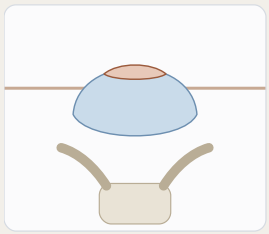
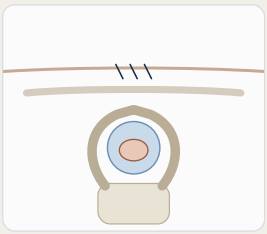
Professor Jason John Labuschagne
PAEDIATRIC AND ADULT NEUROSURGEON

PAEDIATRIC NEUROSURGERY

Myelomeningocele Closure

Information and consent for parents and guardians





This booklet explains open spina bifida (myelomeningocele) and the operation to close it soon after birth. We know this is an emotional time; please ask as many questions as you need.

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PATIENT DETAILS OR HOSPITAL LABEL

Child's name

Date of birth

Parent / guardian

Hospital / file no.

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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

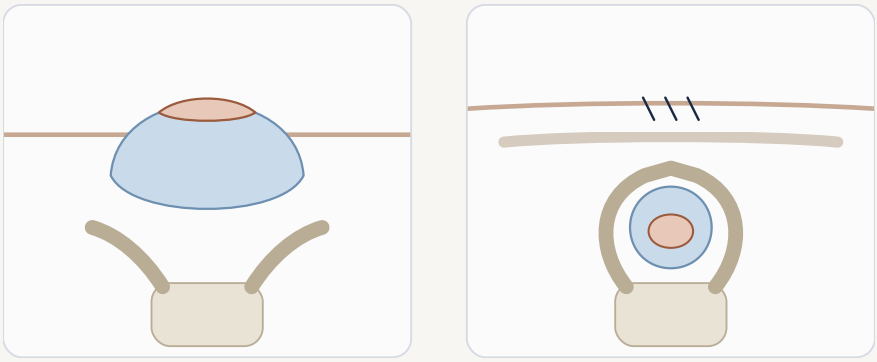
What is a myelomeningocele?

Very early in pregnancy, the tissue that becomes the spinal cord forms a flat plate that rolls up into a tube. In a myelomeningocele, part of this tube does not close and the overlying bones, muscles and skin do not form over it. The baby is born with an open area on the back, where the spinal cord and its coverings are exposed, often on a sac of fluid.

The effect on your baby depends on the level and size of the defect. The nerves below it may not work fully, affecting movement and sensation of the legs and control of the bladder and bowel. Many babies also develop hydrocephalus, and most have a Chiari II malformation, in which the lower part of the brain sits lower than usual.

Why is the operation needed?

The open area must be closed to protect the exposed nerve tissue from injury and to prevent meningitis. Closure is usually performed within the first one to three days of life. It does not restore nerve function that has already been affected, but it protects the function that remains.



Left: the exposed spinal cord tissue on a sac of fluid. Right: after repair, the cord is placed back inside its covering and closed in layers.

How is the operation done?

Under a general anaesthetic, with your baby lying on the tummy, the neural tissue is carefully freed from the surrounding skin and allowed to fall back into the spinal canal. It is gently rolled into a tube where possible. The covering of the spinal cord (dura) is closed to make it watertight, followed by the muscle and fascia layer where available, and finally the skin. If the defect is large, the skin may need to be moved from the sides, sometimes with the help of a plastic surgeon.

02 Alternatives to surgery

- **Fetal (in-womb) repair** is performed in a few specialised centres for selected pregnancies; it is not an option after birth.
- **Delayed closure** may be necessary if the baby is unwell, but it increases the risk of infection.

- **Non-surgical care** of the open area with dressings is not recommended except in exceptional circumstances, because of the high risk of meningitis and further nerve damage.

03 What to expect during and following surgery

Your baby will be cared for in the neonatal intensive care unit before and after surgery, lying on the tummy or side to keep pressure off the wound. A moist sterile dressing protects the defect before the operation, and antibiotics are given.

- **Feeding** usually restarts within a day; breast milk can be expressed and given.
- **Head circumference** and the fontanelle are checked daily, and ultrasound scans are performed, because hydrocephalus often appears after closure.
- **Bladder.** The urine is checked and the bladder may need emptying with a fine catheter; the urology team will be involved.
- **Specialists.** Physiotherapy, orthopaedic, urology and spina bifida teams will see your baby.
- **Going home.** Usually after one to three weeks, once feeding well, the wound is healed and any hydrocephalus is controlled.

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

●●●

- **Hydrocephalus**, needing a shunt or ETV, either during this admission or later.
- Some breakdown or delayed healing of the wound edges, particularly with large defects.
- Collection of fluid under the skin of the back.

Less common

●●○

- Wound infection or meningitis.
- Leakage of spinal fluid from the wound, which may need further surgery.
- Breathing or swallowing difficulties related to the Chiari II malformation.
- Later **tethering** of the spinal cord as your child grows, which may need a further operation.

Rare but serious

●○○

- Further loss of leg, bladder or bowel function.
- Severe infection of the brain or spinal fluid.
- Serious complications of anaesthesia, or death. These are very rare.

05 After the operation: what is normal

- Your baby will lie on the tummy or side for several days while the wound heals.
- Leg movement and sensation are usually similar to before the operation.
- A scar on the back, which grows with your child.

06 Recovery

- **Wound.** Keep it clean and protected from nappy soiling; the nurses will show you how.
- **Bladder care** as advised by the urology team, which may include clean intermittent catheterisation.
- **Lifelong care.** Spina bifida affects many body systems; your child will be followed in a multidisciplinary clinic for growth, development, bladder, bowel, kidneys, orthopaedic and neurosurgical needs.
- **Folic acid.** For future pregnancies, high-dose folic acid before conception reduces the chance of recurrence; please discuss this with your doctor.

07 When to contact the rooms

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

- A tense, bulging fontanelle or a rapidly enlarging head
- Repeated vomiting, or vomiting with headache
- Unusual sleepiness, difficulty waking, marked irritability or poor feeding
- Squint, double vision, eyes turned downwards or blurred vision
- Noisy breathing, breath-holding spells, or difficulty swallowing or feeding
- Fever, especially with any of the other signs
- Redness, discharge, opening or fluid leaking from the back wound
- Reduced leg movement compared with before

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 Closure of myelomeningocele 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