

Telling others about bleeding disorders

Information for women, girls and their parents



Telling others you or your daughter have a bleeding disorder or carry the gene that causes a bleeding disorder is something you will probably have to think about from time to time. Perhaps you already have. Sometimes telling others is straightforward, but there can be times when it's not so easy.

The following information can be used by women, girls and their parents to consider some of the issues about telling others (disclosure). It looks at some of the pros and cons of telling others, and presents a range of situations where disclosure might come up. There are suggestions on how to prepare, and what

information is most useful to share with others. It also talks a bit about protecting your rights, including your right to privacy.

Although **Telling others** has been prepared with women and girls in mind, it may also be useful for men with a bleeding disorder. Their daughters, sisters or nieces may be affected and sometimes they may be the best informed family member to take the lead in talking to them about what this means.

This information covers haemophilia, von Willebrand disease (VWD) and other rare bleeding disorders.

Tips for telling others

Knowing how to tell someone else that you have or carry the gene for a bleeding disorder might not be an issue for you. But it isn't always easy. Being prepared helps. You might find the following suggestions useful.

- Learn about your diagnosis so you can answer commonly asked questions. If you're not sure talk to your Haemophilia Treatment Centre to get more information.
- Wait until you are clear about the meaning of your diagnosis and you've had some time to come to terms with it
- Have up-to-date written information you can leave with the person you are telling
- Choose a time and place where you can talk openly without interruptions
- Practise telling them first – in your own mind, or with a friend, family member, or the haemophilia team social worker, psychologist or counsellor
- If it's someone close to you, give them the opportunity to talk to your Haemophilia Treatment Centre or your doctor, either with you or on their own
- Have a supportive person available who you can contact afterwards if you are telling someone important to you
- Think about what might happen if they tell other people – it might be helpful to talk to them about who else knows
- Give the person some time to get used to this new information about you
- Keep in mind that how you approach the discussion may influence how others react.

Why tell?

Why tell? - key points

- It is up to you whether you tell others about your bleeding disorder
- Telling others can allow the people around you to offer support and help when you need it
- You can take your time thinking about who you want to tell and how it might go. You might decide not to tell some people.

“Be proud! Haemophilia is nothing to be ashamed of. The more people know about the condition, the less likely they are to panic or make false assumptions based on their fear of the unknown.”

“Answer the questions asked – some will want reassurance, some will want their curiosity met. Now I try to read people's reactions to work out what they want to know. And I always try to leave them feeling that I've got this, it's not a drama, it's not a disaster.”

When you are thinking about telling someone, it can be helpful to ask yourself the following two questions: *How does the diagnosis affect this person?* and *Why do I want them to know?*

Often the answer to these questions depends on who the person is. You might want a friend or family member to know so they can give you the support and understanding you need. If you have bleeding symptoms you might want to tell a few key people so you will receive the right care in case of an emergency. If you are in a relationship you might feel your partner needs to know, especially if having children is a possibility. There's a range of reasons for wanting to tell someone. There's also a few reasons why you might want to think it through before disclosing.

Why wait to tell others?

In most cases, whether or not to tell others is up to you. Sometimes there are good reasons to think things through first. Concerns you might have about disclosing include:

- If you are worried your privacy won't be maintained
- Fear that the news will influence an important relationship, for example with a new partner or their family
- Not wanting people close to you to worry about you
- Not knowing how to tell others
- Worrying that you will be treated differently
- Not wanting other people to know your personal information.

Who might I think about telling?

The following sections look at some of the people you might consider telling, and some possible reactions to the news that you have a bleeding disorder or carry the gene.



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



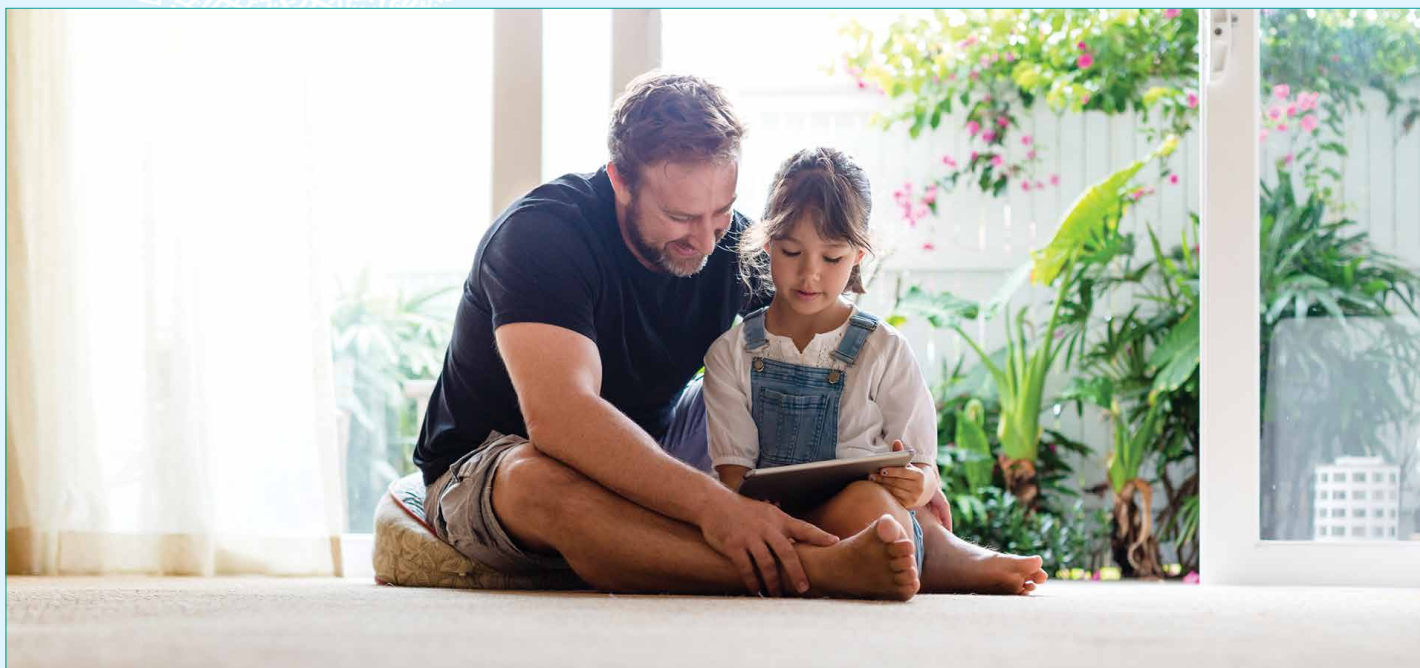
On the other hand, telling family members might help them understand why they have had problems with bleeding such as frequent nose bleeds, heavy periods, or a tendency to bruise easily.

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.

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. ”

Telling a new partner

Telling a new partner - key points

- Some people prefer to tell new partners about their bleeding disorder early in the relationship, while others prefer to wait until it starts getting serious
- Make sure you understand your diagnosis and have some information about your bleeding disorder so that you can discuss it with your partner and answer their questions
- If you have bleeding symptoms, it can be helpful to tell your partner before you have sex so they understand what is happening if there is bleeding
- Leaving it too long in the relationship to tell your partner about your bleeding disorder may cause resentment or mistrust
- If you might have children together in the future, you will need to be prepared for questions about how the gene is passed on and what impact it might have on the child
- Putting off telling your partner may not change how they respond – but it may make you worry for longer
- Speak with your Haemophilia Treatment Centre (HTC) if you would like support in telling your partner.



New intimate relationships can be an exciting time as you get to know one another and grow closer. But knowing if, when and how to tell a new partner about various aspects of your life can be difficult. This includes telling a new partner about having a bleeding disorder or carrying the gene.

Why might you want to tell a new partner? For some women having bleeding symptoms can affect sexual

activity. There may be bleeding during sex, or you may have heavy or prolonged periods, or want to explain how your treatment impacts on your body. You may want to talk about it in the context of having children together. It may also be important knowledge for them to have so that they know what to do in case of an emergency.



“ I’ve always been really open about my bleeding disorder. I explained it, and what it means for my life. It did kind of ruin the mood at the time however! ”

“ I have a port [surgically implanted device for infusing treatment product] on my side and it can be felt often. ”

“ I had a gum bleed midway through our first sexual encounter and he, understandably, freaked out and thought I was dying! ”

“ Telling a partner doesn’t always translate to them understanding. As with most things it’s not until you experience something that you really get it. I’ve had times when there’s the shock of seeing blood during sex and I remind them I have a bleeding disorder. That’s when they realise what it can mean. Open communication is so important in times like this. It’s an experience to see their coping skills, adaptability and grace under fire. ”

“ I don’t have normal periods, I have mid-cycle bleeds and erratic bleeding. So it’s not like I can easily plan for sex on a non-bleed day. And a new partner needs to be OK with experiencing blood and sex - for me having a bleeding disorder means sometimes these aren’t separate. ”



Most people within the general community don't have a lot of knowledge or experience of bleeding disorders, so your partner's initial reaction will probably be influenced by the information you give them and how you talk about it. You will need to explain what it means to have a bleeding disorder or carry the gene. Generally, people don't need loads of information the first time this comes up, but they may have questions for you or need some time to think about it. You don't need to be an expert in bleeding disorders, but it is useful if you're able to give your partner brief answers to their questions, or be honest if you're not sure.

“ Shame makes these conversations harder. We’re so used to hiding away the facts of our periods. Be calm and confident. Know in advance why you want to tell them and what you expect from them once they know. ”

If there is a possibility of having children together you will need to have this discussion at some stage, but you may wonder *when is the best time?* And *what will it mean for the relationship?*

This will include giving them information about the possibilities and options if you decide to start a family. They may want to know about some of the following:

- How does having a bleeding disorder or carrying the gene affect you?
- What are the chances of having a child with a bleeding disorder?
- How would having a bleeding disorder affect the child?
- How does a bleeding disorder impact on parents, and other children in the family?
- Are there options for reducing the chances of having a child with a bleeding disorder?

Make sure you are up to date with medical advances in the prevention and treatment of bleeding episodes, particularly if you carry the gene for haemophilia and don't have symptoms. Women who don't need treatment themselves can make the mistake of basing their information on how things were for their father, brother or other affected relative. Management of bleeding disorders has improved radically in recent years and continues to improve. The prospects for someone born with a bleeding disorder today are very different to those of someone born even a generation before.

Providing current information calmly will help your partner form their own responses. Try to stick to the facts rather than letting your fears and worries drive the discussion.



“I shared my status as a carrier with my partner pretty early on and am fortunate that he has never seemed worried or phased by it. I think he saw what a full and active life my Dad has and that has provided a great example, although he is also aware of the challenges it has posed for Dad.”

Concern about your partner's reaction can be a barrier to starting a conversation. Is it better to tell them 'up front', or do you wait until the relationship is on more solid ground? There is no magic answer to this question – it's an individual decision. You may prefer to tell a new partner early on. If they can't accept the news, in spite of your best efforts at explaining, it may contribute to you deciding not to pursue the relationship. It may feel easier to



let the relationship go before you both get more attached. Or you may decide to wait to tell until the relationship looks likely to continue. Leaving it too long into the relationship can cause resentment or mistrust, especially if you have already shared a lot about yourselves and your plans for the future.

Some women have found that one way of bringing it up earlier is as a discussion about preparing for an emergency, if you were going to be in each other's company for a while. If you have one, you could show them your ABDR card and explain what they would need to do.

Talking to your partner is the best way to find out what their views are on the possibility of having a child with a bleeding disorder. Some partners will accept the possibility, while others will have more negative reactions, which may not change, even with more information. Having different views about this or about family planning options can put a lot of stress on the relationship. Knowing your partner's views early on can help both of you make important decisions about the future of the relationship.

“Have an honest conversation, as it's not going to get any easier, because once you're pregnant, it could be too late. It will also add stress on the relationship if you didn't disclose it beforehand.”

All relationships have their challenges. Sometimes those challenges test the strength of the partnership. Putting off telling your partner probably won't change how they respond – but it may make you worry for longer.

“I was always scared when telling potential partners because of all things in the world the best I can offer is 50/50.”

“Remember you don't have to tell anyone you don't want to. It is your body, your condition and your right to tell people when you feel you are ready. However, opening up early, if it is going to be an ongoing relationship, does help navigate any uncomfortable or embarrassing situations.”

Make sure you understand your diagnosis before you tell a new partner so you will be better prepared for any questions and able to talk calmly. Choose an appropriate time and place to tell them and prepare in advance. See **Tips for telling others**, on page 2 of this resource. If you need help in preparing to tell your partner you can speak to a Haemophilia Treatment Centre counsellor, psychologist or social worker.

Once you've told them, your partner may feel like they have a lot to think about, particularly if having children is a possibility. It's a good idea to have current written information you can leave with them. Your partner might like to speak with members of the Haemophilia Treatment Centre team, or to a partner of someone else who carries the gene. This can usually be arranged by staff at the Haemophilia Treatment Centre.

“You need to be educated about the condition so you can educate. If you can explain it's less scary. There's a lot of stigma associated with it, a lot of people don't understand how much treatment has changed.”

“I told my partner early on but it wasn't a planned conversation. It was in the context of discussing my brothers' haemophilia so the conversation then switched to me.”

Telling your partner's family

Telling your partner's family - key points

- Wanting to be accepted by your partner's family is normal, and it might make telling them that you have a bleeding disorder feel more challenging
- Asking your partner to help explain the bleeding disorder to their family may help to take some of that pressure off you
- Reactions to news about your bleeding disorder will vary. Being informed yourself will help you answer any questions and ease their concerns
- Your partner's family may also be a great source of help and support
- If you find that your partner's family is having trouble accepting your bleeding disorder, seek support. Your Haemophilia Treatment Centre (HTC) may be able to help with this.

It can be a challenge to disclose to a partner's family that you carry a gene for or have a bleeding disorder. This is often tied in with a family's expectations about having children. It's normal to want to be fully accepted by your partner's family, so telling them you could pass a bleeding disorder on to their future grandchildren can feel hard.

If you have known for a while that you carry the gene, you and your partner might already have thought about whether to raise this subject, and the best way to go about it. But sometimes the topic will come up under more difficult circumstances, such as after the birth of a baby with bleeding problems. Family members will often want to know the cause of the baby's condition and you may feel some pressure to explain. This situation can be hard for you as the 'carrier'. Mothers of children with a bleeding disorder, particularly haemophilia, often feel guilty for passing on the condition, or worry that they will be judged by others for 'allowing this to happen'. Enlisting the support of your partner may help to take the focus off you as the 'carrier'.

“I don't think I had that conversation with them. My partner may have told them.”

“There may be times you need to rely on your partner to explain your bleeding disorder to emergency services, doctors, or even other friends and family. When the people closest to you are educated it provides a great safety net.”

All families are different and reactions to this news will vary from family to family. It's usual for there to be a degree of shock or even grief immediately following the diagnosis of a bleeding disorder in a baby. Family members may be worried about the baby's long term health and wellbeing, or anxious about how they will manage if they are involved in looking after the baby. Seeing you manage the care of your baby will help to reduce family members' concerns. Your ability to manage confidently will come with time and experience, and will show your partner's family that your much loved baby will grow and develop normally, and that they can be involved in the child's care too.

Up-to-date information about prevention and management of bleeding episodes can help to work through these concerns. If you're not sure how to talk about the condition with your partner's family, it might help to involve a member of the Haemophilia Treatment Centre team.

Your partner's extended family may also be a great source of help and support. Grandparents and extended family often play an important role in caring for children. These relationships can have a very positive influence on children's development.

Grandparents and other family members may find it valuable to connect to other grandparents and families through local Haemophilia Foundations. They might also benefit from attending a family or community camp or other social events run by the local Haemophilia Foundation. These events provide an opportunity for families to meet others in the same situation. They can share experiences and see the range of activities children with bleeding disorders participate in.

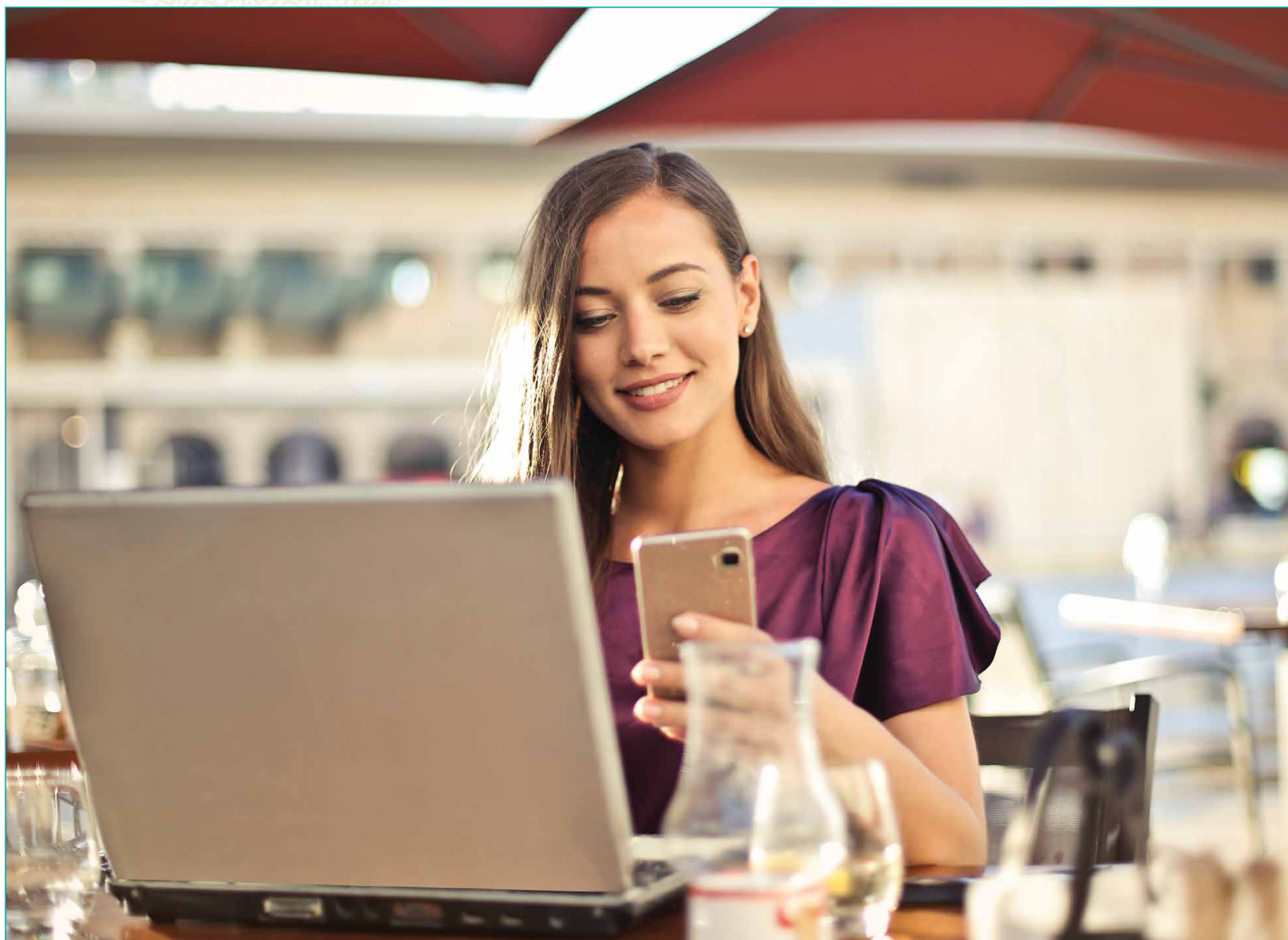


“ My husband's mum came to a Foundation afternoon tea and saw my friend's son who has haemophilia and was just beside herself, because he was scooting around, and he was just a little boy, totally normal, he wasn't covered in bruises and he wasn't in a wheelchair. It was a really important moment for them. ”

In a small number of families, health issues passed on through a parent, such as haemophilia, von Willebrand disease and other bleeding disorders, can influence whether or not a woman will be accepted into her partner's family. Obviously this can be extremely difficult for any woman in this situation. If you are faced with this, it is important that you get support. It may be helpful to speak with one of the counsellors or social workers at the Haemophilia Treatment Centre who can provide your partner's family with accurate information and can support you at this time.



Telling work



Telling work - key points

- You do not have to tell your employer about your bleeding disorder unless your health condition means there is a risk to workplace safety or you may not be able to perform the basic requirements of your job
- You may decide that it's best to tell your manager regardless of any risk, as it may help them to understand your situation and support you
- Disclosing your bleeding disorder to a chosen workmate may mean they are prepared to help you if you have a bleed at work and need medical assistance
- An ABDR patient card can be useful in emergency situations at work: it contains information on your bleeding disorder, treatment details and your Haemophilia Treatment Centre contact details, which can be given to hospital staff
- Before you tell people at work, find out what you can about workplace policies and attitudes
- Be informed about your bleeding disorder so that you can educate others
- Talk to your Haemophilia Treatment Centre (HTC) or union if you would like some help with disclosing your bleeding disorder at work.

Generally you are not required to tell your employer or a prospective employer that you have a bleeding disorder or carry the gene unless it is a risk to the safety of the workplace or you may not be able to perform the basic requirements of the job. There are exceptions, for example, if you're applying to the Australian Defence Force or police force. These exceptions are explained in more detail in the section **What does the law say**, on page 27.

Sometimes it's easier for everyone involved if you don't volunteer information unless asked, but you might decide that it's in your best interest to do so, particularly if you have a bleeding tendency.

“ I didn't see any need to tell them as it wasn't going to affect my work. ”

You may prefer some people at your workplace to know for support. For example, explaining to your manager or a workmate that you have heavy or painful periods might help them to understand what's going on for you, especially if you need extra breaks or time off work. It will also give your employer the chance to make changes to your job so you can continue to work as a productive member of a team, for example, using an option of flexible working hours or working from home.

Having someone look out for you and knowing what to do in an emergency might also be a reason to disclose if you have bleeding symptoms. You might need to discuss what to do if there is an accident or injury. You can start by explaining that you're able to look after minor cuts and bruises, but for something more serious you may need their help. Explain that if there is a head injury or other serious knock an ambulance should be called, and you should be taken to hospital. Tell them this is important even if there is no sign of blood, because unseen bleeding inside the head or body can cause serious problems. Let someone know if you have an ABDR patient card so they can show it to the paramedics (ambulance drivers) or emergency department staff. An ABDR patient card has your bleeding disorder, treatment details and your Haemophilia Treatment Centre (HTC) contact details on it – talk to your HTC about getting one if you have bleeding symptoms.

“ I told my current boss who knows I'm a carrier as she was asking if I knew about my son's condition before he was born. She has been supportive and lets me have a phone in case I get called as I explained that if the hospital calls then I have to go. ”



Susie's story

Susie is not new to telling others about her bleeding disorder. As someone with von Willebrand disease, and as a parent of a child with VWD, she has had to advocate for herself and for him on occasion. But after an accident at work she realised there could be times when she might have to rely on others to do the talking for her.

'I fell down the stairs at work. When I came to a stop I realised I couldn't move. I couldn't call out. I could barely even breathe.' Work colleagues came to her aid. They acted quickly and worked through what had happened and what she might need. As the plans progressed and it became clear that she needed medical assistance, the value of disclosure became clear. Susie's manager, who was also the section's first aid officer, already knew what was important in this situation.

'My manager and I had already had many conversations about VWD. We'd talked about my son with type 3. She had supported me when

I needed to take time out for appointments and when I'd needed to field calls from my son's teachers. And these conversations weren't intrusive. They were caring, based on the facts of my situation, my needs at the time and on her needing to know what might be required of her in just such a situation.'

These conversations formed the basis for her manager's quick actions. 'My manager knew to take the extra step of calling the HTC. She spoke with the Haemophilia Nurse to report my injuries and work out a plan.'

Susie had always thought of her conversations with her manager as a way of looking after her own needs. It was later she realised that it was also about looking after her manager. 'By having these conversations I was helping her to do her job properly.' Disclosing at work allowed Susie to gain valuable emotional support but it also made the difference when she couldn't speak up at a vital moment.

'I had already learned to be my own best advocate. But crucially, sometimes you need to plan and have contingencies for others to advocate for you.'



Before you disclose at work, it's important to judge what response you think your employer will have. If you work for a large organisation there should be workplace policies in place that you can check to get an idea of the organisation's approach and the level of support you can expect. If you work for a smaller organisation that does not have clearly stated policies it can be a bit harder to know how the news will be received.

Before disclosing, you could consider getting the help of your doctor, the social worker or counsellor or other health professionals at your HTC, or your union if you think your boss will react negatively, or if you just want some pointers. There are numerous state/territory and federal laws that protect against discrimination in the workplace if you disclose your status and are treated unfairly because of it.

However, some preparation and experienced advice might help you avoid a negative situation occurring.

If your bleeding disorder is not going to impact on your work, you may prefer to take your time and think carefully before you tell your employer or workmates. Remember – once you have told people, you can't take it back and you will have little control over who they tell.

“ Take time to sit people down and explain that firstly this is personal... that you are not embarrassed or upset you simply want them to understand what it means and what to do if an emergency arises. ”

Tina's story



Deciding whether to tell work about having a bleeding disorder can be tricky. If you do decide to let them know – when and how do you do it? Tina found out the hard way that sometimes it requires a bit of preparation.

Her first experience of telling her employer arose after she had an accident at work. Up until then work wasn't aware she had a bleeding disorder. 'I had to tell work because I had haemorrhaged and had to leave. I was branded "unreliable". Then I had to have a week off because I was passing clots the size of my fist which my boss knew about because it was happening at work. Despite medical certificates my boss decided I was not committed. I was on a short term contract which wasn't renewed so I lost my job'.

Once Tina got the medical care she needed from the Haemophilia Treatment Centre she was much better prepared to deal with it, and to talk about it in her next job. 'It turned out I was anaemic and was put on tranexamic acid [treatment in tablet form]. I got better once I knew what was going on. I was able to explain it to my current boss, and she knows it's under control. She has been supportive and understands that if my son has a bleed I need to leave'.

Taking steps to look after herself and getting the information she needed was a turning point for Tina. 'You need to be educated about the condition so you can educate. If you can explain it's less scary'.

Telling your daughter's school and carers



Telling your daughter's school and carers - key points

- If your daughter has a bleeding disorder, you will need to let her school know and help them put together an 'action plan' in case of an emergency
- Make sure the information in the action plan is kept up-to-date and that you are confident the school knows what to do
- You may want to talk to your daughter about the pros and cons of telling friends at school
- If your daughter experiences bullying or other problems because of her health condition, speak with her school about it
- Anyone caring for your daughter, such as babysitters, will need to know what to do in case of an emergency. It may also be important to explain why she has bruises.
- Some parents have an emergency plan with contact numbers that they leave with babysitters or carers
- Your Haemophilia Treatment Centre (HTC) can help with information for the emergency/ action plan and with educating your daughter's school.

Telling school

If you are the parent of a girl who carries the gene, and who has a bleeding tendency, you will need to let the school know. This is so they can develop a personal or 'action' plan in case of an emergency. In some schools they may need to prepare a more detailed student health support plan. Make sure you keep this information up-to-date, and that you're confident the school knows what to do in case of an injury or emergency. Your Haemophilia Treatment Centre (HTC) can help you develop a plan and can provide information to give to your daughter's school. The medical information you give to the school, including a copy of her ABDR patient card if she has one, should remain confidential. If you're worried about this, ask the school what they will do to protect your daughter's privacy.



“ School teachers, family and friends now know the best thing to do is to stay calm, commence standard first aid treatment, as you would for any other child in regards to a nose bleed or a cut and that for more urgent matters call an ambulance and give them her treatment details. ”

If you have a daughter who carries the gene you might want to talk with her about the pros and cons of telling school friends. On the one hand she may find it helpful to have one or two friends who know what's going on for her. On the other hand friendships can change rapidly in school so she may want to take her time deciding whether to tell and who to tell. Privacy can also be an issue as news can travel fast in the school environment. Very occasionally kids with health conditions can be the target of bullying. If this happens to your daughter consider contacting the school to discuss how this can be addressed.

“ I have a standard letter I give to any new care giver, be it the school or a new parent who asks my child to have a sleepover. It explains in simple terms what haemophilia is, what to do, and finally that it's OK – that I am comfortable with people knowing. ”

Telling early childhood services

If it's possible your daughter has a bleeding tendency it's important that you inform her Pre-School or other Early Learning or Care Service provider. Well-informed staff will recognise when they need to take action if there is an injury or emergency. With the help of the HTC, you can develop a management plan so your daughter is properly looked after until you're able to step in. If your daughter bruises easily it may be helpful to talk openly about this – parents of children with bleeding disorders who have bad bruises have occasionally been suspected of child abuse. Accurate information from the outset can avoid this situation.

“ I can honestly say that not one person has shied away or that my child has been excluded from parties, sleepovers or sport because I ensure that people are at ease. If you are open and explain it in simple common terms people simply say 'oh OK, no problem – I get it'. ”

Telling babysitters

People taking responsibility for your daughter would need to know what to do in an emergency if she has a bleeding tendency. Let them know but reassure them they do not need to treat her any differently, unless there is an injury. If she bruises easily you can explain this, so they know this is normal for her. Some parents have an emergency plan with steps to take and numbers to call and leave this in an accessible place, such as on the fridge or next to the telephone.

“ The other parent did not raise a sweat and it was not awkward. We had the conversation and they were happy to know what to do. ”

“ I have had various conversations with her school teachers, dancing instructors, sports teachers, family and friends to explain the condition. From the outside she does not look 'different' to any other child, however, when you mention bleeding disorder, their faces change. ”

“ People, given the right information about our condition, are no longer nervous. ”

Ask your HTC to help you with the emergency plan. They will have samples you can use and can make it specific to your daughter.

Telling sports teams or coaches

Regular exercise is recommended for us all. If you or your daughter has a bleeding tendency you may wish to let the coach or trainer know what to do in case of injury. The haemophilia nurse or physiotherapist at your Haemophilia Treatment Centre can tell you if there are any additional precautions you or your daughter should take and what you need to let others know about.

For more information about sport or exercise, visit the HFA website: (www.haemophilia.org.au) and the *Factored In* website: (www.factoredin.org.au).

Telling health workers

Telling health workers - key points

- Bleeding disorders are rare so many health professionals may not have experience with them or know much about them.

If you have bleeding symptoms:

- Always tell your doctor, dentist or surgeon that you have a bleeding disorder before you have any medical, dental or surgical procedures, no matter how minor. Ask them to liaise with your Haemophilia Treatment Centre (HTC)
- Being prepared, knowing about your bleeding disorder and taking information along with you will help you to communicate with these services.

Bleeding disorders are rare and many doctors, nurses, dentists and other health professionals may not have encountered them before in their practice. Understanding the impact of bleeding disorders on females is also quite a new area and your health professionals may not know, for example, that both males and females can have bleeding symptoms with haemophilia. It is important to have some personal strategies to help manage your health care when you are using services outside of the Haemophilia Treatment Centre (HTC).

The following tips give examples of strategies some Australian women with bleeding symptoms have used when communicating with health workers:

- Make sure you know what type of bleeding disorder you have and ask the Haemophilia Treatment Centre (HTC) to organise an ABDR (Australian Bleeding Disorders Registry) patient card for you. Show your other doctors, dentist, and other health care providers your ABDR patient card and ask them to liaise with your HTC.



- Consider wearing a medical alert bracelet or jewellery and having an ICE (In Case of Emergency) number in your mobile phone.
- Always inform your doctor, dentist or surgeon that you have a bleeding disorder before having any medical, dental or surgical procedures, no matter how minor.
- Take copies of information booklets, such as the HFA **The Female Factors** resources, to the appointment to help with the discussion.
- Before you have any procedures, contact your HTC and discuss the medical support you may need to prevent bleeding complications.
- Before you start taking anything prescribed by your doctor, naturopath or other health practitioner check with them whether it is safe for someone with a bleeding disorder.

For more information about working with health care professionals to manage your bleeding disorder, see The Female Factors booklet, **A snapshot of bleeding disorders in women.**

What does the law say about disclosure?

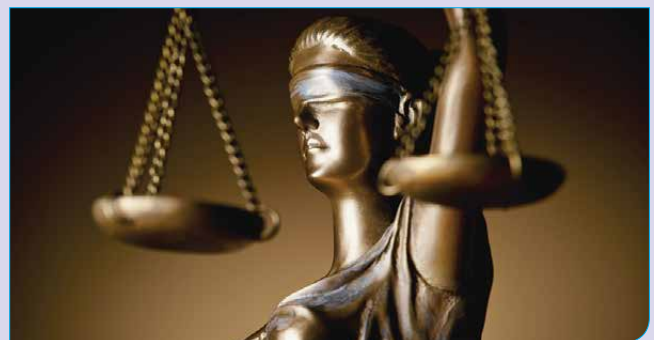
The law and disclosure - key points

- By law you don't usually have to tell anyone about having a bleeding disorder or carrying the gene
- There are a few situations where you will be required to give this information *if asked*.

These include:

- ▶ Applying to join the Australian Defence Force or police force
- ▶ Applying for insurance such as Life and Income Protection Insurance
- ▶ Applying for superannuation
- ▶ Applying for private health insurance
- ▶ Applying for travel insurance
- ▶ Travelling – you may be asked questions relating to your bleeding disorder by customs and security officers or other government officials.
- ▶ Applying for or continuing a job where your condition is likely to have a fundamental impact on your ability to do your work or may pose a risk to occupational health and safety

- If you are unsure whether you need to disclose your bleeding disorder it may be helpful to speak with your Haemophilia Treatment Centre (HTC)
- If you do choose to tell an employer or service provider, by law they are not able to discriminate on the basis of your condition apart from the exceptions above
- If you need information on discrimination you can contact your state or territory Equal Opportunity or Human Rights Commission, or contact The Australian Human Rights Commission (www.humanrights.gov.au). You can also contact your Haemophilia Treatment Centre, local Haemophilia Foundation or Haemophilia Foundation Australia.



By law you don't usually have to tell anyone about having a bleeding disorder or carrying the gene. Your diagnosis is seen as your private information and it's up to you whether to tell someone. There are, however, a few situations where you *are* required by law to give this information if you are asked.

Do you have a 'health condition'?

If you disclose, it is important to be clear about whether you have been diagnosed with a bleeding disorder, e.g. VWD or haemophilia, or whether

you carry the gene but do not have symptoms. Usually organisations that ask questions about health conditions, such as insurers or employers, are assessing risk and will treat having a bleeding disorder differently to being a carrier. You may not be required to tell your employer that you are a carrier if you do not have bleeding symptoms as it is not considered a 'health condition'. If you have any questions about your status, speak to your Haemophilia Treatment Centre (HTC).

You are required to disclose if you are:

1 Applying to join the Australian Defence Force (ADF) or state/territory/federal police forces. The ADF and the police force have very strict medical entry requirements. Members may be sent to remote locations where access to appropriate treatment may not be available, and members may be in active service where the risk of injury is increased. You must provide the ADF or police force medical officer with information about any known health condition so they can make a decision about how relevant it is. If it's not disclosed and causes a problem you can be discharged from the ADF or police force.

2 Applying for insurance such as Life and Income Protection insurance. The law requires anyone applying for life and disability insurance to disclose all matters that are reasonably known to be relevant to the insurer's decision about whether to accept the risk. Some insurance companies will ask about pre-existing health conditions or genetic testing. You will need to answer questions honestly. If you do not answer honestly and the cover is granted the company may be entitled to refuse to pay any subsequent claim and void your cover entirely, even if the cause of a claim is unrelated to the matter which was not disclosed. Insurance companies can ask about results of any genetic testing already undertaken but cannot request that you get this done. If you are refused insurance, or the premiums you are asked to pay appear unreasonably high because of your condition, you can appeal the decision. If you have an insurance claim rejected for any reason you may be able to challenge the decision. If you want to challenge or appeal the decisions, legal advice is recommended.

3 Applying for superannuation. Most default superannuation funds provide contributing members with automatic life and disability insurance under a 'group' insurance policy. These benefits can be tens of thousands of dollars and cover is generally granted without having to answer any questions about pre-existing

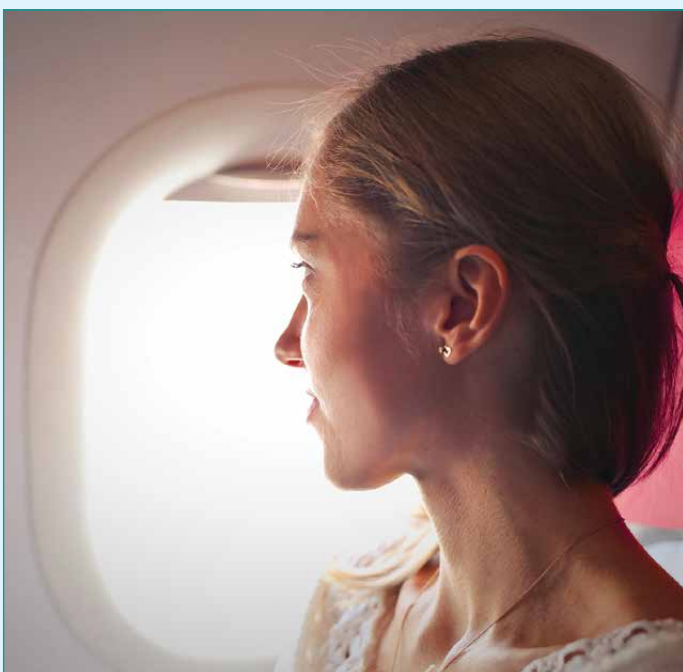


health conditions. Claims caused by pre-existing conditions will usually be covered as long as you have worked normal hours without restriction while you were a member of the super fund. It's important to check your superannuation statements to make sure your contributions are being made and your insurance is maintained so that you remain covered in the event that you cease work due to injury or illness. Self-managed or private superannuation is different from group superannuation and is often used by people who are self-employed or not in regular employment. You can still get life and disability insurance through these funds but the insurer is likely to ask health questions to which you are required to answer honestly. Some schemes will cover you if you haven't needed any treatment for a certain length of time.

4 Applying for private health insurance. Even though private health insurers may ask about pre-existing medical conditions they cannot charge a higher premium based on your medical history, including results of genetic tests.

5 Applying for travel insurance. If you are applying for medical and disability cover under travel insurance you may need to fill out a health questionnaire. You will need to complete this honestly or you might not be covered if you try to make a claim. It's often worth shopping around to see what information is required and what options there are. Some insurers who ask about pre-existing health conditions will allow you to pay a higher premium for travel insurance. If you have an insurance application or a claim rejected because of your pre-existing medical condition you may be able to challenge the insurer under the discriminations laws but that will depend upon whether the insurer can justify its decision.

6 Travelling: At the time of travel you will also need to answer any questions from government officials, such as customs and security officials, about any medication or equipment, but only if asked or you are required to declare it. Airlines and officials may choose not to raise it with you. Read the airline's fine print about their requirements relating to your medical condition and any medical treatment products and equipment you will be taking with you – this information is usually on their website. Speak to your HTC ahead of time to prepare the necessary documentation and have it in your hand luggage just in case.



7 Applying for, or continuing in a job where your condition is likely to impact on your fundamental ability to carry out the work, or if your condition is an occupational health and safety risk. You do not have to disclose your medical condition to your employer or a prospective employer unless it is a risk to the safety of the workplace or you cannot perform the inherent requirements of a job. Sometimes it's easier for everyone involved if you don't volunteer information unless asked. There may be situations at work when you decide it is in your best interest to speak up – see the section above, **Telling work** for more information on this. If you're not sure whether your condition should be disclosed you should speak to your Haemophilia Treatment Centre. However, employers are able to refuse employment if it is considered reasonable to do so based on these concerns. If you don't mention your bleeding disorder when asked on an application form and an accident occurs, you may not be entitled to legal protection. However there are numerous state/territory and federal laws that protect against discrimination in the workplace if you disclose your status and are treated unfairly because of it. Under the Disability Discrimination Act, Anti-discrimination, and Industrial Relations laws employers are required to make 'reasonable adjustments' to accommodate an employee's condition, for example, providing you with a work station that reduces the chance of a bleeding injury through repetitive movements or knocks.

If you are a woman or girl with bleeding symptoms you may want to get further specialist advice about disclosure and applying for any of the above insurance products, and about legal aspects of disclosure in the workplace. If you would like to talk over these issues or get information, it may be useful to speak to the social workers or counsellors, or other health professionals at your Haemophilia Treatment Centre. You can also contact your local Haemophilia Foundation, or Haemophilia Foundation Australia.

For insurance issues, including superannuation and travel insurance, you might also consider going through an insurance broker who can apply on your behalf. If you apply yourself and are turned

down on a product, this can count against you with other applications. For concerns about legal aspects of disclosure at work, including workplace discrimination, you may want to speak with a lawyer or your union representative. If issues arise you may be eligible for free legal assistance through Legal Aid.

“ I had to tell work as I had haemorrhaged and had to leave. I had to explain to my boss. However, she didn't believe me and I lost my job over it. ”

Apart from the above exceptions, you are not required by law to tell future or current employers, teachers, landlords, or other service providers. If you do choose to tell an employer or service provider, by law they are not able to discriminate on the basis of your condition. For example, if a sporting club is worried about you injuring yourself they cannot use your condition as a reason for not allowing you to participate.

If you would like more information about discrimination you can contact your state or territory Equal Opportunity or Human Rights Commission, or contact The Australian Human Rights Commission (www.humanrights.gov.au). You can also contact your Haemophilia Treatment Centre, local Haemophilia Foundation or Haemophilia Foundation Australia.



A final word

Deciding *who, when and how* to tell others about your diagnosis are important decisions. Usually you are not *required* to tell anyone, but you might *decide* it is in your best interest, or someone else's. Before you tell someone think about the pros and cons, and the best way to tell them. Make sure you're well informed so you can give others accurate information. Contact your Haemophilia Treatment Centre if you need information or support along the way.

Sources

Haemophilia Foundation Australia publications

<www.haemophilia.org.au/publications>:

Bleeding disorders and hepatitis C: My choice to tell – family, friends, new partners. Melbourne: HFA, 2009

Bleeding disorders and hepatitis C: My choice to tell – at work. Melbourne: HFA, 2009.

A guide for people living with von Willebrand disorder. Melbourne: HFA, 2010

Living with mild haemophilia: a guide. Melbourne: HFA, 2011

The Female Factors: A snapshot of bleeding disorders in females. Melbourne: HFA, 2016

Haemophilia: a guide for parents of a newly diagnosed child. Melbourne: HFA, 2017.

Other publications:

Australian Haemophilia Centre Directors' Organisation. Guidelines for the management of haemophilia in Australia. Melbourne; Canberra: AHCCDO; National Blood Authority, 2016. <www.blood.gov.au/haemophilia-guidelines>

Australian Human Rights Commission. Disability discrimination. Sydney: AHRC, 2014. <www.humanrights.gov.au>

Chronic Illness Alliance. WorkWelfareWills. Melbourne: CIA. Accessed 26 July 2018 <www.chronicillness.org.au/workwelfarewills/>

Hepatitis Australia. Disclosure of hep C status. Canberra: Hepatitis Australia, 2013. <www.hepatitisaustralia.com>

World Federation of Hemophilia. Rare clotting factor deficiencies. Montreal: WFH, 2014. <www.wfh.org>

Acknowledgements

Written by Marg Sutherland, health educator.

Quotes and personal stories in this resource were contributed by Australian women with a bleeding disorder or who carry the gene and the parents of girls and women. We thank them for their generosity in sharing their experiences.

Thanks also to the HFA Women's Consumer and Health Professional Review Groups for their suggestions on topics and content to include.

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More information

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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.

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