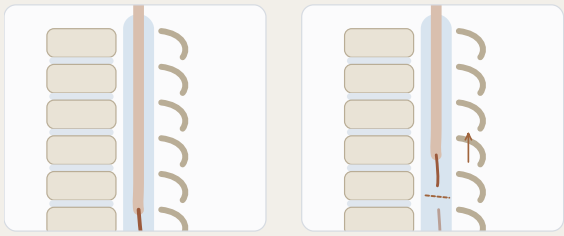
Professor Jason John Labuschagne
PAEDIATRIC AND ADULT NEUROSURGEON

PAEDIATRIC NEUROSURGERY

Tethered Cord and Spinal Dysraphism Release

Information and consent for parents and guardians



This booklet explains closed spinal dysraphism, tethered spinal cord and the operation to release it. Please read it at home, in your own time, and write down anything you would like to ask. You will only be asked to sign the consent section once all of your questions have been answered and you feel ready.

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PATIENT DETAILS OR HOSPITAL LABEL

Child's name

Date of birth

Parent / guardian

Hospital / file no.

Version 1.0 · October 2026

Netcare Unitas Hospital
Room 403, Centurion

Nelson Mandela Children's Hospital
Private Suites, First Floor, 6 Jubilee Road, Parktown North

012 664 6026
HPCSA MP 0530077

01 General information

What is closed spinal dysraphism?

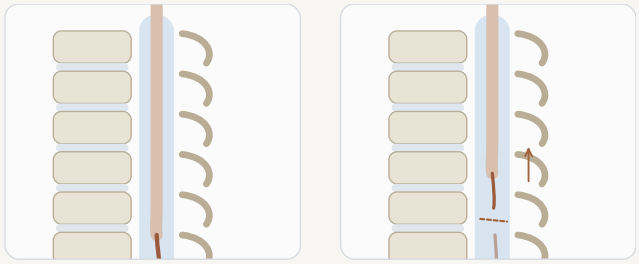
In early pregnancy the brain and spinal cord begin as a tube that closes along its length. Spinal dysraphism describes a group of conditions in which the spinal cord, its coverings or the overlying spine do not form completely. In the closed (occult) types the skin over the back is intact. They include a thickened or fatty filum terminale, a fatty lump attached to the spinal cord (lipomyelomeningocele or spinal lipoma), a split spinal cord, and a dermal sinus, a small channel from the skin that may connect to the spinal coverings.

A birthmark, hairy patch, dimple or lump on the lower back may be the first clue. Some children develop weakness, unequal leg or foot size, foot deformities, back or leg pain, scoliosis, or difficulty with bladder and bowel control. A dermal sinus can allow infection in, causing meningitis or an abscess. The diagnosis is confirmed with ultrasound in young babies or MRI.

What is a tethered cord?

Normally the lower end of the spinal cord hangs freely and moves upwards within the spinal canal as the spine grows. In a tethered cord, it is held down by a thick filum, a lipoma or scar tissue. As your child grows, the cord and nerves are stretched, which can gradually affect the legs, bladder and bowel, particularly during growth spurts.

What does the operation involve?



Left: the spinal cord held low by a tight, thickened filum. Right: after the filum is divided, the cord is released.

Under a general anaesthetic, with your child lying on the tummy, an incision is made in the lower back. Some of the bone at the back of the spine is opened (laminotomy) and the covering of the spinal cord is opened under the operating microscope. Electrical monitoring of the nerves to the legs, bladder and bowel is used to help identify and protect functioning nerves. The tethering structure is divided or removed: a thick filum is cut, a lipoma is reduced as much as is safe, and a dermal sinus tract is removed completely. The dura is closed watertight, sometimes with a patch, and the wound is closed in layers.

The aim is to stop symptoms getting worse. Leg symptoms and pain often improve; bladder and bowel symptoms improve less often but usually stop progressing. In the case of a dermal sinus, the aim is to close the connection between the skin and the spinal fluid to prevent meningitis.

02 Alternatives to surgery

- **Observation** with regular examination, urology assessment and MRI, which may be appropriate for some children without symptoms, especially with certain lipomas.
- **Treatment of symptoms only**, such as bladder management, physiotherapy or orthotics, without addressing the tethering.
- **Surgery at a later stage**, accepting a risk that some function lost in the meantime may not recover.

03 What to expect during and following surgery

Before the operation

- Please tell us about any allergies, bleeding tendencies, medicines (including herbal remedies) and any recent cough, cold, fever or vomiting.
- The anaesthetist will see you before surgery and give clear instructions about when your child must stop eating and drinking.
- Bring a favourite toy, blanket or dummy; familiar things help enormously.
- Where the hospital allows, one parent may accompany their child into the anaesthetic room until they are asleep.

In hospital after the operation

Your child wakes up in the recovery room and returns to the ward once settled. Nurses will regularly check your child's level of alertness, pupils, breathing, heart rate, temperature and the wound, and may wake your child during the night to do this. This is routine and not a cause for worry.

- **Pain relief** is given regularly, first through the drip and then by mouth.
- **Eating and drinking** usually restart within hours, starting with small amounts.
- **Lying flat.** Your child may need to lie flat for a period, often between one and five days, to help the dural closure heal and reduce the risk of fluid leakage.
- **Catheter.** A urinary catheter is usually in place for the first few days.
- **Mobilising.** The physiotherapist helps your child sit up and walk when allowed; legs may feel weak and wobbly at first.
- **Constipation** is common with lying flat and is treated with medicines.
- **Going home.** Most children go home after about three to seven days.

04 Risks and complications

Every operation carries some risk. Most children recover well, but it is important that you understand what can go wrong so that you can make an informed decision and recognise problems early. The risks are listed according to how often they occur; Professor Labuschagne will also discuss any risks particular to your child. The risks of the anaesthetic will be explained separately by the paediatric anaesthetist.

Common

●●●

- Wound pain and back stiffness.
- Temporary difficulty passing urine, or constipation.
- Temporary numbness or tingling in the legs or buttocks.

Less common

●●○

- **Leakage of spinal fluid** from the wound, or a fluid collection under the skin, which may need lying flat for longer, extra stitches or further surgery.
- Wound infection or meningitis.
- Headache when upright, caused by low fluid pressure.
- **Re-tethering** of the spinal cord as your child grows, which may need a further operation in future.

Rare but serious

●○○

- New or permanent weakness or numbness in the legs.
- Worsening of bladder, bowel or sexual function.
- Incomplete release, particularly with complex lipomas.
- Serious complications of anaesthesia, or death. These are very rare.

05 After the operation: what is normal

- Soreness in the lower back for one to two weeks.
- Some temporary weakness or altered sensation in the legs, improving over days to weeks.
- Muscles may feel stiff and sore after lying flat for a few days.
- A scar in the lower back.

06 Recovery

- **Wound.** Keep it clean and dry and protect it from nappies or soiling until checked.
- **Activity.** Gentle activity at first; avoid bending, lifting and rough play for about six weeks. Most children return to school within two to three weeks.
- **Follow-up.** Wound review at about two weeks, then regular follow-up of leg strength, bladder function (with the urology team), growth and the spine.
- **Long term.** Please report any change in walking, bladder, bowel or back pain promptly, as these may indicate re-tethering.

07 When to contact the rooms

Please contact the rooms the same day, or go directly to the nearest emergency department, if you notice:

- Clear fluid leaking from the wound, or a growing soft swelling around it
- Fever, especially with neck stiffness or headache
- Headache when upright that improves when lying flat
- New weakness, numbness or difficulty walking
- New difficulty passing urine, or loss of bladder or bowel control
- Unusual sleepiness, irritability or vomiting

IN AN EMERGENCY

If your child is very drowsy, cannot be woken, is having a seizure that does not stop, or you are seriously worried, call an ambulance or go to the nearest emergency department immediately. Tell the staff about your child's operation and ask them to contact Professor Labuschagne. You know your child best: if something does not feel right, please call.

THE ROOMS · OFFICE HOURS

012 664 6026

Elective appointments and queries, office hours, for both Netcare Unitas Hospital and Nelson Mandela Children's Hospital

AFTER HOURS

After hours, call the hospital switchboard and ask for Professor Labuschagne: Netcare Unitas Hospital 012 677 8000 · Nelson Mandela Children's Hospital 010 133 0600

Emergency services: Netcare 911 · 082 911 | National ambulance · 10177

NETCARE UNITAS HOSPITAL

Room 403, Netcare Unitas Hospital
866 Clifton Avenue, Lyttelton, Centurion

NELSON MANDELA CHILDREN'S HOSPITAL

Private Suites, First Floor
6 Jubilee Road, Parktown North, Johannesburg

08 Consent

Informed consent is a conversation, not simply a signature. The National Health Act 61 of 2003 and the ethical guidelines of the Health Professions Council of South Africa (HPCSA) give every patient the right to be told, in a language they understand, about their condition, the treatment options available, the benefits, risks, costs and consequences of each, and the right to refuse treatment. You may withdraw your consent at any time before the operation.

For a child, consent is given by a parent or legal guardian. In terms of the Children's Act 38 of 2005 (section 129), a child aged 12 or older who is mature enough to understand the benefits, risks and implications of an operation may consent to it, provided that he or she is assisted by a parent or guardian. Younger children are encouraged to take part in the discussion and give their agreement where they can.

THE PROCEDURE

Procedure Release of tethered spinal cord / excision of dysraphic lesion Side / site _____

Condition, in the parent's own words _____

SPECIFIC PERMISSIONS

Blood transfusion, if needed during or after surgery	☐ I agree	☐ I do not agree
Tissue or fluid removed may be sent for laboratory examination	☐ I agree	☐ I do not agree
Anonymised images or results may be used for teaching and research (optional)	☐ Yes	☐ No

Questions I have discussed

Please write down any questions you asked and any particular concerns that were discussed.

My acknowledgement

Please tick each statement.

- ☐ I have read this document, or it has been read to me, and I understand it.
- ☐ Professor Labuschagne has explained my child's condition, the proposed procedure, its expected benefits, and the alternatives, including the option of no treatment.
- ☐ The risks and possible complications, including those particular to my child, have been explained in language I understand.
- ☐ I have had the opportunity to ask questions and raise concerns, and these have been answered to my satisfaction.
- ☐ I understand that no guarantee has been given about the outcome, and that the procedure may not improve, and could worsen, the condition.
- ☐ I understand that if an unexpected finding or a life-threatening event occurs during the procedure, the surgeon may carry out further treatment that is necessary to protect life or prevent serious harm.

- [ ] I understand that the anaesthetic will be explained by the anaesthetist, who will obtain consent for it separately.
- [ ] I understand that my medical scheme may not cover the full cost of treatment, that I am responsible for any shortfall, that separate accounts will be rendered by the hospital and the anaesthetist, and that a quotation is available on request.
- [ ] On the basis of the above, I request that my child undergo the procedure described.

PARENT OR LEGAL GUARDIAN

Full name _____ Relationship to child _____

Signature _____ Date and time _____

CHILD'S AGREEMENT (WHERE APPROPRIATE)

I have been told about my operation, I have been able to ask questions, and I agree to have it.

Child's name _____ Age _____

Signature _____ Date _____

SURGEON'S STATEMENT

I have explained the child's condition, the need for treatment, the proposed procedure and its expected benefits, the material risks including those specific to this child, the reasonable alternatives including no treatment, and the likely consequences if those risks occur. I have offered the opportunity to ask questions and have answered them as fully as possible.

Surgeon Professor Jason John Labuschagne HPCSA no. MP 0530077

Signature _____ Date and time _____

INTERPRETER (IF USED)

I have accurately interpreted the contents of this document and the discussion between the doctor and the parent or guardian.

Full name _____ Language _____

Signature _____ Date _____

WITNESS

Full name _____ Capacity _____

Signature _____ Date _____

A copy of this signed document will be kept in the medical record and a copy offered to the parent or guardian. Personal information is processed in accordance with the Protection of Personal Information Act 4 of 2013. · Professor Jason John Labuschagne · HPCSA MP 0530077 · Version 1.0 · October 2026