



Inherited Bleeding Disorders (IBD) Team
Home Treatment with Emicizumab
Information for Families

Introduction

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

Prophylaxis at home with Emicizumab **When will you be ready?**

Hemlibra (Emicizumab) is a manufactured therapeutic antibody that can be used as prophylaxis for boys affected by severe haemophilia A or haemophilia A with inhibitors. Prophylaxis reduces the risk of spontaneous bleeding into muscles and joints. Emicizumab is given under the skin (subcutaneously) weekly, two weekly or four weekly depending on clinical indication.

Emicizumab is ONLY used as prophylaxis.

Oral tranexamic acid and sometimes intravenous factor VIII (8) will be needed for

- Joint and muscle bleeds
- Nose and mouth bleeds;
- Surgical or dental intervention

You will keep tranexamic acid and two doses of factor VIII at home in case they are needed for an acute bleed.

Bleeding into muscle and joints can be extremely painful and can lead to long term mobility difficulties particularly when there have been repeated bleeding episodes.

Haemophilia management with emicizumab reduces the risk of bleeding and, once you are ready to give at home is less disruptive to family life as the journeys to and from Hospital 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.

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

All children with severe haemophilia are on 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 emicizumab

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 if needed 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.

Self-treatment

We like to teach children to treat themselves as early as possible and definitely before they start high school. Children learn as they watch you at home and us in the hospital. We can offer 1:1 training or support parents in training their child to self administer.

Recording treatment

It is important for all treatment to be recorded as soon as possible after it is given. If an extra dose of factor is required due to a bleed, please record this also.

Haemtrack is an electronic recording system which is accessible through the Haemtrack phone app or website that is used across the UK.

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 son has injured himself or you think he has a bleed

Use usual first aid first! PRICE

Ensure you have your factor concentrate and tranexamic acid in case it is needed.

Protect and (pain killers). Make sure your son 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 you son has an elbow or shoulder bleed he should rest his arm and not use it to lift or carry things. If the bleed is in to a joint or muscle in his leg he should not walk but rest as much as possible.

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.

If the symptoms of a possible bleed continue please contact the nurse specialists for advice. Where they are unavailable please go straight to the accident and emergency department taking one of your two doses of emergency factor VIII with you.

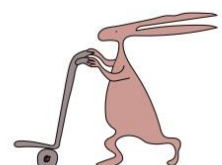
Links

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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