



## GUIDELINE

# Myelomeningocele: Infant Care

<b>Scope (Staff):</b>	Nursing and Medical Staff
<b>Scope (Area):</b>	NICU KEHM, NICU PCH, NETS WA

### Child Safe Organisation Statement of Commitment

CAHS commits to being a child safe organisation by applying the National Principles for Child Safe Organisations. This is a commitment to a strong culture supported by robust policies and procedures to reduce the likelihood of harm to children and young people.

This document should be read in conjunction with this [disclaimer](#)

## Aim

To provide consistent evidence base care and information to these infants and their families.

## Risk

Inconsistent care increases the risk of post-operative complications including infection. Inconsistent information and incorrect referrals delays care and treatment, also causes increases stress/anxiety for parents and carers.

## Background

Myelomeningocele occurs when a sac containing the meninges, spinal fluid and elements of the spinal cord protrude through an open vertebral lesion. It may be covered with skin or thin membrane.

The care of an infant with myelomeningocele requires a multidisciplinary approach coordinated by the neonatology team and involves spinal rehabilitation team, neurosurgery, urology, orthopaedics, physiotherapy and social work.

Surgical closure of open lesion is usually recommended in the first 24 hours to reduce the incidence of infection and trauma to the exposed tissues.

Please refer to Appendices for [Neuro-Urology Protocols](#).

## Key points

- **LATEX ALLERGY:** infants with myelomeningocele have a high risk of developing latex allergies. It is therefore important to avoid any contact with products containing latex. Instead, silicone, portex or vinyl; gloves, dummies, catheters and teats should be used.
- Place red allergy alert/risk band on the infant and place an ADR (Allergies and Adverse Drug Reactions) Sticker in the patient's notes and on the medication chart and write 'LATEX'.
- Place allergy alert notice on cot/warmer.
- 90 to 95% of infants with an open myelomeningocele will develop hydrocephalus, especially after back closure; these infants should have daily head circumference measurements completed by the consultant or senior registrar.
- Care must be taken to protect the exposed meninges in the spinal lesion until surgical closure can be performed.

## Pre-Operative Investigations and Management

- The infant must be nursed prone and not dressed to prevent injury to the lesion. Use an incubator or radiant warmer.
- Immediately after delivery the lesion must be covered with a sterile dressing.
  - Use a silicone based dressing, suggest Mepilex (or a non-stick dressing such as paraffin impregnated gauze if silicone is unavailable) and a non-adherent dressing pad to protect the lesion. This type of dressing can be lifted for inspection and replaced without changing. NOTE: Do not use jelonet.
  - Hold in place with tubular netting if necessary.
  - The dressing should be protected from soiling with a plastic flap. Care should be taken to prevent contamination as potential for infection is high. Minimal tape should be applied to the skin due to sensitivity to tapes and to prevent dermal stripping. Avoid the use of sleek, ensure all tape is latex free.
- Ultrasound examination of the head and kidneys. (Note: MRI of head and spine is usually requested).
- Liaise with the Spinal Rehabilitation Team regarding treatment, education and assessment of motor function.
- Support the family with good communication and information.

## Post-Operative Care

- Nurse prone, routine post-operative observations and pain relief. Continue monitoring whilst nursed in prone position. Follow any further instructions as per the post-operative orders.
- If plastics are involved with the surgical closure – take note to follow specific post-operative management.
- Careful assessment and management of pressure areas is essential. The use of pressure relief devices i.e. coziny mattress should be considered.
- Daily head circumference by the consultant or senior registrar in anticipation of developing hydrocephalus.
- **Wound care:** Dressing left intact as per post op orders of Neuro and Plastic Surgeons.
  - Refer to Stomal Therapy/CNS Spinal Rehab for wound management issues.
- **Preventative care for excoriation of the peri anal area due to incontinence:** Use paraffin with each nappy change.
  - Refer to CNS Spinal Rehab if further treatment is required.

## Bladder Care

Indwelling Catheter (IDC) to be inserted at time of surgery. Urinary retention is common due to abnormal innervation of the bladder causing a neurogenic bladder.

IDC is removed when neonate can be positioned safely to do so, following renal ultrasound. Refer to Urology protocols [Appendix 1 and 2](#) A MCUG should be ordered if achievable as an inpatient, otherwise to be done on discharge as outpatient prior to outpatient clinic appointment.

**CIC is to commence if the following features are present:**

- Open spinal defect
- Significant post void residuals
- Long dry intervals (retainer rather than dribbler)
- USS shows pelvicalyceal or ureteric dilatation
- MCU shows reflux or small trabeculated bladder
- The CIC is to be performed 6 times a day (with existing cares) until reviewed by the spinal rehab team.

Open spinal defect will automatically require CIC.

Parents will be educated on how to perform CIC by the SRT nurse.

- PCH Health Facts: [Clean Intermittent Catheterisation for Boys](#)

- PCH Health Facts: [Clean Intermittent Catheterisation for Girls](#)

## Orthopaedics

Refer for assessment if there are concerns regarding bone anomalies of the legs.

A hip ultrasound is required at 6 weeks of age.

## Discharge

- If the infant is to be nursed prone refer to Home Monitoring Clinic for apnoea home monitoring.
- Discharge Medication: [Co-Trimoxazole](#)
  - PCH Health Facts: [Co-trimoxazole \(Bactrim®, Resprim®\)](#)
- Follow up by the Spinal Rehabilitation Team (which includes neurosurgery, orthopaedics and urology reviews.) as requested.
  - Open lesions - 6 week combined rehab/urology Neurosurgery(Spinal Rehab clinic) with MCUG and bladder function assessment outpatient appointment. [See Appendix 2.](#)
  - Closed lesions – 3 month combined rehab/urology/ Neurosurgery (Spinal Rehab Clinic) with renal ultra sound scan and bladder function assessment outpatient appointment. [See Appendix 1.](#)
- Neonatal clinic as indicated for general neonatal and developmental follow up.

### Related CAHS internal policies, procedures and guidelines

#### Neonatology Guidelines

- [Post-Operative Care](#)
- [Pre-Operative Care](#)
- [Urethral Catheterisation](#)

#### Neonatology Medication Protocols

- [Trimethoprim and Sulfamethoxazole \(Co-trimoxazole\)](#)


### References

1. [Danzer E, Johnson MP](#). Fetal surgery for neural tube defects. *Seminars Fetal Neonatal Medicine* 2013 Oct 8. pii: S1744-165X(13)00087-5. doi: 10.1016/j.siny.2013.09.004. [Epub ahead of print]
2. Sorwack, J. Lubicky, J. (2001). *Caring for the child with Spina Bifida*. Shiner Hospital for Children. American Academy of Orthopaedic Surgeons
3. Wyszynki, B. (2006). *Neural Tube Defects: From Origin to Treatment*. University Press: Oxford.

4. Brand, M. Part 2 Examining the Newborn with an open spinal Dysraphism. <i>Advances in Neonatal Care</i> . 2006; 6(4) 181-196
5. Liptack GS, Dosa NP. Myelomeningocele. <i>Pediatrics in Review</i> Vol. 31 No. 11 November 1, 2010 pp. 443 -450
6. Spinal Rehabilitation Team (P.M.H.) Perth Childrens Hospital 2017.

<b>Useful resources (including related forms)</b>
PCH Health Facts: <a href="#">Clean Intermittent Catheterisation for Boys</a> PCH Health Facts: <a href="#">Clean Intermittent Catheterisation for Girls</a> <a href="https://www.spinabifidaassociation.org/resource/latex-allergy/">https://www.spinabifidaassociation.org/resource/latex-allergy/</a>

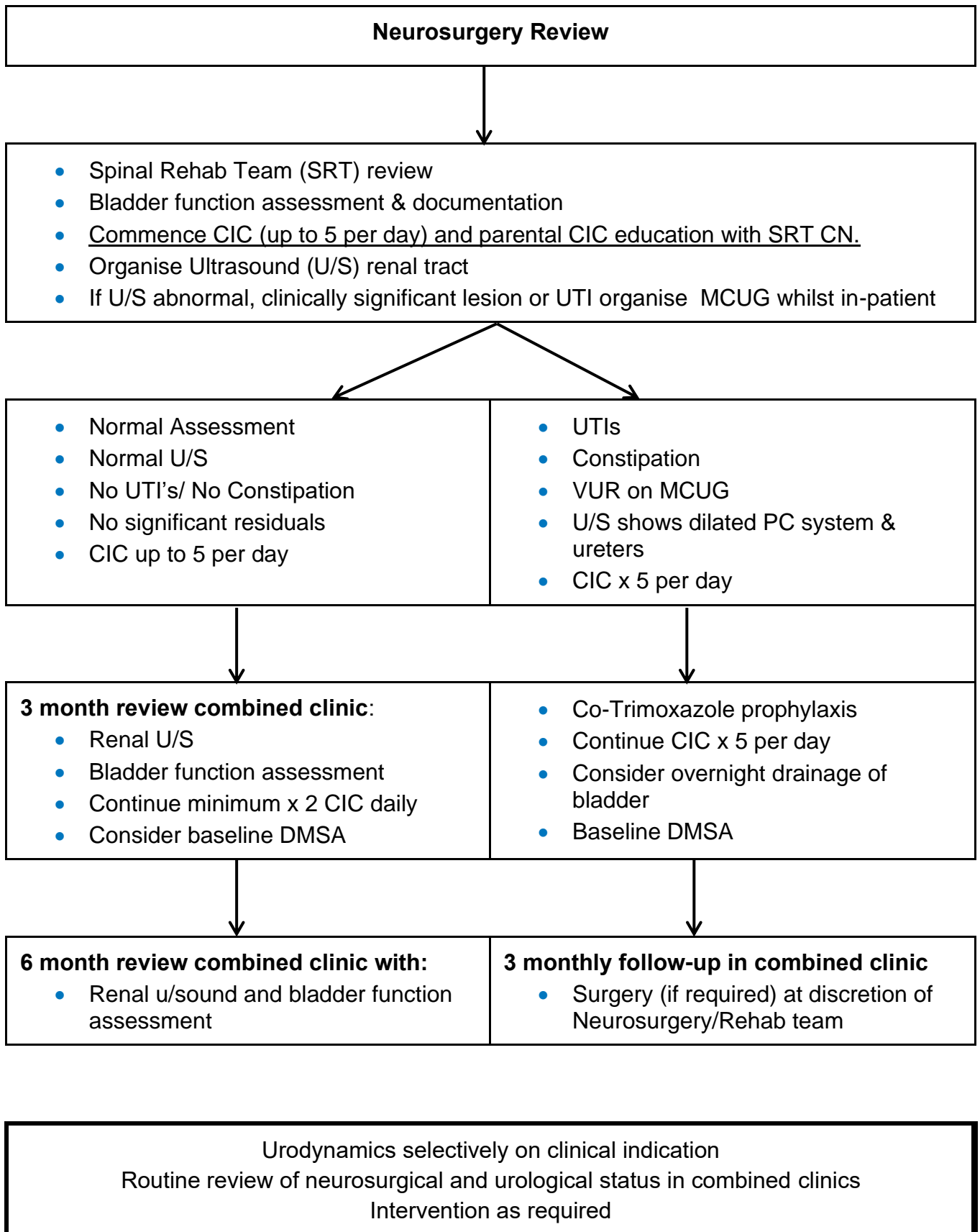
This document can be made available in alternative formats on request.

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	<h2>Healthy kids, healthy communities</h2>				
	Compassion	Excellence	Collaboration	Accountability	Equity
Neonatology   Community Health   Mental Health   Perth Children's Hospital					

## Appendix 1: Neuro-Urology Protocol for Closed Spinal Lesions



## Appendix 2: Neuro-Urology Protocol for Open Spinal Lesions

### NICU receives newborn infant

- Neonatal team to organise U/S of urinary tract and head
- Commence prophylaxis Co-Trimoxazole

### Neurosurgery to close spinal lesion

- Commence early CIC and parental CIC education
- SRT CN to assess bladder and commence CIC x 6 daily pre/post Neurosurgery
- MCUG to be done as soon as feasible after surgery when baby can lie supine
- 6 week follow up in combined clinic with renal U/S

Urologist may decide to cease CIC in select cases if:

- Continuous dribbling of urine with an empty bladder
- MCUG – no VUR
- Normal renal U/S
- No UTIs
- Normal Bowel function

It is important to continue and comply with CIC if:

- Residual urine/dry intervals
- Renal U/S shows ureteric dilation/ pelvicalyceal dilation
- MCUG shows reflux/ small trabeculated bladder
- UTIs
- Constipation

- Baseline DMSA (at the discretion of the Urologist)
- Book U/S of renal tract & CNS bladder function review at 3 months of age
- Ongoing review of CIC by SRT CN/CNS
- Urodynamics done selectively if required

**Combined Clinic with above results**

- Baseline DMSA at 3 months
- U/S renal tract & review at 3 months
- Consider circumcision
- Ongoing review of CIC by SRT CN/CNS
- Continue CIC x 5 per day
- Urodynamics done selectively if require

**Combined Clinic with above results**

- 6 monthly U/S of urinary tract & bladder function assessment for 18 months
- Post 18 months, annual review with U/S and bladder function assessment
- Urodynamics only done selectively for specific clinical indications

**Review with results in combined clinic every 6 months**