



Inherited Bleeding Disorders (IBD) Team

Carers of a child with an IBD – All About You

Information for Parents and Carers

Introduction

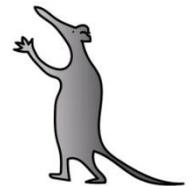
This leaflet aims to provide you with general information about support for you as the carer of a child with an IBD. If you are ever worried about your child please contact your IBD Team or take your child to the Accident and Emergency Department.

Information for carers - all about you

Your child has been diagnosed with an inherited bleeding disorder (IBD).

This diagnosis might have been expected, known to be a possibility or unexpected. However it is that you become aware of your child's diagnosis it can leave you with a mix of emotions and wondering about treatments and day to day practicalities. Sometimes these feelings and thoughts don't hit you as soon as your child is diagnosed but appear, sometimes unexpectedly at a later date.

The IBD nurse specialists are here to provide you with support, advice, information, education and training when you need it.



Support

Shortly after diagnosis we can put you in contact with another family whose child has the same condition. It can be helpful to talk to other families to find out about their experiences and how they manage their child's condition at home.

The nurse specialists are happy to arrange a time to see you outside of your child's routine clinic appointments.

We routinely have three planned informal family events each year with other activities arranged periodically. Although arranged by the IBD team the events have developed at the request of the families we work with. These are opportunities to meet other families and share tips and ideas from parent to parent and child to child.

David Lloyd gym, where parents and carers chat while the children join organised activities.
A weekend camping in Wales

A Christmas show followed by lunch

The Haemophilia Society <https://haemophilia.org.uk> can provide further information and support. They run weekends away for families with children who have been newly diagnosed with an IBD as well as other activities.

Often families find support through social media, such as the Haemophilia Society Facebook site.

Practical support

There may be a time where you are unable to treat your child due to illness, ongoing poor health, or you simply need a break. If this happens please contact the IBD nurse specialists. We can talk together about the best way for us to provide support.

Each year we will send you a newsletter with service and treatment developments and updates as well as activities scheduled for education, training and support.

We ask you for feedback on the service with an annual questionnaire. The results from the questionnaire help us to provide the service you want.

At times you may need more than we can provide and we can refer you on to other services including:

- Genetic service for information, testing or genetic counselling
- Adult haematology service if you are having any bleeding problems
- Psychology services
- Any other services you feel will help you

Haematology Nurses: 8.30am-5.00pm 0151 252 5070

Nicki Mackett: 07584 234 526 nicki.mackett@nhs.net

Catherine Benfield: 07876 132 163 catherine.benfield@nhs.net

This leaflet only gives general information. You must always discuss the individual treatment of your child with the appropriate member of staff. Do not rely on this leaflet alone for information about your child's treatment.

This information can be made available in other languages and formats if requested.

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