

LIVING WITH MILD HAEMOPHILIA

“There’s a line in the poem ‘Desiderata’ – ‘Beyond a wholesome discipline, be gentle with yourself’. I would not be able to express it any better. The key: get on with life; enjoy your wife, children, friends, work, holidays.”

“If you get to know other people with mild haemophilia and their families, you can see for yourself that it is a manageable condition and there are people there to help you through this.”

“In the last few years I have been involved with a support group and I have derived a great deal of pleasure from it. It’s good to be aware that you’re not the only one out there with a problem.”

CONNECTING WITH OTHERS

Although mild haemophilia may only affect people at certain times in their life, people with mild haemophilia and parents of children often comment that it is helpful to talk to others in a similar situation and know that they are not alone. Haemophilia Foundations are a great way to connect with others and share experiences on managing mild haemophilia.

State and Territory Haemophilia Foundations have:

- Newsletters and web sites to update people with bleeding disorders and their partners, families, friends and carers
- Social activities where people can meet, talk about common experiences and enjoy a meal or a day out, such as family camps, Christmas parties, men and women’s groups, grandparents’ groups.



Haemophilia Foundation Australia also supports:

- A youth program run by young people affected by bleeding disorders
- Internet-based communities and social networking sites for people affected by bleeding disorders.

TRAVEL TIPS

Plan ahead! Travelling is a wonderful opportunity for activity and adventure, and it can be much more enjoyable if you are prepared for all possibilities:

- Talk to your Haemophilia Centre beforehand if you are travelling interstate or overseas. They can help you prepare depending on your individual situation. They can also advise on documentation, medication and travel insurance
- Discuss with your Haemophilia Centre if you need to take treatment with you
- You may not need them, but just in case, find out the contact details of Haemophilia Centres along your route
- You will need to obtain travel insurance for overseas travel
- Consider telling your travelling companions what to do to help you in case of an emergency
- With airplane and overseas travel you may need further documentation to carry medication and treatment equipment through security and customs – talk to your Haemophilia Centre about this well in advance and allow plenty of time to prepare the documentation.

Useful travel web sites:

- Smarttraveller – www.smarttraveller.gov.au
- World Federation of Hemophilia Passport (global treatment directory) – www.wfh.org
- Medicare Australia (Travelling Overseas section) – www.medicareaustralia.gov.au

MOVING INTERSTATE OR OVERSEAS

Let your Haemophilia Centre know if you are moving interstate or overseas. They can help with making sure your medical information and treatment plans are passed on to the Haemophilia Centre where you will be living. Your Haemophilia Centre or HFA can also advise on the Haemophilia Centres available.

Once you arrive in your new location, it is important to see your new treatment team and register as soon as possible. Your new treatment team will want to understand your particular situation and health needs. They will prepare a new treatment plan and discuss how your treatment can be managed locally. As most people with mild haemophilia do not need treatment very often and may only need treatment in an emergency, it will be immensely valuable to be prepared and prevent delays in getting appropriate treatment if an emergency occurs.

Getting to know other people affected by bleeding disorders in the local community can be important to understand how things work and feel connected. There are State and Territory Haemophilia Foundations in most parts of Australia and haemophilia community organisations around the world. Contact HFA or check the HFA web site for information on local haemophilia organisations.

SPORT AND OTHER ACTIVITIES

Physical activity and regular exercise have great benefits for everyone. For people with mild haemophilia it can be a way to keep muscles and joints strong and even prevent injuries and bleeds.

Being active and healthy can be a balance between taking on physical challenges and preventing injuries. Ask the Haemophilia Centre team for advice on sports and other physical activities and the risks involved, based on your individual health and situation.



If you have mild haemophilia, participation in sport is a positive way to mix with a wide range of people, enjoy the physical aspects of life, control weight and maintain physical fitness which will help to reduce the risk of injuries.

Improving muscle development and increasing skill levels at sport can protect joints and prevent injuries and bleeds. At the same time, individuals may find that for them certain sports or activities are more likely to result in bleeds.

Generally children and adults with mild haemophilia need to try out different sports and physical activities that they enjoy to see what they can and can't do. Many take part in all kinds of sports. In most cases, using current safety guidelines and protective equipment means that people with mild haemophilia can participate in the same sports as their friends – which is especially important for children as they grow up. The main concern is the risk of head injuries. Extreme contact sports, including wrestling and boxing, are a high risk for severe injury and are generally not recommended. If you have questions about the suitability of a sport or activity, check with the Haemophilia Centre.

You may wish to advise a sports coach what to do in case of injury.

Further reading: The book *Boys will be boys: a guide to sports participation for people with haemophilia and other bleeding disorders* by Brendan Egan (Melbourne: Royal Children's Hospital, 2005) has valuable information about participating in sports and preventing injury. Available from HFA and Haemophilia Centres.

WORKING

Most people with mild haemophilia will be able to follow their chosen career.

Mild haemophilia will not usually impact on your work. There may occasionally be problems if jobs are very physically demanding, involve repetitive movements or standing for long periods or cause workers to knock parts of their body. If you find you are having unusual elbow bleeds, aching muscles or neck, swelling and bruising (haematomas) from knocking against equipment, or any other problems, contact your Haemophilia Centre for advice. They may be able to suggest suitable protective equipment or give other suggestions to manage the problems.

An exception to this is the Australian Defence Force (ADF), which has very strict medical entry requirements based on the potential need to send staff to remote locations and for them to be involved in active service. If you have mild haemophilia, you are obliged to disclose your health condition to the medical officer when you apply for entry so that a decision can be made about how relevant it is. If it is not disclosed and causes a problem, you can be discharged from the ADF.

Who should I tell at work?

If your situation changes - you start a new job or are diagnosed with mild haemophilia or have some related health problems – you may find you have to think about telling others in your workplace about your haemophilia. In most cases, whether or not to tell others is entirely up to you.

If mild haemophilia is not going to impact on your work, you may prefer to take your time and think carefully before you tell your employer or work colleagues. You may be in a better position to understand when and where it may be relevant once you are more familiar with your workplace or with your diagnosis – but once you have disclosed, you will have little control over this personal information.

If mild haemophilia is relevant to your work, or questions are asked on your employment application, it may also be worthwhile to look more closely at what the job entails and why the questions are asked.

When you are thinking this through, you may find it valuable to talk it over with the Haemophilia Centre, who can advise you on your situation and provide supporting documentation if necessary. They can also give suggestions on plans to manage emergencies.

“I let HR and Reception know that if I’m injured or unconscious to ring an ambulance. And I’m prepared – I make sure there is an ice pack in the fridge at work.”

INSURANCE AND SUPERANNUATION

Some insurance and superannuation companies will ask questions about pre-existing health conditions, including bleeding disorders, in their policy application forms.

You will need to answer questions honestly if questions about health conditions are asked in insurance policies. If you do not provide this information, the company can refuse to pay any claim on the policy where your bleeding disorder is a contributing factor. If you are refused insurance or premiums are higher, you can appeal the decision.

Familiarise yourself with the income protection insurance available under your superannuation. You may decide to take out more cover to provide for a future emergency.

Different companies have different options, so shopping around for your best option could be beneficial. Read the insurance policy carefully and don’t hesitate to seek advice before completing it. It may be useful to speak to your Haemophilia Social Worker or Counsellor or HFA for more information.

SCHOOL AND CHILDCARE

Having mild haemophilia will not usually affect your child’s ability to attend school. Most bleeding will be the result of normal schoolyard injuries and can be managed with standard first aid. However, it is always possible that a more serious bleed could occur and key staff at the school may need to learn how to identify a more serious situation and how to manage this.

Well-informed day care and school staff can be very helpful. It is important that they have the facts about mild haemophilia, but that the information isn't over-dramatised and any false fears are allayed. You may find it useful to organise information sessions for staff at day care or school – Haemophilia Centre staff are usually very experienced in this and happy to assist you. Your child may or may not want to educate their classmates – most young people want to be treated normally, so the value of this would depend on each individual situation.

- When they are old enough, your child needs to know how to handle their own common bleeding problems, such as nosebleeds. If the child is very young, a staff member will need to learn how to manage them
- Provide the day care centre or school with information on mild haemophilia and how to manage your child's condition
- It is important that the day care or school staff can contact parents or guardians at all times, in case of emergency. It may also be helpful to provide the telephone number of your child's Haemophilia Centre.



What about babysitters?

Generally those taking responsibility for a child with mild haemophilia would need to know what to do in case of an emergency. If bleeding symptoms are rare, you may decide not to tell them specifically that your child has mild haemophilia. However, if your child bruises easily, it may be helpful to be open and talk matter-of-factly about your child's haemophilia with the babysitter: parents of children with bleeding disorders who have bad bruises have occasionally been suspected of child abuse and some accurate information can make this less likely.

FRIENDS AND NEW PARTNERS

It can be valuable if some close friends, partners and family members know about your or your child's health conditions. They can give you or your child support at times of health problems or concerns, or if others are being negative or unhelpful. If they know what to do in emergencies, they can watch out for you or your child and help to deal with accidents or injuries.

However, sometimes there can be negative reactions when you tell friends, family members or new partners. They may be upset or have inaccurate beliefs about bleeding disorders or be overly concerned for your or your child's health. They may tell other people you wouldn't have chosen to tell. New partners may be concerned about what it means for them or any children you may have together in the future.

These negative responses can happen because many people know little about bleeding disorders and sometimes have preconceived ideas about them. It can be worth remembering it is not a reflection on you and you are not responsible for their reaction.

When you are considering whether to tell someone it can be helpful to ask yourself whether mild haemophilia will impact on them and why they need to know.

Preparing to tell others

- Learn about mild haemophilia and your own health situation first, so that you can answer any questions. If you are not sure, talk to your Haemophilia Centre
- Bear in mind that your knowledge and attitude to haemophilia will influence how others understand and accept it
- Have some accurate printed information ready to give them to read in their own time
- Practice telling them first – in your own mind, with a friend or with a social worker or counsellor
- Choose a time and place where you can take some time and talk openly and safely
- Give them the opportunity to talk to your health care team for more information
- Have a supportive person you can contact 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.

New partners

If you are beginning a new relationship, the decision if, when and how to tell your new partner about your bleeding disorder might require some thought.

Your new partner may have a lot to think about, particularly if there is a possibility of having children together in the future. They may appreciate the opportunity to talk to your Haemophilia Centre team or to talk to a partner of someone else with mild haemophilia.

When to tell? It is up to you:

- You may prefer to tell a new partner early on. It may make no difference or even bring you closer together. But if they can't accept the news, it may feel easier to let the relationship go before you both become attached
- You may prefer to wait until the relationship has progressed and looks likely to continue. You may feel you need to know them better to have an idea of how they might react or whether they would respect your privacy.

If you would like to talk this over or get information, you can talk to the Haemophilia Social Worker or Counsellor or ask the Haemophilia Centre to refer you to a counsellor. The Haemophilia Centre, HFA or your local Haemophilia Foundation can also help with finding others in similar situations to talk to.

“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.”

“Growing up, I found it difficult to get a grip on my condition without someone like a counsellor to talk about my thoughts and concerns.”