

Advice after heart surgery

Information for parents of young people with congenital heart disease



Leeds children's
hospital

caring about children

LEEDS CONGENITAL
HEARTS

Wound Care

The wound site should be kept clean and dry to make sure healing continues.

Normal washing and bathing is allowed but it is advisable not to soak the wound for the first four weeks after surgery. Your child can have a shallow bath or shower (standing with their back to the water) avoiding washing the wound. Ensure that the wound is dried thoroughly by gently patting. We advise that you avoid using creams or lotions on the wound.

Protect the wound from direct sunlight as this can hinder healing and may make the scar more noticeable. In time the scar should fade to a fine line.

Contact the Cardiac Nurse Specialists or Ward L51 if the wound shows any sign of the following:

- Redness or swelling
- Discharge of any kind
- Increased pain.

If any wound care or removal of stitches is needed after you go home this will be arranged with your GP's surgery or a community nurse.

Signs and symptoms to look out for

Your child will have an appointment in the cardiology clinic around two weeks after discharge home. This will include a scan to check there is no fluid around the lungs or heart.

In the meantime, please contact us immediately (via the Nurse Specialists or Ward 51) if your child has any of the following symptoms, as it may be a sign there is a problem:

- Increased breathlessness
- Loss of colour
- Severe tiredness/lethargy
- Persistent dry cough
- Vomiting repeatedly
- Fever

Discomfort

Should your child suffer any discomfort on discharge home, mild pain relief, e.g. paracetamol (syrup or tablet) may be given.

This can be obtained over the counter from your local chemist.

If your child continues to complain of pain/discomfort for more than a couple of weeks contact your GP for advice.

Medicines

You will be provided with a two week supply of any medicines your baby/child needs when you go home.

It is important that you do not run out.

You will be given a letter for your GP (and one for your pharmacist if the medicines will need to be ordered specially), make sure you give these to them straight away so they know which medicines they will need to prescribe/dispense. The letters are not a repeat prescription; you need to see your GP for this.

If your baby is under six months you will need to sterilise the syringes that you use to give the medicines.

We do not advise you mix medicines into bottles/drinks as your child may not receive the full dose.

It is important that medicines are given at the right time.

What if my child vomits after having medicines?

You may repeat the dose of medicine if your child has a large vomit within 15 minutes of having the dose.

Do not repeat the dose if it is longer than this as it is impossible to know how much will have been absorbed.

If in doubt **do not** repeat the dose.

Give the next dose of medicine at the normal time.

If vomiting persists contact your GP.

Activity

Normal mobility should be resumed as tolerated but care must be taken not to damage the wound site by strenuous activity.

Very few children need to restrict their exercise. You will be told of any restrictions by your consultant. Please encourage your child to become involved in normal activities in school and at home.

Your child should not return to school for approximately six weeks from discharge, which is usually around the time of their consultant appointment.

Physical sports such as football, netball, etc should be avoided for at least six weeks, to prevent injury to the wound site.

Swimming can be recommenced after four weeks if the wound site is completely healed.

For further advice about activity contact:

Sarah Hibbert

Specialist Physiotherapist

Tel: 0113 392 6361

Email: sarah.hibbert3@nhs.net

Food and drink

Children

Generally children with heart problems do not need to follow a special diet. Like all children their meals should be well balanced and include fresh fruit and vegetables. The family health visitor or practice nurse can offer advice on healthy eating.

Babies

You will only be discharged from hospital once feeding has been established; this may mean a short stay at your local hospital before going home. Your health visitor will be informed on discharge and will continue to monitor your baby's progress and give advice on weaning.

If your baby has been started on high energy feeds or calorie supplements you will be given a small supply to take home and you will need to obtain further supplies on prescription from your GP.

The dietitian from your local hospital will usually be involved in your baby's care after discharge if she/he is on a high energy formula or calorie supplements.

Immunisations

Unless you are told otherwise we strongly recommend that your child follows the normal immunisation programme. Allow four weeks from any surgery before recommencing immunisations.

Sleep

It is quite normal for the sleep patterns of young children to be affected by a stay in hospital. They may need extra reassurance and comfort at night for a short period of time.

Infective Endocarditis

Most patients with congenital heart disease are at increased risk of getting endocarditis. It is a rare infection of the inner lining of the heart. To prevent this infection a healthy diet, good dental hygiene and regular visits to the dentist are important. The symptoms are very similar to flu, but persist for longer than a week with no obvious cause. If your child has these symptoms then please seek medical advice. More detailed information can be found in the *Infective Endocarditis* leaflet on the website.

Mycobacterium Chimaera

Approximately 1 in 5000 patients having cardiac surgery might be affected by this infection. There have been reports of Mycobacterium Chimera causing serious infections in a very small number of patients having operations on their heart valves.

The level of risk of this infection is very small but symptoms may have many of the same features of other illnesses including:

- Unexplained temperatures, night sweats, joint or muscular pain.
- Unexplained weight loss.
- Increasing shortness of breath.
- Nausea, vomiting or abdominal pain.
- Abnormal levels of tiredness/fatigue.
- Pain, redness, heat and / or pus around the surgical site.

If your child experiences any of these, they may need to be seen by your GP or other healthcare professional. It is unlikely that the symptoms will be caused by this infection; however it may need to be excluded by your doctor.

Hospital Accommodation

If you have used the hospital accommodation you will realise the benefits to families and that it is very limited. If you have had the use of a room please remember to return your key to the ward before you leave. If you forget and take them home please return them to the ward straight away.

Useful Contacts

Once you have been discharged home the Cardiac Nurse Specialists are available to answer questions and discuss concerns, as well as helping with problems that may arise at nursery or school etc due to your child's heart condition. They can also be a link between the hospital and any other medical professionals involved in your child's care.

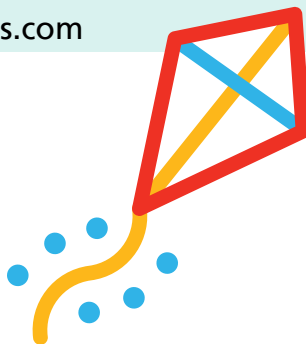
Children's Cardiac Nurse Specialists

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