Royal Manchester Children’s Hospital

Cervical Operations Requiring Halo Vest Fixation For Children With Mucopolysaccharidosis

Information For Parents and Carers
Why does my child need a halo vest system?

If your child’s Doctor sees certain changes in their neck bones and spinal cord they may plan to do an operation to try and prevent or slow down further deterioration. This is a planned operation, which involves a general anaesthetic, with a period of recovery on a neurosurgical ward. The halo vest system is used to stabilise the cervical spine (neck bones), or correct their alignment following this operation.

The halo vest system can be a little frightening for both you and your child when you first see it in place, this information has been written to help answer questions and prepare you in advance.
What is halo vest system?

A halo vest system is a special piece of equipment which is made up of three parts, these are:

1. A rigid plastic vest, which has a sheepskin lining.
2. A ring (halo) which goes around the head, which is attached via pins to the skull.
3. Four support rods which join the vest to the halo.

Once the halo vest system is fixed, it is on for approximately three to four months in order to allow fusion of the neck bones to take place and protect the spinal cord from any damaging movement. After this time an X-ray will be taken to look at the position of the bones. The halo vest system can be worn whilst having X-rays or MRI (magnetic resonance imaging) scan.

The halo vest system equipment is made from material that is strong and light so it is easy for your child to move around.

Are there any risks?

If left untreated this condition could result in further damage to your child’s spinal cord. Once the halo has been fitted any knocks to the halo can be painful; therefore boisterous activity should be avoided. The bars should not be pulled in any circumstances.
What happens before the operation?

You will be given an appointment a few weeks prior to your child’s planned surgery date to see the Orthotist. They will measure your child for the correct size of halo and vest system; this will be their named halo vest system. This early appointment allows time for the vest, which comes as two separate pieces, a front and a back, to be altered to accommodate any spinal curvatures, and any devices for delivering medication or food, for example a central line or gastrostomy. Once any alterations have been made, the halo vest system will be stored at the hospital and taken to the ward prior to your child’s surgery date.

You will have received information in your child’s admission letter about how to prepare your child for the operation. Please bring larger clothing that fastens up the front or down the back, as putting clothes on over your child’s head is difficult once the halo vest system is in place.

Please bring any medicines your child is currently taking to hospital when they are admitted.

We will try to admit your child the day before their surgery date as this will allow the final preparations to take place, such as a visit from the Anaesthetist (the Doctor who administers the anaesthetic in the operating theatre).

Your child should not have anything to eat or drink for the specified amount of time prior to surgery; the nursing staff on the ward will inform you of this. It is very important that you follow these instructions otherwise your child’s operation may have to be delayed or even cancelled.

The Doctors will explain the operation in more detail, discuss any worries you may have and ask you to give your permission for the operation by signing a consent form. If your child has any other medical problems, particularly allergies, please tell the Doctors about these.
A bed on the Intensive Care Unit (ICU) is required as standard procedure even though it may not be needed. The Consultant will check the availability of such a bed on the morning of the surgery. Unfortunately there is no guarantee that a bed will be available due to emergency admissions, if this is the case your child’s operation will be postponed to a future date.

**What happens after the operation?**

If your child does not require admission to the Intensive Care Unit they will return to the neurosurgical ward to recover.

When your child returns from the operating theatre there will be a red bag containing an emergency spanner; this should accompany your child wherever they go as it may be needed in an emergency to remove the halo vest system. This should only be performed by a qualified Doctor, with previous experience of the halo vest system. The ward Doctors will advise you what to do and where to go if any of the pin sites become loose after discharge home.

Your child will have been given some pain relief at the end of their operation, so they should not be in pain when they wake up. The Nurses will regularly make sure that your child has enough pain relief to keep them comfortable. If you feel that your child is in pain, please let the Nurses know.

A Physiotherapist will come to see your child after the operation, to offer help and advice regarding moving around the bed, and subsequently sitting, standing and walking. Your child’s vision will be restricted as they can no longer turn their head to the side or look down to see objects that may be on the floor. Your child will need to take extra care because of this.
Learning to look after the halo vest system equipment

Once your child has recovered from the operation, the ward staff will show you how to manage and care for the equipment. This will include:

**Looking after the pin sites**

Following the operation the pins will be cleaned with saline solution and checked twice daily to ensure that they are secure and tight. The ward staff will instruct you how to perform these procedures.

**You must never pull on the support rods that join the halo ring to the jacket as this will cause tension on the skull pins.**

When your child is discharged home you should check the pins and use cooled boiled water to clean the pin sites on a daily basis as directed by the ward staff. If you have any concerns regarding the pin sites such as oozing, pain or if the pins become loose you should contact the ward or your GP for advice.

You will be given an appointment to return to the ward one to two weeks after your child’s discharge so that the halo can be checked.

It may take you and your child some time to get used to the halo vest system. If you have any questions, either whilst your child is in hospital or after they go home, please speak to a member of the ward staff. Contact details are given on page 11 of this leaflet.

**Vest care**

A sheepskin liner must always be used inside the vest. You will be given a spare sheepskin liner; the Nurses on the ward will show you how to change it. The sheepskin should be kept dry at all times, if it does get wet, it will need changing.
**Skin care**

Skin care underneath the sheepskin is difficult. Your child will not be able to have a bath or a shower, but areas that you can reach should be washed and dried every day.

**Hair washing**

The easiest way to do this is whilst your child is lying on the bed, using an inflatable hair washing device (like a small paddling pool, which drains the water via a pipe into a bucket placed under the bed). These can be purchased online at various websites such as www.essentialaids.com, www.amazon.co.uk, www.mobilitybuddy.co.uk or from high street pharmacies such as Lloyds Pharmacy. Cover the sheepskin to make sure it does not get wet during the process. Try not to knock the pin sites as this can be painful and may cause them to become loose.

**Clothing**

Clothing will not pass over the head and halo. Clothing/nightwear that fastens either up the front or down the back is advisable, short sleeved items are easier to manage. Clothing which is a size or two bigger than usual is helpful as there is more room to accommodate the vest and the support rods. Some families have bought larger T-shirts, cut them up the back then sewn Velcro to fasten them. Lower body clothing should not be affected.
Sleeping

Depending on your child’s underlying condition, turning in bed will require assistance from an adult. It will take time to adjust to sleeping with the halo equipment on. Using one or two pillows for support should make your child more comfortable. When your child needs to get out of bed, they should roll onto one side and then use their arms to push upwards into a sitting position, if they are able to do this. Children with mucopolysaccharidosis (MPS) usually require assistance from an adult to help them turn and get out of bed.

Diet and eating

At first, the sensation of swallowing may feel different as your child will be unable to move their neck and it may take a little time for your child to adjust. Your child will also find it difficult to see their food. A height adjustable table could be useful to assist mealtimes.

Getting Moving

If your child already has a wheelchair or buggy, you should bring this to the hospital so that we can assess its suitability for use with the halo and vest system. The strength of your child’s muscles prior to surgery, together with the effects of the MPS will affect how your child moves around after the operation.

During their stay in hospital, the Physiotherapist will see your child after their operation to help them adjust to the halo vest system. Once they have recovered from the surgery your child will be encouraged to sit with support, firstly in their bed and then in a chair.

If your child was able to walk before surgery, they may be initially unsteady after surgery as they need time to adapt to the halo vest system. We may offer a walking frame to assist walking in the initial phase. Stairs and street kerbs are better negotiated sideways.

Your child should continue to use an appropriate car seat and wear a seatbelt in the car.
School

If you are worried about how your child is going to cope at school, please speak to the Doctor, Physiotherapist or Nurse.

Your child should be gradually re-integrated back into school. Your child should not take part in physical education (PE), games, swimming or any other ‘rough and tumble’ activities whilst wearing the halo vest system.

It is advisable that any outdoor time at school should be supervised such as break times and lunchtimes. An appropriate wheelchair or buggy may be used.

Your child may find it difficult to read or work at a level desk. An angled work surface or laptop may be helpful.

Removing the halo vest system equipment

Your child will need to come back into hospital in order to have the equipment removed. They will have X-rays to check that everything is healing satisfactorily before it is removed and replaced with a collar. A collar is used as the neck bones are still changing shape for the next six months. In addition the neck muscles may initially feel weak as they have not been used normally while the halo vest system was fitted. A general anaesthetic is not usually required to remove the halo.
After the halo and vest system has been removed your child will need to:

- Wear the neck collar **all day for 4 weeks**, however, the collar can be removed at night for sleeping. After this period of time the collar can be removed for a short period each day whilst your child is sitting quietly, for example when watching television, you can gradually increase the time out of the collar over the next few weeks. The collar can be removed at night for sleeping.

- Wear the collar all day **at school for 3 months**.
- Wear the collar in the car or for **travelling for 6 months**.

You should call the hospital if:

- The pin sites ooze or bleed or become painful.
- The pins become loose.
- The equipment becomes broken or loose.

**Contact details**

If you need any advice following surgery please contact the nursing staff on **Ward 78 on telephone number 0161 701 7800.** They are available 24 hours a day.
No Smoking Policy
The NHS has a responsibility for the nation’s health.
Protect yourself, patients, visitors and staff by adhering to our no smoking policy. Smoking is not permitted within any of our hospital buildings or grounds.
The Manchester Stop Smoking Service can be contacted on Tel: (0161) 205 5998 (www.stopsmokingmanchester.co.uk).

Translation and Interpretation Service
Do you have difficulty speaking or understanding English?

आपनी कि इंग्लिशतै बुझते किंवा बुझाते परेयें ?  (BENGALI)
क्या आपको अंग्रेजी बोलने या समझने में कठिनाई है ?  (HINDI)
तमें भाषा हर्दिं है तत्पर फरखान मुख्तारी कल्याण हो ?  (GUJARATI)
वि डाउनट्रेट अंग्रेजी चेहरा वापस न्यायिक विषय है ?  (PUNJABI)
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