



# Spinal surgery – questions to ask

This factsheet is aimed at helping families decide what questions they need to ask when considering whether to go ahead with spinal surgery where scoliosis (an unnatural sideways, twisting curvature of the spine) is present. It should be read in conjunction with our general factsheet on spinal surgery called “Surgical correction of Spinal Deformity in muscular dystrophy and other neuromuscular disorders.”

Prior to any decision about surgery, time needs to be made available for a range of questions to be discussed. It is helpful to be given both verbal and written information. Some families also appreciate the opportunity to speak with people (preferably with the same condition) who have had spinal surgery.

If a child or adult has a neuromuscular condition in which scoliosis can be a feature they should attend a specialist clinic where their spine can be checked on a regular basis. If a scoliosis starts to develop spinal surgery may be offered. Scoliosis is commonly seen in Duchenne muscular dystrophy and in spinal muscular atrophy (types 2 and 3). It is also seen in some types of congenital muscular dystrophy and in other rarer neuromuscular conditions.

## Questions to consider asking:

### Questions about the surgery

- ▶ Why is the surgery needed?
- ▶ Is the aim of the surgery to prevent, improve or maintain a situation?
- ▶ What are the expected outcomes of the surgery? (both positive and negative)
- ▶ What are the risks associated with the surgery and what are the level or severity of these?
- ▶ What is the risk of mortality?
- ▶ What does the surgery involve and what procedures or techniques are used?
- ▶ How long will the operation take?
- ▶ What problems may occur if we decide not to go ahead with the surgery?
- ▶ What other options can be considered?
- ▶ Can we change our minds at a later date - what is our “window of opportunity”?
- ▶ What time scale are we working to and when is the surgery likely to take place?
- ▶ Does the surgery allow the spine to grow?
- ▶ If so, what are the additional risks of this over a fusion (non growing) procedure?

### Questions about the arrangements for surgery

- ▶ Where will the surgery take place?
- ▶ How long will the stay in hospital be?
- ▶ Who will perform the operation and what level of experience do they have?
- ▶ What other specialists are involved (for example anaesthetists) and what experience do they have with people with this neuromuscular condition?
- ▶ Will an intensive care bed be required and if so, why?



- ▶ What the likelihood is of the surgery being postponed and if this happens how quickly can it be rearranged?
- ▶ What pre-operative tests and checks are needed and when and where will these be done?
- ▶ Is there an opportunity to meet the medical, nursing and therapy staff prior to the admission?

## Questions about practical issues – when in hospital

- ▶ Are parents or partners able to stay in hospital with the patient or is accommodation available and if so, is there a charge for this?
- ▶ Are we entitled to any financial help with travel, parking, subsistence or accommodation costs?
- ▶ Are there any restrictions on visiting?
- ▶ What does the patient need to bring into hospital with them - any specialist equipment?
- ▶ How much care are parents or partners expected to provide whilst the patient is in the hospital?
- ▶ What special arrangements can be made to accommodate the patients' disability?
- ▶ How much privacy will the patient have?
- ▶ How much physiotherapy will be provided and will the physiotherapist attend to the needs caused by the neuromuscular condition as well as the surgery?
- ▶ What access to specialist Occupational Therapy support will there be?
- ▶ Who will assess changed seating and wheelchair needs?
- ▶ Who will act as our "keyworker"?

## Questions about practical issues – planning for going home

- ▶ Which local staff need to be involved in follow up and who will liaise with them?
- ▶ Is a period in respite care, such as children's hospice, available immediately after leaving hospital and who will arrange this?
- ▶ How will the patient get home, will transport be provided?
- ▶ How much time off school, college or work will the patient need and will they need to go back part time at first?
- ▶ Are there any specific physiotherapy restrictions?
- ▶ If so, who will communicate those?
- ▶ When can normal activities be resumed?
- ▶ When can the patient resume specific activities such as horse riding, swimming and sexual relationships?
- ▶ Will the patient lose any abilities or need to alter the way he or she performs certain tasks for example eating?
- ▶ Who will give advice about equipment needs?
- ▶ Is the patient likely to need new equipment after the surgery and if so, do we need to organise this beforehand?
- ▶ Will we need to reconsider wheelchair or vehicle provision?
- ▶ Who will give advice or training on moving and handling issues?
- ▶ What problems may arise, what do we need to "look out for"?
- ▶ Is the patient likely to have pain or discomfort and if so, where and how is it managed?



- ▶ Who do we contact for advice if there is a problem, is there a key person at the hospital we can liaise with once back home?
- ▶ Who will ensure we are coping at home?
- ▶ What arrangements for follow up are there?

Anxiety may be raised by lack of information. Decisions may be easier when as full a picture as possible is obtained. No question is “silly” or unimportant. Do ask about anything that concerns you.

It is helpful to have a list of the professionals involved in the patient’s care (along with their telephone numbers and contact details), and to bring this list with you to hospital appointment

#### **Disclaimer**

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## Here for you

The friendly staff in the care and support team at the Muscular Dystrophy UK’s London office are available on **0800 652 6352** or **info@muscular dystrophyuk.org** from 8.30am to 6pm Monday to Friday to offer free information and emotional support.

If they can’t help you, they are more than happy to signpost you to specialist services close to you, or to other people who can help.

**[www.muscular dystrophyuk.org](http://www.muscular dystrophyuk.org)**