

Tips

These are various tips and tricks that other parents have found work for them.

- Just treat the kids normally. Don't wrap them up in cotton wool. Let them do what they want, using commonsense. But keep an eye on them from a distance.
- What I've found (is that) all kids are different, so are the parents.
- Read all the information you can get your hands on and don't stress too much.
- Speak to other families. Everybody remembers the diagnosis and share with others.
- Select reading material carefully – take advice of others. Use the Haemophilia Foundation for support.
- Be clear about the treatment process. It took us 18 months of bleeds to learn what was best for our son.
- Use all support that is offered to you.
- Guilt is unnecessary.
- Life goes on and you need to accept that you cannot change things.
- Don't panic, especially the first time you need to take your child to hospital for treatment.
- You are not alone. It is tough at times. Lots of worries at times, but it can be controlled and life can be normal to a certain extent.
- Try and relax and be calm. However, allow yourself time to adjust and be reassured all is fine and it is very manageable.
- It's hard to understand because you can't see it in the child. But he is still a beautiful, fun-loving, gorgeous child and all will be well and manageable. Everything has a reason and is all positive. You're not alone ever!

- Take things day by day and life will be great.
- I suggest to anyone to contact the Foundation for support and understanding.
- You may not know much now, but it's just like learning to drive a car. At first you're nervous but before long you're an old hand at it.
- Lots of other people have gone through this too and most are more than willing to help.
- One day sooner than you think, you will look at your little boy and totally forget he has haemophilia. It won't always dominate your thoughts and he will seem 'normal' to you again once you know how to manage the disorder.
- Don't baby your child. If he falls, don't make a big deal of it. Let him be the one to say (when he can talk, or by his actions) when he needs treatment. Act calmer on the outside than you may sometimes feel.
- All the knowledge in the world can't beat experience.
- The irregular/emergency bleed stage does finally stop and life does return to normal on prophylaxis.
- Get as much knowledge as you can so that the theory can support you. Once you know what to look for and what to do when you find it, you're okay.
- When you know what you're doing, don't let Emergency Centre doctors push you around.
- Don't read grizzly stories of treatments in the past without first learning about current treatment procedures.
- Be confident in your 'gut feelings' – parents know their child better than the doctors.
- Always wear seatbelts in the car.
- Keep parking money handy for unexpected hospital trips.
- Encourage your child to wear a MedicAlert or Talisman.
- Doctors and nurses don't listen to hysterical parents. Keep calm.
- Don't be secretive when talking about haemophilia. It's okay to have it.

- Don't believe everything you hear about haemophilia from people who are not experienced. There are many misconceptions about this condition.
- Don't be frightened by the experiences of other parents. There is no typical person with haemophilia – your child will not necessarily have the same problems as another.
- Treat all bleeds early to avoid long term joint damage.
- Build up a relationship with the staff at a Haemophilia Centre who can provide information, care and support. If you are far away from a Centre, choose a GP you can trust and who is prepared to liaise with the Haemophilia Centre.
- Retain your sense of humour.

Tricks

- Keep a piece of paper handy. Every time you have a question, write it down. Come appointment time, you won't forget to ask anything.
- Keep a diary record of your hospital visits including the doctor's name, treatment given, time waiting and responses to treatment. It can all quickly blur together otherwise.
- Use Emla cream before an injection to numb the area.
- Leave phone numbers of where you will be, the Haemophilia Centre etc with babysitters, daycare staff and teachers.
- Relieving stress can help reduce bleeds. A relaxed and happy person with haemophilia often has less bleeds.