

Scottish Muscle Network

Patient Information Leaflet

About my Spinal Fusion

Frequently asked questions

You may have discussed with your doctor at the hospital, the benefit of having spinal fusion but may still feel a little anxious. In this leaflet we have put together some questions which we have been asked by other young people who have undergone this surgery. This leaflet has been prepared with the help from parents and young people who have been through the surgery already but remember, you can phone any member of the team if you have questions which are not in this leaflet, and we will be happy to help.

Why is this surgery recommended?

You will be offered this surgery if the curve in your back is felt to be changing. Once the curve reaches a certain angle, we know that the curve will continue to get worse without some form of surgery. When the curve becomes worse, it can make sitting more difficult, and you may feel more uncomfortable. This is something that you can discuss with your parents, caregivers and the specialist doctors you see at the hospital. The decision to have this surgery is yours and we will give you as much information as we can to help you make up your mind.

What are the benefits of having a straight back?

Studies have shown us that once the curve gets to a certain level, it causes discomfort. As you spend most of the day sitting, it is important that you are in a comfortable position within your wheelchair. Also, studies have shown that having a spinal fusion increases your life expectancy if you are at risk of scoliosis (curvature) worsening without the surgery. This means that for many people who would go on to develop a curve in their spine, that may shorten their life due to the fact they are more at risk of serious chest infections, keeping the spine straighter will mean that it is easier to look after the chest during chest infections and can help them live a longer, healthier more comfortable life. There are many things we can do to increase our life expectancy such as eating healthily, quitting smoking, taking regular exercise etc. This is another step in our healthy lifestyle pattern as it will allow our lungs to work the best way, they can without one side becoming squashed by the spinal curve. As you get older, it is also better to have a straight back as this makes finding a suitable wheelchair much easier.

How long will I be in hospital?

You will normally be in hospital for 10 – 14 days. Some people are in longer depending on how the surgery went and some have a shorter stay in hospital. Everyone is different; some people get over surgery quicker than others, so it depends upon your own healing time.

Will it be sore?

Some people have said that the operation itself is not sore as you are given ample pain relief. At first, the pain relief will be given through an infusion. Some people will also have a pain relief patch that sticks to the skin as well as medicines that can be swallowed.

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Where will I be when I wake up?

When you wake up you will be in the intensive care unit (ICU) so the nurses can keep a close eye on you. You will be able to get a look at the unit the day before you have your operation so you will be familiar with your surroundings when you awake. There are a lot of nurses who will be there to look after you as well as your family or caregivers.

Will there be lots of tubes and monitors?

Yes, but don't worry. These are perfectly normal, and everyone has them after this operation. There will be a cuff around your arm to monitor your blood pressure and you will have sticky pads on your chest so we can check your heart. You will have a drain and a catheter, and you may have a face mask and a tube connected to the machine which helps you to breathe. Some people don't like the feeling but it's not for long and you'll be quite sleepy.

How will I get to the toilet afterwards?

When you wake up you will have a lot of tubes and monitors. There will be a little tube (catheter) going into your bladder that will allow you to go to the toilet without having to leave your bed. This tube stays in until you can get up to the toilet with some help, so it won't be there for more than a day or two. Your bowel will not need to move initially as you will not be eating solid food. You will get your fluids through a tube that goes into your arm and your nutrition will go through a tube that goes into your stomach (nasogastric tube). It is important after your operation to make sure you have all the nutrients you need to help your spine heal. You will be encouraged to get back to normal eating as quickly as possible, so you won't need these tubes for very long at all.

I always sleep on my side at home; will I have to sleep on my back?

No, this is not necessarily the case. You will lie on your back as well as either side. Lots of changes in position will help you heal and you will be helped into a comfortable position with 3 lots of pillows etc. by the ward staff as well as your parents and carers who will be shown how to help you move and change position.

When will I go back to the ward?

You will go back to the ward after a few days. During this time your family will be shown the best way to look after you and they will get a chance to help you to the toilet and look after you as they would at home but with the help and advice of the nurses. You will be taught how to do log rolls and in fact this is something you can practise with your physiotherapist and parents / carers before you have the surgery. to remember that the management of your muscle symptoms will not be significantly altered by knowing the precise genetic cause of your metabolic myopathy. Regular exercise and having a healthy diet and avoiding any triggers remain the mainstay of our advice to you.

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Can someone stay with me?

Yes, your parent or carer can stay with you all day except during ward rounds and the nursing handover. There is accommodation close by for night time and if you need someone during the night, the nurses can phone for your parent or carer to come over.

Do you think I might die during the operation?

All general anaesthetics have risks attached to them but to limit any complications that could occur, we carry out several tests before the operation. These include breathing and heart checks as well as an anaesthetic assessment and x-rays and we will only offer you this surgery if we think you are strong enough to get through the operation and the recovery period.

What tests will I have?

The pre-op assessment is a long day. You will have heart scans, x-rays and you will meet some of the people who will be involved in your surgery like the ICU Consultant and Respiratory Consultant and you will already know your Spinal Surgeon. It's a good idea to take things with you to keep you busy in between all these appointments.

I can feed myself just now, will this change after surgery?

Sometimes after surgery your head can feel a little heavy as your spine is now straighter than before and your neck muscles will be working a little differently. It can take a few weeks for your body to adjust to this new position. It is however, important that your wheelchair is assessed as following your spinal fusion your seating system will need to be adjusted. The physiotherapist from the Spinal Service will contact your local therapist before your operation to make sure your wheelchair has all the necessary requirements. If you need a different wheelchair, this will be organised before your operation.

After your surgery, the wheelchair will be adjusted to fit your new position and a lot of care and attention will be given to ensure it is set up correctly for you. With a different wheelchair and a new straighter back, eating and drinking may take a bit of getting used to and your physiotherapist and occupational therapist will help you adjust to your new position.

Are there other risks involved with this surgery?

All surgery has risks, and your medical team will weigh up these risks against the benefits of having the surgery done. For example, there is a risk of infection after any form of surgery, but this is usually treatable with antibiotics. There is also a risk of the bones not healing properly and sometimes another operation may be required to fix this, but this is rare. There is also a chance that the nerves could be damaged, but this risk is small.

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I have special equipment I use at home, will the hospital have the same equipment?

It is not possible for the ward to have exactly the same equipment that you have at home but, if possible, we will arrange with you to bring any special equipment in to the ward that you feel is essential. It would be a good idea for your family and you to visit the ward beforehand if you are concerned about the equipment, this will give you a chance to view what we have and make alternative arrangements if necessary.

Is there anything else I should bring with me?

You should bring things that make you feel comfortable. Comfy pyjama's, fluffy warm socks, your favourite cuddly toy, your favourite drinks and snacks and games and puzzles and books to keep you entertained. You may want to bring your own familiar slings if you are already used to being supported in your moving and handling with a hoist. Some people will even bring their own sheets, so they smell like home. It's entirely up to you! You might also want to consider an easy hairstyle for after the surgery.

What will it be like when I go home?

For a few weeks you will have to take it easy until you get used to your new straight back. Your parents and carers will also need to get used to moving and handling you in a slightly different way. If you are at all concerned, contact your physiotherapist. You will still need to have pain relief for a few more weeks so make sure you have discussed the best medicine for pain with the medical or nursing staff.

If you are worried about anything at all then remember you can phone your Consultant or Nurse Specialist for advice

My mum and dad lift me out of my chair. Will they still be able to do this after surgery?

The surgical procedures that are used to help straighten your spine make your spine very stable but the way in which you need to be moved will be decided by your Consultant who did the surgery. This is because he has knowledge of your spine and can advise your family and carers more accurately.

We do recommend that you use a hoist sling that comes right up your back and supports your head as well as a good snug fit around your hips. Your physio / OT / District Nurse will be able to order you the correct sling with the best fit and will liaise with the spinal team to make sure it is the right sling for you.

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Can I still join in P.E., sports and swimming after my surgery?

When you can go back to your usual activity should be discussed with your spinal surgeon. It is generally recommended that moderate activity should be halted until the bone grafts have healed and your surgeon will keep an eye on this for you. You will be able to do some of your activities before then and your spinal surgeon will advise you. Your surgeon will be able to give you more information on this as each person is different and it will depend on the level of surgery you have had and how quickly you heal.

Is there any other equipment I might need?

If you normally have a shower, you may need to change the shower chair to one that tilts and reclines with a head rest to give you a bit more support. If you have a bath, then check with your OT in case you need a different support to sit in in the bath. Your physio and OT can also check that the way you get in and out of the bath will still be suitable after your surgery.

Summary

This is a general overview of what you can expect. Your treatment and management before, during and after will be adapted to suit you and your personal circumstances. For further information please contact your local neuromuscular team.

Thank you to the families and young people who helped put this leaflet together.