



Inherited Bleeding Disorders (IBD) Team

Home Treatment Clotting Factors

Information for Families

Introduction

This leaflet aims to provide you with general information about starting treatment at home with clotting factors. If you are ever worried about your child please contact your IBD Team or take your child to the Accident and Emergency Department.

Home treatment with replacement clotting factors. When will you be ready?

Home treatment brings with it the opportunity to give prophylaxis before daily activities and treat injuries promptly, minimising pain and reducing the risk of long term joint and muscle damage. Giving treatment at home is less disruptive to family life as the journeys to and from the Haematology Treatment Room become less frequent.

Readiness for home treatment is different for each family. There is no rush for you to take on this clinical role we will go at your pace.

For some, learning the practicalities of giving treatment is priority while for others a detailed understanding of the bleeding disorder is felt important before thinking of administering treatment. For many the biggest challenge is imagining accessing your child's veins or port a cath.

We aim to work with you as you gradually take over the clinical management of your child's bleeding disorder. We do not want your independence from the Haematology Treatment Room to leave you feeling isolated or feeling solely responsible for making tricky treatment decisions.

The aim for all the children is the same:

- To minimise acute, damaging and painful joint and muscle bleeds
- To maximise school attendance
- To maximise safe participation in activities

Most children with severe and moderately severe bleeding disorders receive full prophylaxis by the time they start infant school.

Home delivery

Along with our pharmacy team we work with a home delivery company to ensure that you have prescribed treatment delivered to you at home. Deliveries are usually made every 8 or 12 weeks and can be made to you at home or to an alternative address of your choice.

We will ask you to complete a registration form which is then sent along with a prescription and ancillaries list to the homecare company. The home care company will contact you to check your requirements, schedule a delivery and explain to you the process of placing your next order.

Giving replacement clotting factor

We will take time to help you learn how to give treatment. We do most of the training in the Haematology Treatment Room (HTR) but we know that giving treatment at home is different to the hospital environment so we will also come to your home to help you to start giving treatment there. We will also help you to find the best place to store treatment and equipment.

We prefer there to be more than one person who is able to give your child treatment. The second person does not have to be a family member, but it does need to be someone you can trust.

How much treatment to give

Prophylaxis and treatment doses are recorded in the Treatment Plan from your most recent clinic letter

The same information is written on the prescription that comes to you with your home treatment delivery. You should record each dose on Haemtrack.

Treatment and Port-a-caths (ports)

Most children with severe bleeding disorders not eligible for subcutaneous medication need a port so that they can have regular treatment.

Ports are put in in theatre under anaesthetic

Ports are usually implanted in the chest wall and are particularly helpful for infants and small children providing a larger target where small veins make giving treatment difficult

Ports make treatment at home possible at an early stage

Ports can be used for several years and ideally are not removed until treatment can successfully be given into veins at home.

Training to give treatment through a port includes learning how to use mix treatment, put a needle into a port safely as well as how to use a sterile technique.

Treatment and butterflies

Butterflies are used to give treatment into small veins in the arms hands or feet

Once your child's veins are big enough and you have mastered the technique, this is the ideal way to give factor as prophylaxis or for a bleed

Self-infusion

Learning to give factor is an on-going process. Children learn as they watch you at home and us in the Haematology Treatment Room.

We can provide 1:1 training from 7 years of age onwards.

Our aim is to for your child to be confident to self-treat by the beginning of high school.

Recording treatment

It is important for all treatment to be recorded as soon as possible after it is given. This helps you to make sure prophylaxis is given regularly and also shows when extra doses of treatment have been needed for injuries or joint or muscle bleeds.

Haemtrack is an electronic recording system which is accessible through the Haemtrack phone app or website that is used across the UK. It helps to build a picture of whether we are prescribing the right dose and frequency for prophylaxis and shows us any difficulties with joint and muscle bleeds or injuries.

As part of your preparation for home treatment we will give you an information leaflet about Haemtrack and once you have had the opportunity to read it and with your consent we will show you how to use the system.

**If your child is injured or may have a bleed
Use usual first aid first! PRICE and then give replacement clotting factor.**

Injury: If your child is injured and the injury is not settled quickly by usual first aid and PRICE prepare and give treatment, do not wait to see if a bleed develops

Spontaneous bleed: At the area of suspected bleed if your child describes discomfort or an odd sensation or there is restricted or painful movement, tenderness on touch, heat or swelling do not delay, start PRICE and prepare and give treatment at the earliest opportunity.

Protect and (pain killers). Make sure your child is in a safe place and that the injured or painful area at risk of being knocked, paracetamol may be needed to help the pain to settle

Rest- Rest the affected joint or muscle. If your child has an elbow or shoulder bleed the arm should be rested and not used to lift or carry things. If the bleed is in to a joint or muscle in the leg rest as much as possible, no walking.

Ice- Apply ice, wrapped in a towel, or a cold pack to the affected joint either by using an ice pack, crushed ice in plastic bag or frozen vegetables, apply for 10-15 minutes. Ice helps to reduce pain and muscle spasms as well as reducing swelling and redness. Ice alternating with heat can also help to reduce pain, particularly when the bleed is into a muscle.

Compression- Applying pressure to the injured area will help slow blood flow; the pressure can also provide comfort. A Tubigrip bandage is a good example of compression and can be used over the knee, ankle, elbow or wrist. Compression is often too painful in the early stages of a bleed.

Elevation- Raise the injured arm or leg above the heart although this may seem difficult you can prop an arm and leg up with cushions or pillows. This helps to reduce the blood flow to the area and lower blood congestion to slow the bleeding.

Please let the IBD team know if your child has had an injury or had a spontaneous bleed so that we can help you to develop a treatment plan. If you continue to be concerned after giving treatment or are unable to give treatment please go straight to the accident and emergency department where possible taking your treatment with you.

Links

The Haemophilia Society website <https://haemophilia.org.uk/>

Alder Hey Children's NHS Foundation Trust <https://alderhey.nhs.uk/>

Contact Information Haematology Nurses 8.00am-5.00pm 0151 252 5070 with answer machine. Queries will be reviewed by the end of the next working day.

Sharon Thind: 07584 234 526 sharon.thind@alderhey.nhs.uk



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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