

## LIVING WITH MILD HAEMOPHILIA

*“Mild haemophilia makes you unique, rather than different. Be proud of your uniqueness!”*

Most people with mild haemophilia find that with awareness and planning their bleeding disorder has little impact on them. They can live full, active and independent lives.

At various stages of life, issues relating to mild haemophilia can arise for a person or their family. It might be about how to help a child play and have fun while dealing with potential bruises or bleeds. Or it could be dealing with situations or emotions like feeling overwhelmed by diagnosis, or that you or your child is somehow different from others, or taking the next step in a personal relationship.

These are some suggestions put together by people with bleeding disorders, parents and Haemophilia Centre teams:

### TIPS FOR LIVING WELL

#### **You are not alone**

- Stay in regular contact with your local Haemophilia Centre and make sure you keep up with anything new. The Haemophilia Centre team is there to help and can give you advice or talk over any problems or concerns
- Keep in touch with your Haemophilia Foundation for updates on new information and to share experiences and enjoy a chat with others who know what it's like.

#### **Be informed and aware**

- Know what type of haemophilia you have: haemophilia A (factor VIII deficiency) or haemophilia B (factor IX deficiency)
- Learn how to prevent bleeding and how to deal with it when it happens
- Make sure you and your family are aware of early warning signs of potentially serious bleeds, such as bleeds in the head

- If you use treatment product, know which one you use
- Your Haemophilia Centre team can help with learning about bleeds and how to manage them
- Ask the Haemophilia Centre team for advice on sports, work and other physical activities and how to manage any risks involved, based on your individual health and situation.

### **Tell other health professionals that you have a bleeding disorder**

- Let your dentist or your doctor know you or your child have a bleeding disorder
- Advise your Haemophilia Centre team in advance of planned medical or dental procedures so that any procedures such as surgery, childbirth or dental procedures that may result in bleeds can be managed in liaison with the Haemophilia Centre team
- Keep the treatment wallet card from your Haemophilia Centre on hand. Show it to your or your child's other doctors and dentist and ask them to liaise with your Haemophilia Centre
- Consider wearing a medical alert bracelet and having an ICE (In Case of Emergency) number in your mobile phone

### **Control and manage risks**

- You or your child can live a normal active life, but everyone's experience is different. Know your limits and plan around them.

### ***Enjoy what life has to offer!***

