CLINICAL GUIDELINE	
Myelomeningocele: Infant Care	
Scope (Staff):	Nursing and Medical Staff
Scope (Area):	NICU KEMH, NICU PCH, NETS WA

This document should be read in conjunction with this DISCLAIMER

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 co-ordinated 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.

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.
    - Complete Allergy Reporting Form MR120 and place in notes.
    - 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; all infants should have daily head circumference measurements.
- 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 (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.
    - Hold in place with tubular netting.
    - 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 use of sleek.

- 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.
- 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 in anticipation of developing hydrocephalus.
- **Wound care**: Dressing left intact as per post op orders of Neuro and Plastic Surgeons. Refer to Stomal Therapy/CNC 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 Stomal Therapy/CNC Spinal Rehab if further treatment is required.
- **Bladder Care**: Indwelling catheter to be inserted at time of surgery - to remain until MCUG or until assessment of bladder function. (Can be removed at end of MCUG).

  Urinary retention is common due to abnormal innervation of the bladder causing a neurogenic bladder. A renal and bladder ultrasound and MCUG are routinely performed in all infants. In addition the SRT Nurse measures residual urine volumes to determine if intermittent urinary catheterisations (CIC) should be performed.

If the following features are present:

- Significant post void residuals
- Long dry intervals (retainer rather than dribbler)
- USS shows pelvicalyceal or ureteric dilatation
- MCU shows reflux or small trabeculated bladder

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Then CIC to commence

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

If none of these features are present:

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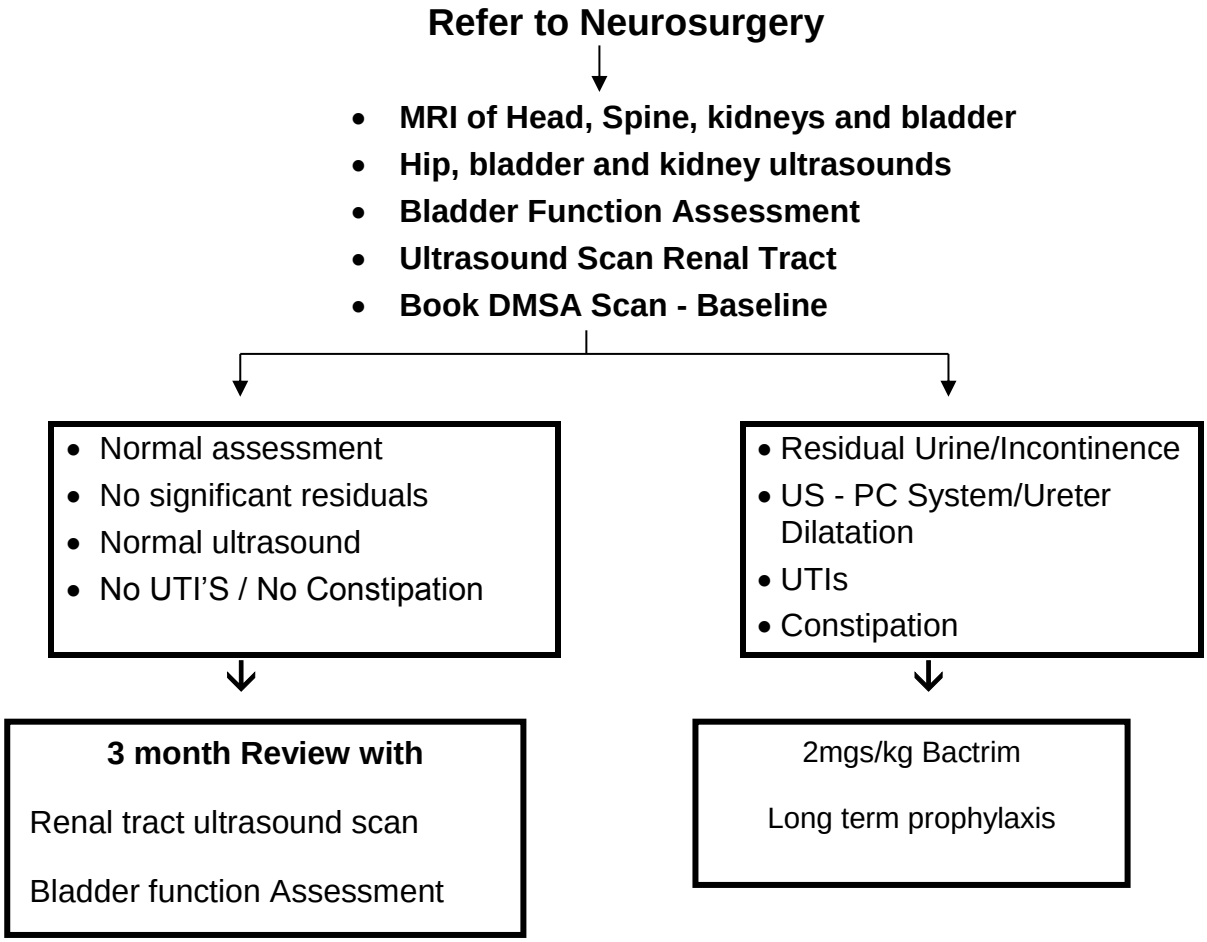
No CIC but stay on Bactrim

Please follow CAHS Clinical Practice Manual - Urinary Catheterisation: Intermittent Self Catheterisation (For Parents) and Urinary Catheterisation: Insertion and Management (For Nursing Staff).

- **Treatment dose 5 mgs/KG Trimethoprim should continue for 5 days post MCUG followed by 2mg /kg once daily prophylaxis.**

- **6/52 Follow up combined Rehab/Urology/CN with renal tract ultrasound and bladder function assessment.**

Neuro-Urology Protocol for Closed Spinal Lesions



Orthopaedics

Assessment **if there are concerns regarding** bone anomalies of the legs.

Discharge

- If the infant is to be nursed prone refer to Home Monitoring Clinic for apnoea home monitoring.
- Follow up by the Spinal Rehabilitation Team (which includes neurosurgery, orthopaedics and urology reviews.) as requested.
  - Open lesions - 6 week combined rehab/urology/CN with renal ultra sound scan and bladder function assessment outpatient appointment.
  - Closed lesions – 3 month combined rehab/urology/CN with renal ultra sound scan and bladder function assessment outpatient appointment.
- Neonatal clinic as indicated for general neonatal and developmental follow up.

Related CAHS internal policies, procedures and guidelines
CAHS Clinical Practice Manual - Urinary Catheterisation: Intermittent Self Catheterisation (For Parents)
CAHS Clinical Practice Manual - Urinary Catheterisation: Insertion and Management (For Nursing Staff)

References and related external legislation, policies, and guidelines

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. Advances in Neonatal Care. 2006; 6(4) 181-196
5. Liptack GS, Dosa NP. Myelomeningocele. Pediatrics in Review Vol. 31 No. 11 November 1, 2010 pp. 443 -450
6. Spinal Rehabilitation Team (P.M.H.) Perth Childrens Hospital 2017.

Useful resources (including related forms)

https://www.spinabifidaassociation.org/resource/latex-allergy/

This document can be made available in alternative formats on request for a person with a disability.

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