

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.

