

# Children Being Admitted for Correction of Complex / Neuromuscular Scoliosis

Additional Information for Parents / Carers



Paediatric  
Spinal Service  
Trauma and  
Theatres  
Centre

## Why is surgery required?

The aims of the surgery are to stop the curve of the spine from getting worse and partly straighten the spine as much as is safely possible, to provide a good balance of the head, trunk and pelvis. For example, children and young people with neuromuscular or syndromic conditions can have problems with their sitting balance, so having surgery may help them to improve the sitting position, enabling them to sit longer and avoid pressure sores. An improved sitting position may also assist with the independent use of the hands.

Surgery benefits posture and can help to improve associated respiratory and gastro-intestinal difficulties.

Real outcomes are difficult to measure in patients with mental incapacity; however research has found that the majority of carers and parents are satisfied with the outcome of the surgery, particularly with the following aspects – sitting position, physical appearance, level of function and ease of nursing care.

## Who makes the decision about surgery?

Scoliosis surgery is major surgery and therefore the risks and benefits must be carefully considered. The choice to have surgery is a joint decision, involving the patient (when possible), family, carers and the scoliosis team. The scoliosis team includes the surgeons, anaesthetists, paediatrician, specialist nurse and other supporting staff.

After the child has been individually assessed and the child's, parents' and carers' opinions noted, the team have a multidisciplinary meeting before making the final

decision regarding surgery. All factors are taken into consideration and time given for all to make the right decision.

## What are the problems related to surgery?

Any surgery carries risks and these are heightened when a child has other medical problems. All risks relating to your child are explained to you before a consent form is signed.

The body shape and seating position would change following surgery and this may mean alterations in equipment and aids, for example wheelchair adaptations. The occupational therapist will see your child before surgery to make an individual assessment of need, discussing concerns, establishing what is already in place and planning any necessary changes where possible.

Stabilising the spine will restrict mobility of the trunk and also increases the height of the trunk. Rarely, children who have problems with their arms but can feed themselves may find eating more difficult, as they cannot lean forward so their hands cannot reach their mouths as easily.

## Equipment changes

We work closely with the hospital paediatric occupational therapist, who in turn will liaise with the community occupational therapist. They will support you and arrange supplementary and/or different equipment needed where possible. This may take some time to arrange so it is important for them to meet you and your child before you come into hospital. The specialist nurse will arrange this.

After surgery, the increase in height and change in body shape may necessitate changes to wheelchairs. A wheelchair review appointment needs to be made for approximately six weeks post surgery when your child should be feeling stronger and wounds are healed. If wheelchair adaptations are necessary it takes around eight weeks. It may be possible for your child's existing chair to be temporarily modified to enable the chair to be used whilst you wait for the new one. A member of wheelchair services will be invited to visit your child in hospital a few days after surgery to plan this.

The Occupational Therapist will assess the following practical aspects of your child's care both before and after their surgery:

- How your child moves around in bed, and how good posture can be maintained in bed. Sleep systems can be used but are not essential.
- How your child transfers from bed to chair and back again (safe moving and handling). This is relevant if they do this independently or use a hoist and slings.
- Your child's ability to feed themselves as they may require more assistance or alternative equipment to continue with this following surgery.

## Communication

If your child is unable to speak, it would be helpful if you could let staff know any strategies he / she uses. If a communication book is used, it would be helpful if it could be brought in.

## Nutrition

Before surgery, it is important that your child is a healthy weight. If your child is overweight, it is helpful for them to have been on a weight reduction programme. If your child is underweight, a dietician will have been asked to prescribe appropriate build up drinks. Occasionally it may be advised that your child needs a gastrostomy (feeding tube directly into the stomach) fitted in a separate surgical procedure first.

Gastric reflux has been found to be a problem for some children following scoliosis surgery and this has to be taken into account before the operation.

## Constipation

Constipation is a problem for many children following scoliosis surgery. For children with existing medical problems this can be an issue before surgery as well. It is important that your child's bowels are opened just before surgery, so please inform the team if constipation is an issue, and more/different medication may be prescribed. Similarly if loose stools are a problem, please let us know, as we may need to consider treatment to avoid contamination of the wound.

## What to bring into hospital

In addition to clothing, toiletries etc (see Ward 22 information leaflet), please bring into hospital all medications and prescribed feeds, as it cannot be guaranteed that the ward will be able to get these. If your child usually uses a hoist, please bring in the sling. Please also bring their wheelchair if one is used. If you are unsure about what to bring in, please contact the specialist nurse or ward staff.

## Illness

It is vital that your child is in the best possible health prior to surgery. Please contact the specialist nurse or ward staff if he/she is unwell, e.g. develops a cough, cold, diarrhoea or vomiting.

Immunisations should not be done for at least two weeks before and after surgery.

## Going home

If your child is wheelchair dependent, he / she will have to be able to tolerate sitting in the wheelchair for one to two hours, and be able to be hoisted comfortably before they can be discharged home. Your child will have to be comfortable and tolerating diet and fluids well.

## Hygiene

It is important that the wound is protected from becoming infected. Pads should be changed more frequently and if the dressing becomes contaminated, it needs to be removed, the area cleaned, and a new dressing applied as soon as possible.

For smaller children, please roll them from side to side rather than lifting the legs when changing their pads.

Please check for pressure areas regularly, as the new posture leads to different sitting / lying positions.

## Contacts

**Specialist Nurse** - Cheryl Honeyman

cheryl.honeyman@stees.nhs.uk

Office: 01642 850850 ext 56267

Mobile: 0793 536 1881

**Ward 22:** 01642 854522 (24 hours)

**Paediatric Intensive Care Unit:** 01642 854667 (24 hours)

**Mr Raman Kalyan's secretary:** 01642 835564

**Mr Waleed Hekal's secretary:** 01642 835914

## Comments, compliments, concerns or complaints

South Tees Hospitals NHS Foundation Trust is concerned about the quality of care you receive and strives to maintain high standards of health care.

However we do appreciate that there may be an occasion where you, or your family, feel dissatisfied with the standard of service you receive. Please do not hesitate to tell us about your concerns as this helps us to learn from your experience and to improve services for future patients.

## Patient Advice and Liaison Service (PALS)

This service aims to advise and support patients, families and carers and help sort out problems quickly on your behalf.

This service is available, and based, at The James Cook University Hospital but also covers the Friarage Hospital in Northallerton, our community hospitals and community health services. Please ask a member of staff for further information.

Author: Paediatric Spinal Service, Trauma and Theatres Centre

---

**The James Cook University Hospital**

**Marion Road, Middlesbrough, TS4 3BW. Tel: 01642 850850**

Version 2, Issue Date: October 2014, Revision Date: October 2016