

Post Surgical Information for Health Visitors and Community Nurses

This leaflet has been written for health professionals in the community caring for children who have just undergone heart surgery.

Congenital heart conditions can range from simple to complex. Some conditions can be corrected with one operation and more complex conditions will require a series of operations, which could result in a palliative repair.



Before discharge the doctors and the ward nurses will have discussed with the parents proposed treatment plans and any further surgery their child may require. All parents should have a patient hand held record. Often timing of proposed treatment depends on the child's health and rate of growth. Therefore the child will be assessed regularly at Southampton outpatient's clinic, or at a cardiac clinic held at the local hospital.

The parents are given the following information;

- The child's heart condition and the operation they have had
- Proposed treatment plan and surgery in the future
- Information about medications the child is taking, when and how to give them
- How to arrange repeat prescriptions
- Advice and information regarding any special feeds or diet
- Details of follow up appointment
- How to contact the liaison team for information and support once at home
- Details of useful websites and support groups

Children are reviewed at Southampton usually one week after going home. However if they live a long distance from Southampton it may be possible for them to see one of our Cardiologists when they hold a clinic at a local hospital.

The child's GP will have been informed of the surgery the child has undergone and any medications s/he is taking.

Wound Care

The wound should be kept clean and dry. On discharge the child should be able to shower or bathe normally although parents are advised to avoid long soaks for the first four weeks.

Stitches will dissolve and therefore do not need to be removed.

The wound should be protected from direct sunlight as this can hinder healing and make the scar more noticeable.

It is very important for parents to contact Ocean Ward if the wound develops any redness, swelling fluid or pus, or if their child develops a temperature.

If the child experiences any discomfort once at home parents are advised to give Paracetamol.

Diet

Generally babies and children with heart conditions do not require a special diet and should follow age-appropriate recommendations. Many who may have found feeding hard work will do better with feeding and growth after surgical procedures are completed.

Some babies, however, do experience feeding difficulties and need supplements or altered feeds.



If children have an identified problem, need special feeds, supplements or have feed/top ups, parents will have been given a detailed feeding plan from the ward dietitian, with copies for the Primary Care Team.

Establishing appropriate feeding prior to discharge is a ward priority, but close monitoring of growth during the first couple of months post discharge into the community, is vital.

If the child is taking a long time to feed and is experiencing poor weight gain please contact the liaison team for further advice. Tel: **023 8079 4659**.

The dietitian can be contacted on tel: 023 8079 4588

(If the child has Down's Syndrome please use the 'Down's' centile chart)

Activity

Parents are advised to restrict energetic exercise such as climbing, cycling, excessive running and participation in swimming, sports and games for the first six weeks.

If the child has had a sternotomy (wound on the child's chest where the surgeons have cut through child's chest bone) parents are advised not to pick their child up from under the arms for six weeks, as this puts strain on the chest area. They are shown to pick their child up by supporting the back and lifting under the legs.

During their first appointment following discharge parents will discuss with their child's Cardiologist when the child can return to school or nursery. Usually we suggest after six weeks

Immunisations

Unless there is a specific reason we recommend that all children be fully immunised. Their immunisations program can start, or be continued, four weeks after surgery.



Please ask the Cardiac Nurse Specialist for specific advice on immunisations if the child has no spleen, Di George's Syndrome or chromosome 22q deletion.

Children on warfarin therapy should be given their immunisations subcutaneously rather than intramuscularly to prevent bruising

Generally children who have a complex heart conditions are advised to have the annual flu vaccination.

General Information

We are aware that going home for many of our families is an extremely anxious time. We always stress the importance of the role of the Health Visitor and Community Nurse and the support you can provide.

If any of the following symptoms are observed please contact the child's local hospital or GP or Ocean Ward:



- If the child has a temperature for more than 2-3 days
- Vomits or has diarrhoea lasting more than one day
- Has become increasingly tired
- Has feeding problems that are unusual for the child
- Has increased sweating, especially during feeding
- The child is not putting on weight
- Has breathing problems or breathing faster than usual
- Face is puffy/or eyes
- Redness, fluid or pus from the wound

Changes in a child's heart condition usually happen slowly over several days or weeks.

Parents are advised to:-

Visit GP promptly with their copy of a discharge letter to get a prescription.

They will only be given a 7-day supply of medications on discharge from hospital.

Pharmacies often require a week to obtain some medications.

If pharmacist has problems obtaining medicines they should ring Southampton Hospital Pharmacy tel: 023 8079 4161

The Cardiac Nurse Specialist can provide more detailed information regarding an individual child's treatment and prognosis as required. See contact numbers at end of leaflet.

We have also provided you with a list of the websites and support groups.

Contact numbers for Cardiac Nurse Specialist

Telephone: 023 8079 4659 office/answer phone. Any messages will be answered by the end of the day.

To bleep ring 02380 777222, bleep 2478. It is best to use the bleep message if you would like a prompt answer.

Ocean Ward tel: 023 8079 6470.

Websites and Support Groups for Congenital Heart Disease

For information and parent forum please go to: www.Oceanward.co.uk

Children's Heart Federation

Help line 0808 808 5000,

Heart diagrams and Information leaflets: www.childrens-heart-fed.org.uk

Little Heart Matters

Helpline 0121 456 4521

Heart diagrams, Information leaflets and Message Board: www.lhm.org.uk

Down's Heart Group

Heart diagrams. Information leaflets: www.dhg.org.uk

British Heart Foundation

Information leaflets and videos: www.bhf.org.uk

Cincinnati Children's Hospital

www.cincinnatichildrens.org

American Heart Association

www.americanheart.org

Rush Children's Heart Centre

www.rchc.rush.edu

Variety Children's Heart Circle

www.rchc.ca

PediHeart Website

www.pediheart.org

Arrhythmia Alliance

Hospital for Sick Children Toronto

www.sickkids.on.ca/childphysiology

Melbourne Children's Hospital Australia

www.rch.org.au/rch/index.cfm?doc-id=1495

Please note that the accuracy of information provided by these sites cannot be guaranteed and that the information provided on a certain condition may not all be of relevance to a specific individual.

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