Top tips for parents



Having a child who has been newly diagnosed with haemophilia is a worrying time for any family. Whether you have a family history or not, this condition is a daunting one.

Normally diagnosis occurs in a baby - a baby who will soon be, or already is, mobile - bumping and falling as they learn to crawl and walk and do all the things babies do!

This can lead to a great deal of anxiety for parents, who are not only desperate to keep their little bundles safe but also need to learn all about what it means to have a bleeding disorder.

The following top 10 tips for a newly diagnosed family should help ease some of the anxiety of those early days post diagnosis.

1. Ask questions

No matter how small or trivial they sound, ask your HTC. They will have the answers and there is nothing worse than second guessing.

Have a question list in a notepad at home all the time, so if something springs to mind you can jot it down and take it along to your next appointment.

That way you can also jot the answers down in the same place and refer to them later.

2. Research

Knowledge is power. Equipping yourself with a full understanding of haemophilia and what it means medically will give you a great basis for your future.

Research treatment options and make sure you know what to look out for when it comes to bleeds. You will become an expert before you know it.

3. Share your knowledge

Share your knowledge with anyone who plays a role in your child's life. Extended family and close friends need to be as involved as they can and have an understanding of the condition.

They will feel more confident in being around your child if they understand Haemophilia and know what to look out for, and you will feel more relaxed knowing they have that knowledge.

4. Take one day at a time

Looking too far into the future can be overwhelming. Take things one day at a time.

Getting through each day after diagnosis can be tough but focusing on the here and now will help you and as time passes the future will become less daunting.

Together For Life

To find out more, visit **haemophilia.org.uk** or contact us on **020 7939 0780** or at **info@haemophilia.org.uk**

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5. Adapt your house

Some people say there is no need to make adaptations to your house but if you feel more relaxed with edges padded and foam mats galore then go for it, every little helps in terms of protection for your little one.

Also, your child will pick up on your worry so if padding your house out helps with your anxiety as well as protecting your child, then it's a win win.

6. Create 'safe zones'

Create some places where your child is safe. Whether it is their cot with safe bumpers, a bouncy chair or a travel cot as a play pen, just having a few areas in your house where your child can be safe and sound when you need 5 minutes is a godsend.

Having these safe areas is fantastic for your baby's protection and for your sanity! It's impossible to watch them all the time!

7. Go for a walk

Pop your baby in the buggy and go for a walk! Fresh air is brilliant for both of you and a walk is a brilliant time to clear your head.

While you get exercise your little one is taking in the world around them from the safety of their pushchair.

8. Remember siblings

If this is a scary time for you, imagine what it is like for an older brother or sister who isn't quite sure what is going on. Include them, teach them and embrace them.

They are part of this journey and a very important part at that. They will be there to protect their sibling and they need to understand Haemophilia just like everyone else.

9. Use social media

It is unlikely you will know anyone else with Haemophilia unless it runs in your family. Social media is a brilliant place to meet other parents going through what you are.

Join forums and discussion groups, search relevant hashtags and follow organisations. These are all brilliant places to ask questions and find support from others who have been exactly where you are.

10. Join the Haemophilia society

From a website bursting with information to fantastic events including Newly Diagnosed weekends, the Haemophilia Society are the only charity dedicated to bleeding disorders in the UK and will help you on your journey.

Tips courtesy of The Woods family @ haemophiliamama_uk