

MCN for Neonatology

West of Scotland

Neonatal Guideline



Assessment and Management of Babies with Spina Bifida

Introduction

This guideline describes the assessment and management of babies with spina bifida (SB). It is applicable to all healthcare professionals caring for mothers and babies in the West of Scotland.



Figure 1. Myelomeningocele

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Antenatal management

- Following suspected diagnosis of SB the family should be offered review by their local fetal medicine specialist. This appointment should be within 3 working days and will consist of a detailed ultrasound assessment of their baby, and if confirmed an explanation of the identified SB. Fetal karyotyping may be offered locally, particularly if the anomaly is not isolated. The implications for long term (childhood and adulthood) outcomes should be discussed including mobility, bladder and bowel dysfunction. The following management options should be discussed; surgery after birth, fetal surgery or termination of pregnancy.
- The family should be offered referral to the regional fetal medicine centre for more detailed discussion as to the severity of the SB and the management options. The option of fetal therapy requires certain criteria to be met including:
 - Singleton pregnancy
 - No serious maternal medical or obstetric history
 - Defect commencing between level L1 and S1 with hindbrain herniation
 - Gestational age between 19+0 and 25+6 at time of proposed fetal surgery
 - Fetal kyphoscoliosis less than 30 degree
- Written information leaflets and links to appropriate support groups should be provided. The regional fetal medicine team will facilitate further counselling of the parents by the neurosurgical and neonatal teams if required to aide their choice of management.

- If the family wish their baby to be considered for fetal or neonatal surgery ongoing antenatal care of the pregnancy, the surgical procedure, place and mode of birth, neonatal care and childhood follow-up will be discussed by the multidisciplinary team. Amniocentesis and fetal MRI are required for pregnancies wishing onward referral to London/Leuven for fetal surgery. If the family request termination of pregnancy the regional fetal medicine specialist will support the parents by making the appropriate arrangement in conjunction with their local team.
- The ongoing antenatal management will be shared by the local and regional fetal medicine teams.
- Planned delivery of the baby will be arranged at the Queen Elisabeth University Hospital for all pregnancies on a neonatal surgery pathway within the West of Scotland, and for all pregnancies within Scotland that have undergone fetal surgery.
- Timing and mode of delivery will be determined by a number of factors including fetal surgery, size of defect, maternal obstetric history and ongoing fetal surveillance.
- The family should have the opportunity to tour the neonatal unit and meet the infant feeding team before delivery.
- Perinatal management plans should be documented clearly in the maternal electronic records.

Delivery room management

- The baby should be assessed and stabilised as per NLS guidelines.
- They should be kept prone or side lying (to avoid pressure on the sac or nerves) unless a supine position is required for cardiorespiratory stabilisation.
- The defect should be covered with occlusive wrapping (e.g. *Clingfilm*) for protection and to minimise heat loss.
- Exposure of the baby to latex should be avoided to reduce their risk of developing subsequent latex sensitivity.
- The family should have the opportunity to see their baby prior to transfer to the neonatal unit. If possible a delivery room cuddle may be facilitated with care taken to protect the integrity of the sac.



Figure 2. Myelomeningocele

Management in the neonatal unit

- The baby should be admitted under joint care of neonatal and neurosurgical teams, and the neurosurgical registrar should be informed of the admission.
- The baby should be nursed prone in an incubator to protect the defect and prevent heat/fluid losses. The bed should be horizontal with no incline unless directed otherwise by neurosurgeon. Pupil size and level of consciousness should be documented along with routine observations.
- The occlusive wrapping should be carefully removed and the defect assessed for size, location, covering and evidence of CSF leakage. Ideally medical photography of the defect should be arranged to coincide with this. If there is a CSF leak intravenous cefotaxime should be prescribed.
- If the area is soiled it should be irrigated with sterile 0.9% sodium chloride using a 20ml syringe to clean it. The skin should be dried and the defect covered with an appropriately sized Mepitel (silicone) dressing and a non-adherent absorbent dressing (e.g. Interpose). If significant CSF leakage persists extra sterile swabs may be required. Surgifix size 5 or 6 is positioned over the dressing to hold it in place. A barrier should be placed between the dressing and the anus to prevent soiling. Tape should be avoided to preserve skin integrity.

- The baby should be examined for associated anomalies and signs of neurological dysfunction including abnormal lower limb tone or movements, fixed deformities, reduced anal tone, palpable bladder and poor urinary stream. The OFC should be measured and plotted along with birth weight.
- If the baby has been born out with the regional surgical centre the timing of transfer should be discussed on a conference call coordinated by the *ScotSTAR* neonatal transport team (emergency contact number 03333 990 222), and including the receiving neurosurgical and neonatal teams. If the baby is born overnight this discussion can take place the following morning unless there are specific concerns that necessitate earlier discussion..
- The baby can be enterally fed unless fasting for theatre.

Preoperative workup in regional neonatal surgical centre

- Cranial and renal ultrasound scans should be requested. These are routine scans that can be performed during normal working hours.
- The neurosurgical team will assess the need for any further preoperative imaging e.g. MRI of brain and spine and they will arrange this as necessary. Ensure the MRI consent form is completed and signed by the parents and neonatal consultant to avoid any delay to imaging.
- Take preoperative bloods – FBC, routine biochemistry and two group and save samples. Rarely the neurosurgical team will require X-match but they will indicate if they want this.
- Take routine admission swabs for microbiological culture, which may inform the choice of subsequent antibiotic therapy.
- Contact medical illustration to arrange clinical photographs if not already done, get parental consent for these.
- Arrange non urgent orthopaedic and urology reviews: bleep orthopaedic registrar on 18421 and inform on call paediatric surgical registrar of baby's admission.
- Commence intravenous vancomycin at 6 am on the day of back closure (even if baby is already on cefotaxime). If back closure is not undertaken before the baby is 48 hours old then all babies with CSF leak should have vancomycin added to their prophylactic antibiotic regime.

Peri / postoperative management

- If not already inserted an indwelling urinary catheter should be placed in the neonatal unit prior to transfer to theatre for back closure. The catheter should remain in situ until the baby can be nursed on their back and the commencement of clean intermittent catheterisation (CIC) is planned – see below. This is primarily to ensure that the urinary tract is decompressed but also helps to prevent urinary contamination of the back wound.

- The baby should be nursed prone or side to side to prevent soiling of the wound. The bed should remain horizontal with no incline unless directed otherwise by neurosurgeon.
- Regular postoperative nursing observations / neuro observations as requested by the neurosurgical team, this will include assessment of pupil size and level of consciousness.
- The baby should be monitored for pain using a validated assessment tool, and appropriated analgesia provided as per local guidelines.
- The wound will be dressed in theatre. The dressing should remain in situ until instructed by the surgical team – this is likely to be a minimum of 48 hours - a wound swab should be collected at the earliest sign of inflammation.
- IV antibiotics should be continued for 48 hours post operatively. Thereafter the baby should be commenced on prophylactic trimethoprim 2mg/kg once daily. Suspected infection of the central nervous system should be discussed urgently with the local microbiology team.
- The OFC should be measured daily and the baby assessed for any signs of increasing intracranial pressure.
- A repeat cranial ultrasound scan should be performed 48 hours post surgery and initially twice weekly thereafter. (If a ventriculo peritoneal shunt is subsequently required then refer to Congenital Hydrocephalus Guideline for pre / perioperative management but check baby's microbiology results for organisms that might influence the choice of perioperative antibiotic cover.)
- Physiotherapy assessment and management should commence as soon as appropriate after surgery with a formal assessment of muscle function performed ideally before 10 days post operatively.
- The decision to commence CIC is made in conjunction with the urology team once the baby can be nursed on their back. It is best started during the working week when the urology specialist nursing team are available to perform bladder assessment and to train the family in the technique. They are contactable as follows; Susan McCartney (85764), Yvonne Maxwell (85801) or Mark Craig (85765), or via Royal Hospital for Children switchboard (0141 201 0000) for outside calls.
- Oxybutynin 0.2mg/kg twice daily should be started once CIC has commenced.
- Once the back wound is stable and the baby can be moved and positioned normally arrange an MCUG and a hip US (these investigations can only be undertaken in the radiology department) and inform urology and orthopaedic teams when these investigations have been performed. These investigations should be performed prior to discharge.

Discharge planning

The neonatologist / neonatal discharge liaison nurse should co-ordinate an MDT meeting at least seven days prior to anticipated discharge date to ensure all necessary follow up is in place. This should include:

An appointment at the combined (neurosurgery/orthopaedics/urology) spina bifida clinic which runs on the second Monday of every month. The timing of the first review is generally determined by the neurosurgical team and follow is usually:

- Neurosurgery follow up 1-3 months specified by neurosurgical team on a case by case basis.
- Urology follow up 3 months with repeat renal tract ultrasound followed by DMSA scan at 6 months.
- Orthopaedic follow up 6 months unless receiving ongoing treatment for talipes or dislocated hips.

In addition all babies should be referred to their local Child Development Centre at discharge. Routine neonatal follow up is not required unless there are co-existing neonatal morbidities.

Document Properties

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Implementation and review dates

Implementation date	01/07/25	Next review	15/05/28
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Appendix 1

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CHECKLIST FOR BABIES BORN WITH SPINA BIFIDA

(Use in conjunction with the WoS Neonatal Guideline on "Assessment & Management of Babies with Spina Bifida")



Date done

Pre - op

Cranial ultrasound _____

Renal ultrasound _____

FBC, biochem, G&S x 2 _____

Screening swabs _____

Clinical photographs _____

Inform urology team _____

Inform orthopaedic team _____

Operation day

Start vancomycin at 6 am _____

Insert urinary catheter in NICU _____

Post – op

Measure OFC daily _____

Stop IV antibiotics after 48 hours _____

Start trimethoprim 2mg/kg _____

Cranial USS 48hrs post op (then twice weekly until stable)

Urology nurse assessment	_____
Remove catheter once CIC started	_____
Start oxybutinin once CIC commenced	_____
Physio charting by day 10 post op	_____
MCUG	_____
Hip ultrasound	_____

At discharge (ensure all involved teams happy to discharge)

MDT pre discharge meeting including health visitor

Book appointment at combined spina bifida follow up clinic,
timing determined by neurosurgeons

Renal USS / DMSA @ 3 months, clarify with urology team who
should order these

If ongoing orthopaedic management for talipes / dislocated hips
clarify timing of follow up

Refer to local Child Development Centre

No routine neonatal follow up (unless co-existing neonatal
morbidity)