might be affected. But I knew I needed to talk to her because the day might come when she would have some decisions to make.'

'I sat down with her when she was about 15 and told her she had an X that was normal and an X that was not normal. Since then she has

understood the situation if she were to have a child. Her response has been "I'll take that risk". She's aware of the new treatments and, looking ahead, of a potential cure. She isn't fearful of what the future brings if she decides to have children. I don't think she would hesitate.'

Looking back, Zev has a few tips about talking to girls who might have the altered gene. 'I don't think you need to worry a child about heredity, but you might have to talk about periods before they start and encourage her to tell you if she has heavy periods. Then when she starts to date you can talk about how it's inherited. Girls might not want to talk a lot about it but they shouldn't be left to guess.'

'Normalising haemophilia by making it part of general family conversation helps. Often there's no obvious signs of haemophilia with current treatments so men with haemophilia might put it on the back burner. But these conversations need to be had. You shouldn't protect your kids from things that might be necessary.'

When to tell

Some parents begin telling their daughters from an early age so they grow up knowing about the possibility. This creates opportunities for a gradual learning process throughout childhood. Other parents might leave it until she is older and better able to understand what it will mean for her. Whenever you decide to talk with her, consider how much a girl of her age and maturity would want to know, and is likely to understand. Using language appropriate for her age will help with this.

“ I would strongly encourage parents to tell their child and siblings about the condition as soon as practicable – in words they understand. ”

It's wise to let your daughter know she might have the gene for a bleeding disorder before she starts getting her period. Many girls who carry the gene will not be affected, but heavy periods (also known as heavy menstrual bleeding, abnormal uterine bleeding or menorrhagia) can be a symptom of a bleeding disorder. Menstrual bleeding can be especially heavy when a girl first starts having periods due to the surge in hormones involved in starting menstruation. This can be distressing, particularly if girls haven't been told this is a possibility.

Heavy periods can affect a girl's wellbeing, for example, by causing low blood iron levels (anaemia) which can lead to fatigue and lack of concentration. Some girls need help to recognise and manage heavy or painful periods. Telling your daughter what to look out for before puberty will give her time to come to terms with the possibility that she might have bleeding symptoms before she reaches her teens, when she may be very sensitive to the fact that she could be 'different' in some way. It will also give an opportunity to step in quickly if she does have heavy periods or other bleeding problems and needs a medical management plan to control or prevent bleeding and pain. This way she will be able to access appropriate support instead of hiding it or putting up with it.



“ I would probably tell them before they get their period and I want them to feel they can be open and honest with me so I will tell them if you get periods, let mummy know and monitor their periods closely to see if they have any issues. ”

“ Heavy periods aren't normal and can make life pretty hard. It's OK (and even good!) to talk about it and to support others by sharing your story about being a carrier. ”

“ I needed to talk to them about how their periods were going. With a teenager's natural reserve about anything to do with their bodies, this could sometimes be an awkward conversation. ”

Haemophilia - who will carry the gene?

- **ALL daughters of a man with haemophilia** will carry the gene. They are known as '**obligate carriers**'.
- **NO sons of a man with haemophilia** will inherit haemophilia from him
- There is a **50% chance that each child of a woman who carries the gene** will also carry the gene or have haemophilia.

Bleeding symptoms

It is now recommended that all girls who might carry the gene for haemophilia have their clotting factor level tested early in life, or as soon as they seem to have bleeding problems. Factor level testing provides information about whether someone is at greater than normal risk of bleeding.

Having clotting factor levels checked is not the same as testing for carrier status, which requires a separate laboratory test. **Normal factor levels will not tell you if a girl carries the gene.** A girl might not have bleeding symptoms but might have the gene for haemophilia and be able to pass it on to her children.

Checking factor levels early allows girls with low levels to be identified and managed appropriately before they have problems with bleeding. Unlike males with haemophilia, where the factor level is nearly always the same within the same family, the factor level in females who carry the haemophilia gene is unpredictable, and varies between female family members. So a mother who carries the gene and who has normal clotting factor levels can have a daughter who has lower than normal levels, if that daughter also carries the gene. It's important for girls to have their own levels checked and for them to understand what the results mean. Having your daughter's levels tested can be an opportunity to talk with her about the possibility of carrying the gene. Keep in mind that a girl who carries the gene for haemophilia can have completely normal clotting factor levels.

The same variation in bleeding symptoms can occur within families with VWD. Girls who have VWD can experience bleeding symptoms including heavy periods, even if other female relatives with VWD haven't. It's better to raise this with her before she reaches puberty so you can both be prepared.

Girls with rare clotting deficiencies may also need to be educated about the possibility of bleeding symptoms. Speak to your HTC haematologist about how having a rare clotting factor deficiency or carrying the gene is likely to affect your daughter.

VWD and rare clotting factor deficiencies - inheritance

Inheritance patterns for VWD and rare clotting factor deficiencies depend on the type of disorder. They follow an **autosomal** pattern (not sex-linked; affecting males and females equally). The inheritance pattern is either **recessive** (both parents carry the gene) or **dominant** (only one parent carries and passes on the gene), with different chances of passing the gene on.

For more information about inheritance patterns for your particular bleeding disorder

- visit the HFA website - www.haemophilia.org.au
- or ask your Haemophilia Treatment Centre.

“ I started telling my daughter from an early age that “she had special blood” just like mum, and we have been open and frank with our family and friends. ”

Having the conversation

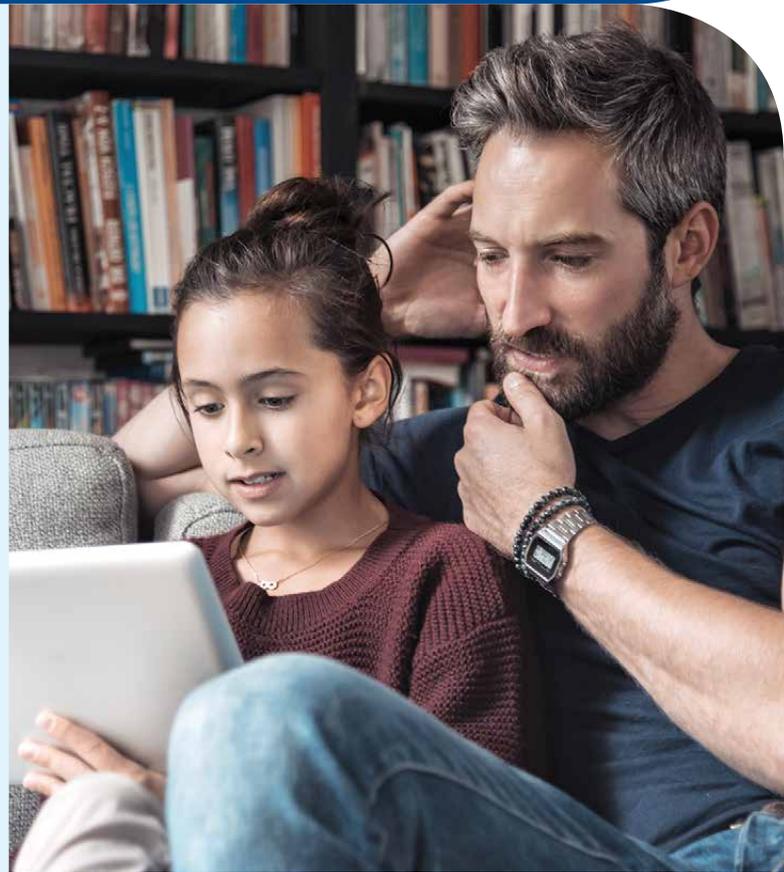
Generally, children are very good at picking up on emotions. Before you tell your daughter, check that you're able to manage any concerns so you can approach the topic calmly. This will make it easier to give your daughter whatever information and support she needs at this time.

Talking through any worries you have for your daughter first with the haemophilia nurse or the psychologist, social worker or counsellor at your HTC can help you to prepare. Different Centres have different staff available. Some Centres may offer you the option of seeing a local counsellor, especially if you do not live nearby. But remember you can always contact HTC staff by phone to talk through your concerns. They have a great deal of experience with the impact of bleeding disorders on families and have up-to-date knowledge about treatment. This can help you to clarify your thoughts.

The way you speak to your daughter about the possibility of carrying the gene or about bleeding symptoms will influence her attitude. Some parents find it works best to discuss these issues over time, as they come up, rather than saving it up for 'the right time'.

Once you have told your daughter check in with her from time to time and make sure she has access to the most up-to-date information on the bleeding disorder and carrying the gene. This includes information on the availability of laboratory tests that indicate whether or not she carries the gene and what that means if she plans to have children herself. As she reaches childbearing age the HTC can help with information and advice about genetic testing and can provide a referral to a genetic counsellor, if needed.

It is strongly recommended that females consider finding out whether they carry the gene for haemophilia BEFORE they become pregnant. Genetic testing can take time, sometimes many months, and some prenatal testing for haemophilia relies on knowing the family gene alteration. If your daughter already knows the HTC staff and has gone on to have testing for the gene and knows her carrier status, she will be much more



prepared for pregnancy decisions. She will not be caught unawares if she has an unplanned pregnancy, and have to make many decisions quickly around family planning options, sometimes with limited information or choices.

“ In time, years down the track from now, I will have the discussion about family planning and all that it entails with my daughter. Who knows where we will be by then. ”

“ Education is the key 'factor', not the number 'nine' factor. Life for all women with a bleeding disorder, including my daughter, is becoming brighter each day. ”