

Advice for the parents and carers of children with severe inherited bleeding disorders

Other formats

If you need this information in another format such as audio tape or computer disk, Braille, large print, high contrast, British Sign Language or translated into another language, please telephone the PALS desk on 01271 314090.

How to get help

During working hours, ring Bristol Children's Hospital, as the team there will be able to offer advice both to you and to us in advance of your arrival.

If your child has had an injury, administer a dose of factor as soon as possible and, if you can, bring a supply of factor with you.

If she/he has had a severe injury, a head injury, an abdominal injury or is still bleeding then you should go straight to the Accident and Emergency department at North Devon District Hospital. If possible, please let staff on Caroline Thorpe ward know you are on your way.

If your child has less serious symptoms and you think your child needs to be reviewed on Caroline Thorpe Ward, please ring us on the number overleaf.

You will be able to recognise some potential problems in your child, such as a joint bleed or an obvious injury. Occasionally, however, unusual symptoms can occur which you should be aware of.

Symptoms to look out for

If your child experiences any of the following, you must take him/her to the Accident and Emergency Department at North Devon District Hospital or to the nearest Accident and Emergency Department:

- A head injury
- A swollen, painful joint or muscle which limits your child's ability to move around
- Blood in their urine or poo (this may not look like fresh blood, but more like tar)
- Coughing up or vomiting blood
- A persistent nosebleed or bleeding from the mouth
- A severe or sudden headache

- Unexplained drowsiness
- Severe back pain, especially if they cannot straighten their leg because of pain.
- Pain in their tummy
- In babies and children who are not yet talking, refusal to eat, irritability or drowsiness which can indicate a bleeding episode.

Useful telephone numbers

North Devon District Hospital 01271 322577

Caroline Thorpe Ward nurses' station 01271 322704

Non-urgent queries:

Dr Rebecca Rub 01271 322628

Dr Jason Coppell 01271 349198

Bristol Royal Hospital for Children switchboard 0117 9230000

In-hours paediatric haemophilia clinical nurse specialists:

Anna Farrell / Caroline Roberts 0117 342 8721

Mobiles: 07747 004 996 / 07920 545 620

Email: anna.farrell@uhbristol.nhs.uk / caroline.roberts@uhbristol.nhs.uk

Out of hours, ring the BRHC switchboard and ask for the paediatric haematology / oncology doctor on call.

Reference

Emergency and out-of-hours care for patients with bleeding disorders – standards of care for assessment and treatment. Approved by UKHCDO advisory committee April 2009.

PALS

The Patient Advice and Liaison Service (PALS) ensures that the NHS listens to patients, relatives, carers and friends, answers questions and resolves concerns as quickly as possible. If you have a query or concern call 01271 314090 or e-mail ndht.pals@nhs.net. You can also visit the PALS and Information Centre in person at North Devon District Hospital, Barnstaple.

Have your say

Northern Devon Healthcare NHS Trust aims to provide high quality services. However, please tell us when something could be improved. If you have a comment or compliment about a service or treatment, please raise your comments with a member of staff or the PALS team in the first instance.

'Care Opinion' comments forms are on all wards or online at www.careopinion.org.uk.

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