

Telling friends and family



Telling friends and family - key points

- Many women find sharing their feelings with close friends or family helps them come to terms with their diagnosis
- Friends and family can give support, and help you deal with accidents, injuries and medical problems
- Some friends or family might react in ways that aren't helpful
- Challenges in telling family can include: how much your family already knows about bleeding disorders, whether they have or might have an altered gene or bleeding disorder, and what your relationship with your family is like
- Does your diagnosis mean that other family members need to be tested to see whether they have a bleeding disorder or carry the gene?
- Even if your other family members have a bleeding disorder, your family may struggle to understand what you are going through
- On the other hand, families who have experience of living with a bleeding disorder can often be a great source of information and support
- Your Haemophilia Treatment Centre can help you with these discussions.

Whatever you decide about telling people, it can be valuable if at least a few people close to you know. Many women find sharing their feelings with close friends or family helps them come to terms with the diagnosis. People who care about you can give you support if difficulties arise or if others are being negative or unhelpful. If you have bleeding symptoms they can watch out for you and help to deal with accidents or injuries.

On the flip side, some friends or family can react in a way that's not helpful. Perhaps this is because they don't know much about bleeding disorders, or they don't understand what having a bleeding disorder or carrying the gene means to you. They may be overly worried about your health, or anxious about the wellbeing of future generations. You need someone who will support you, not burden you with their concerns. Who you go to for support is a personal decision. Choose someone you trust and who cares about your wellbeing. If you sense friends or family are overwhelmed or don't understand you can always come back to the Haemophilia Treatment Centre.

“It's good to be informed and educated for your own sake, and so you can communicate your needs to others.”

“Telling friends anything personal can be hard, even embarrassing; so when you decide to tell them about haemophilia it is not something that you say as a passing remark.”

“I have always been pretty open with people around me about it – which has helped me accept it.”

Shauna's story

The journey for women with bleeding disorders is not always straightforward, and there's still so much that is being discovered to help guide the way. One thing that is clear for Shauna is when it comes to telling others it's usually easier for everyone to be open and honest.

Shauna was very young when she was diagnosed with von Willebrand disease. She was barely 12 months old when she was admitted to hospital for excessive bleeding. 'I was hospitalised after biting my lip. It bled all night, soaking my entire cot. We had a diagnosis before being discharged.'

Armed with the information they needed, Shauna's parents made a point of telling anyone involved in her care about her bleeding tendency. 'From a young age my teachers and friends' parents were often made aware of my VWD so they usually told their students or children. My peers always "just knew" and it seemed normal. As I've gotten older I usually bring it up with new friends whenever I have a particularly visible bruise. I've always been quite open about my bleeding disorder with my friends. Often they are quite interested to learn about my bleeding escapades.'

One of the reasons Shauna makes a point of telling friends is so they know what steps to take if there's an incident. 'Always be transparent with your friends. It's important that they know the basics of what to do in

the case of an emergency.' She also finds it keeps her on her toes regarding her condition. 'A great way to educate yourself is through educating others.'

Shauna's advice about telling partners is to be open. 'They see how it impacts you on a personal level, but when your partner understands what you are going through they can help you through the hardships.'

Sometimes Shauna finds herself protecting her partner from worrying about her. 'I've learnt that I often play down the symptoms when my partner is surprised watching me have a particular type of severe bleed for the first time. But it's really important to be open and keep them informed because they might be the one that has to tell others, including health professionals, if something happens. Knowing they are educated makes me feel safer.'

For Shauna talking openly about having VWD is how it's always been for her. 'Talking about your bleeding disorder is like talking about your hair colour - it's just a part of who you are!'



How will my family react?

Families are where people often turn for support throughout life, and they can be a great source of help and advice. However, sometimes talking to family members can be challenging.

Things that can affect how you might feel about discussing your diagnosis include:

- whether or not your bleeding disorder is new to your family
- each family member's view of the bleeding disorder, for example, do they view it as a life threatening condition, or as something that can be well managed, or is it something they know very little about?

- whether your diagnosis means the family member you're telling might have the altered gene or bleeding disorder too
- the relationship you have with your family, or individual family members
- your family's ability to support one another.

All families are different, and everyone's situation is unique. The following sections take a closer look at some of the more common issues that come up for females and their families around disclosure. Many of the issues are similar across all bleeding disorders while others are specific to each disorder, as described below.

Telling family members who have lived with haemophilia

Haemophilia is a condition that often affects the whole family, including members who don't have a bleeding disorder. The impacts of living with this condition are felt by everyone. Each family member has their own relationship with the condition. Women and girls can feel that haemophilia has defined them in some way, for example as the carer, or as the sibling that missed out on the extra attention that their brother received. Girls have often grown up seeing the difficulties faced by brothers, fathers, uncles or grandfathers with haemophilia. These experiences can influence how you feel about

discussing your diagnosis with your family. They might also affect how the news is received

Being diagnosed with carrying the gene for haemophilia can be an emotional time. Even though you've been given the diagnosis, you may feel haemophilia 'belongs' to the male members of the family who have the condition. You might believe that being diagnosed as carrying the gene should feel easier when you compare it to the difficulties your male relatives have been through. Some women and girls feel they don't really have a right to feel upset about their diagnosis. This feeling can create a barrier to open discussion.

If you have a family member with haemophilia telling them might be quite straightforward, but for some women it's not easy. Perhaps you feel you should protect them from your feelings, especially if you have often minimised your own needs within the family. If you are used to shielding family members such as brothers with haemophilia from life's ups and downs, you might find it harder to talk to them about

“ In those days your parents weren't exactly up front about haemophilia. Mum used to just say that some of the older family members were “bleeders” and that's all she said. ”

your own diagnosis. Or you might be worried that being upset about your diagnosis in front of your brother or other family members could make them feel worse about their condition. It's not uncommon to have quite complex feelings about your brother's haemophilia, including jealousy, resentment, guilt, anxiety and a sense of being left out. This web of emotions can be tricky to sort out, and you may want to seek the support of the Haemophilia Treatment Centre psychologist or social worker to assist with this, or ask the Centre to refer you to a counsellor. This support can also help you with planning how to discuss your diagnosis with family members.

You might also be unsure how to discuss your diagnosis with your father, and other male relatives who have haemophilia. Even when fathers, or other family members, have a positive outlook on their own haemophilia they could still be worried for you when you tell them you have the altered gene. Mothers often feel guilty for being a carrier and passing the gene on to their daughters, and fathers can too, even though it's no-one's fault.

“ I think my dad was more worried about me than I was. ”

Each member of your family, both male and female, will have their own view of haemophilia. This view can be influenced by their own experiences, or memories of their brother, father or grandfather's struggles. Family members who are unaware of the huge improvements in treatments in recent years may be worried that you or your children will have to deal with the same debilitating conditions people faced a generation or more ago. Their reaction will be quite different from families where haemophilia has been well managed, and life has felt reasonably normal.

It's important to remember that family members who have experience of living with haemophilia can also be a great source of information and support. They often understand the difficulties you face and can give practical advice and assistance. The challenges that haemophilia has brought to your family may have helped build strong ties. This bond could be what gets you through difficult times if they arise.



“ We have really great family support so having all our parents, and brothers and sisters around us helps. ”

“ As their parents we have watched both our daughters' growth and are proud of their ability to support each other and make things happen - for example, when one was struggling with a bleeding complication at a hospital, the other advocated for her until she was transferred to the Haemophilia Centre. ”

If you're concerned about telling your family about your diagnosis consider getting some extra support. Stay in touch with the Haemophilia Treatment Centre - they can talk things through with you, and support your other family members too. They can also refer you to other counselling services if that would be helpful.

Telling family members with von Willebrand disease or a rare clotting factor deficiency

Families with von Willebrand disease (VWD) and rare clotting factor deficiencies may not be aware they have a bleeding disorder especially if symptoms are very mild. News that your family might have one of these disorders can be met with surprise and concern.

“My immediate family learnt about mine and my child’s diagnosis at the same time as I was finding out. It was a bumpy road with a few false diagnoses but I really felt they were involved and experiencing it with me.”

Telling family members who may need to think about getting tested

If you are the first person in your family to be diagnosed with the altered gene for a bleeding disorder you might be faced with the challenge of explaining to other family members that they could have it too. Your siblings (brothers and sisters) will need to know that they may also be affected. They could have an undiagnosed bleeding disorder that has not previously been detected, or they could carry the gene.

Sisters with haemophilia or brothers and sisters with other bleeding disorders like VWD could carry the gene. Letting family members know gives them the opportunity to find out if they have the bleeding disorder or gene and whether that will affect their own health or their children’s health. The Haemophilia



On the other hand, telling family members might help them understand why they have had problems with bleeding such as frequent nose bleeds, heavy periods, or a tendency to bruise easily.

Parents who learn they may have passed the disorder on can feel guilty, particularly if their son or daughter’s symptoms are more severe than their own. Like so many conditions, your family’s reactions to your news will be influenced by what they already know about the bleeding disorder, and its impacts on the family up until now. Having accurate information about the condition helps. Your Haemophilia Treatment Centre, HFA or state/territory based Haemophilia Foundation is also able to provide information and support to family members at this time.

Treatment Centre can assist with information about who might be affected in your family, and can help you plan how to tell them. They can support all affected family members considering genetic or other kinds of testing.

In the meantime, think about how your family member would like to be given this news - for example, over the phone or in person, with other family members present or on their own. Learn what you can about the bleeding disorder and carrying the gene so you can answer their initial questions. Have information you can leave with them and let them know how to make contact with the Haemophilia Treatment Centre for the specialised testing they will need.