CenTre Neural Tube Defects

Trust ref: C10/2025

1. Introduction and Who the Procedure Applies to

This guideline is aimed at all health care professionals involved in the care and transfer of infants within the CenTre neonatal transfer service.

Aim

- The location of local neonatal/paediatric neurosurgical team
- Specific management issues related to the transfer of babies with neural tube defects
- Identifying relevant clinical management issues related to the transfer of babies with neural tube defects

Key points

- The paediatric neurosurgical team based at QMC Campus of Nottingham University Hospitals NHS Trust are located on Ward E40, they will generally accept babies >2kg
- Babies with neural tube defects must be transferred prone, or side-lying if this is not achievable
- Using absorbent (incontinence pads) is generally indicated for this group of babies
- Direct dial numbers for paediatric neurosurgery lead nurses:
    - 07811 069006
    - 07812 276732

Abbreviations used within this document:
NTD – Neural Tube Defect
EMNODN – East Midlands Neonatal Operational Delivery Network
LNU – Local Neonatal Unit
NICU – Neonatal intensive care unit
SCBU – Special Care Baby Unit

2. Standards and Procedures

NTDs are a group of birth defects in which an opening in the spine or cranium remains from early in human development. Current incidence of NTD is around 12 per 10,000 (0.12%) of live births[1]. EMNODN incidence is anecdotally noted to be increasing, the latest record being 13.6 per 10,000 pregnancies.

NTDs are classified into 2 main groups, **open** and **closed** defects, with open defects being the more common. Open defects occur when the brain, spinal cord and/or meninges are exposed through a defect in the skull or vertebrae and skin. Closed defects are covered by skin or other membranous layer (see appendix).

Myelomeningoceles (open Spina Bifida) are the most common NTD that are likely to require transfer to a neurosurgical centre. Anencephaly is the most common NTD but most infants die within a few hours, however, babies with anencephaly could potentially be transferred.

A significant number of the babies with NTDs will have been diagnosed antenatally and the parents will have received further counselling, usually from a Consultant Neurosurgeon. Some of these babies will have therefore been born in the neurosurgical centre, however, there are always situations where the babies have been born elsewhere or have been diagnosed postnatally. It is these babies that will require transferring to the neurosurgical centre.

Neuorosurgical Team Location

The paediatric neurosurgical team based at QMC Campus of Nottingham University Hospitals NHS Trust provides care for the EMNODN region as well as Peterborough and Northampton. They have the paediatric ward E40, located on E-floor in East Block. Staff on E40 are always available to give advice over the phone should the need arise, and the specialist nurses for paediatric neurosurgery can be contacted on:

- 07811 069006 or 07812 276732

The paediatric ward can take well newborn term & near-term babies once initial assessment has been performed on NICU/LNU/SCBU. Babies less than 2kg would not routinely be admitted to E40 and would therefore need transfer to NICU. Communication with the Paediatric ward is imperative to ensure the safest care location.

The next closest neurosurgical centres are in Sheffield and Birmingham.

Transport Management

The referring unit may have discussed the baby with the receiving neurosurgical team before contacting CenTre, and therefore a care-plan will have been decided and should be followed. If the referral has come direct to CenTre before the referring unit has sought advice from the local neurosurgical team or if they were unable to contact the team, we can arrange a conference call with the Transport Consultant, the referring team and the Nurse in-charge on Ward E40.

Closed lesion NTDs will, at most, require a ‘nurse-only’ transfer. If the baby’s condition allows, it may be advisable for the baby to be discharged home and allow the family to take the baby to the appropriate neurosurgical centre. Open lesion NTD’s should be transferred with a nurse and medic.

Clinical Management

Airway & Breathing

The majority of babies with NTDs requiring ambulance transfer will not have respiratory problems any more significant than supplemental oxygen, however, babies with

myelomeningoceles and a significant hydrocephalus may be susceptible to airway compromise owing to increased neck flexion if lying supine[2].
These babies must always be transferred prone, and can then be nursed prone or laterally in the hospital setting.
Babies with encephaloceles may have breathing impairment either because of airway obstruction or central apnoea. A clear transfer plan will need to be identified at the time of referral.

Fluids

Open lesion NTDs have an increased risk of fluid loss, however, as this is not from the central compartment the risk is low. Standard intravenous fluid infusion regimens should be applied that are appropriate for the baby's age.
If the baby has been taking full enteral milk feeds it is advisable to stop feeds and use intravenous fluids unless the transfer is less than 1 hour travel time.

Sepsis

Closed lesion NTDs do **not** require antibiotic prophylaxis. The NUH Neurosurgical team do not recommend antibiotics for babies with open lesion NTDs unless there is clinical evidence of infection. In this event, commencing first line early-onset intravenous antibiotics as per local policy is all that is required.

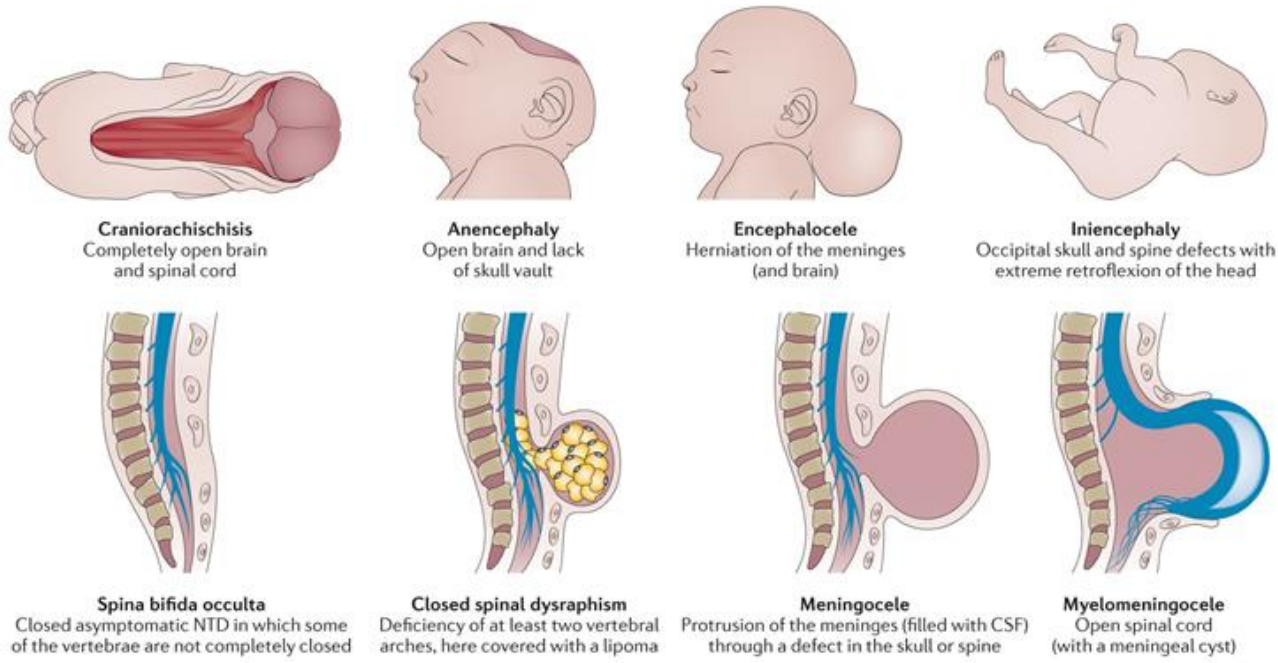
NTD Care & Positioning

All babies transferred with NTDs must be positioned prone. Side-lying is an acceptable alternative if the equipment allows.
Although myelomeningoceles can be found in most spinal regions, the majority are located in the lower lumbar region of the spine. In this instance it is not possible to nurse the baby wearing a nappy and so they will need to be nursed on an absorbent sheet (inco. pad).
Persistent 'dribbling' incontinence from bladder and/or bowel dysfunction can cause skin excoriation; this may worsen with motion vibration.
Lower limb movement may be reduced or absent.
Open lesion NTDs require dressing with saline soaked gauze covered with cling-film, and the gauze should be kept soaked and changed at least 4 hourly to prevent the defect adhering to the gauze.

Clinical Observations

Physiological monitoring and observations should be performed in accordance with CenTre guidelines and the clinical condition of the baby.

Appendix 1 – Types of NTDs



Types of NTDs[3].

3. Education and Training

None

5. Supporting References

1. Khoshnood B, Loane M, de Walle H, et al. Long term trends in prevalence of neural tube defects in Europe: population based study. October 2015. BMJ 2015;351:h5949. doi: https://doi.org/10.1136/bmj.h5949
2. Resuscitation Council (UK). 2016. **Appendix 4: Antenatally diagnosed conditions that require forward planning.** Newborn Life Support, 4th Edition, pp99-100.
3. Copp A J, Adzick N S, Chitty L S, *et al.* **Figure 1: Overview of neural tube defects**. April 2015. Nature Reviews Disease Primers. https://www.nature.com/articles/nrdp20157/figures/1

6. Key Words

Myelomeningocele, Anencephaly, Neurosurgery, Hydrocephalus, Encephalocele, Lesion

The Trust recognises the diversity of the local community it serves. Our aim therefore is to provide a safe environment free from discrimination and treat all individuals fairly with dignity and appropriately according to their needs.
As part of its development, this policy and its impact on equality have been reviewed and no detriment was identified.

EDI Statement

We are fully committed to being an inclusive employer and oppose all forms of unlawful or unfair discrimination, bullying, harassment and victimisation.

It is our legal and moral duty to provide equity in employment and service delivery to all and to prevent and act upon any forms of discrimination to all people of protected characteristic: Age, Disability (physical, mental and long-term health conditions), Sex, Gender reassignment, Marriage and Civil Partnership, Sexual orientation, Pregnancy and Maternity, Race (including nationality, ethnicity and colour), Religion or Belief, and beyond.

We are also committed to the principles in respect of social deprivation and health inequalities.

Our aim is to create an environment where all staff are able to contribute, develop and progress based on their ability, competence and performance. We recognise that some staff may require specific initiatives and/or assistance to progress and develop within the organisation.

We are also committed to delivering services that ensure our patients are cared for, comfortable and as far as possible meet their individual needs.

CONTACT AND REVIEW DETAILS	
Guideline Lead (Name and Title) Original Guideline (T Styche)	**Executive Lead** Chief Nurse
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Details of Changes made during review:

Date	Issue Number	Reviewed By	Description Of Changes (If Any)
Jan – April 2020	**1**	CenTre governance team	**New**
Feb 2025	**2**	CenTre governance team	**New to UHL PAGL**