

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 scootering 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.

