Title of document	**NWNODN Guidance on Referral and Transportation of Palliative Care Babies - End of Life Plan of Care**
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NWNODN Guidance on Referral and Transportation of Babies
Content

NWNODN Guidance on Referral and Transportation of Babies
For End of life care plan

Referrals of babies with an End of Life plan of care to the Northwest Neonatal transport teams are infrequent, but require specific and careful management. These transfers may include repatriation back to the local neonatal unit or for hospice care.

1. Hospice transfer:

Referral to a hospice may not involve cot bureau or transport team, if their own team or Rainbow Trust transfers the baby. Some hospices will transfer babies, but not always on call or if require respiratory support. If a baby is to be referred to a hospice for compassionate extubation, the transferring doctor may be required to stay for extubation and to certify the death depending on local policy. Contact the hospice at the earliest convenience for clarification, **prior** to discussion with parents.

1.2 Criteria for hospice transfer

All hospices will accept babies for end of life care. All hospices will also accept babies who have already died if parents would like to spend more time with them. They will cancel respite to be able to accommodate all end of life care, so it would be very rare to them not to accept a referral. There are no specific criteria for acceptance into a hospice – just ring them and discuss the baby.

Hospices do not run a 9-5 Monday to Friday services. They are able to accept referrals at any time of day and would prefer you to ring as soon as you know of a potential referral. As neonatal doses of medication are difficult to acquire quickly in the community, the local neonatal team will need to arrange some anticipatory medication (guide in Advanced Care Plan -ACP). These drugs can be provided by the trust pharmacy to take out of the hospital. These drugs should be given directly to the parents or hospice. Connect NW will not be responsible for transferring the drugs if they are undertaking the transfer, these can be given to the family as in normal discharge medication. Information on NWNODN website, ' Care plan for babies receiving palliative care at home or hospice'.

1.3 Prescription for 'Out of Hospital' Palliative care

The drugs to prescribe are a one week course of:

Paracetamol 10 mg/kg/dose PRN OG/NG (6-8 hourly/max 4 doses in 24hrs)
Morphine Sulphate 50 micrograms/kg/dose PRN OG/NG (4 hourly/max hourly) **[put 12 hrly for pharmacy dispensing]**
Buccal midazolam 100 micrograms/kg/dose PRN (4 hourly/max hourly) **[put 12 hrly for pharmacy dispensing]**
Plus any other drugs as per plan of care

Further prescribing advice of controlled drugs is available from the BNFc, Local Trust Datasheets and the Association of Paediatric Palliative Care Formulary.

2.0 How To Transfer

2.1 Hospital to Hospice Transfer

There are four main methods of transfer from hospital to hospice:

1. Parents own vehicle
2. Hospice vehicle (hospice staff will do the transfer, parents can travel with them
3. Rainbow Trust(Sean Tansey, Family Support Manager - NW Team.Rainbow Trust Children's Charity.

   DDI: 0161 628 2194
   Mobile: 07827 878 205

4. Ambulance (one parent/carer can travel with them providing sufficient seating is available within the ambulance)

If the baby does not need respiratory support the first three options are ideal. It is more likely that they will be transported in the Hospice vehicle due to parental confidence. All that is needed is a car seat – however with planning the hospice can supply this.
If an ambulance transfer is required for a baby who does not need respiratory support or the use of a transport incubator, then this will be undertaken by the referring neonatal unit staff. A NWAS ambulance vehicle is available within a 2 hour window on a 24/7 basis for palliative care transfers where the patient is not expected to survive beyond 48 hours. In other circumstances an ambulance vehicle would normally be available within a four hour window and the transfer would be undertaken by the neonatal unit staff.

If the baby is receiving any form of respiratory support the following considerations need to be made prior to transfer

1. Is the ventilator / CPAP required for transfer?
2. Do you think the baby is going to die quickly once the respiratory support is removed?
3. If the plan is to transfer on respiratory support then the plan should be discussed about stopping it following arrival at the hospice and carry out a compassionate extubation there or remove CPAP there.
4. It is much easier to move a baby without respiratory support and this decision must be made with the parents.
5. If respiratory support is to continue for the transfer then an ambulance must do the transfer.
6. The Transport team will not be available to stay once at destination, to support in compassionate extubation, and a clear plan needs to be in place, as acute intensive care transfers will always take precedence.
7. A doctor or other suitably qualified practitioner from the referring unit will accompany the Connect NW transport team, or meet them at the destination, to manage this in a controlled and unrushed manner. The referring unit staff will need to organise return transport to their place of work.

2.2 Transfer to home

Currently the Connect NW transport service does not transfer discharged babies home, regardless of needs e.g. respiratory support, fluids, suction, pumps. Paediatric transport team NWTS may be contacted if the baby is >2kg on 08000 84-83-82. Please give at least 24-48hours notice if possible.

Please ask referring consultant to contact their local community paediatric and palliative care nursing team team for further support and advice.

3.0 Documentation

3.1 NWNODN Advanced Care Plan (ACP)

Before referral, the Advanced Care Plan (ACP) should be completed by the referring consultant. This is available in all Northwest Neonatal units and on the NWODN neonatal network website http://www.neonatalnetwork.co.uk/nwnodn/palliative-care/

This Plan of Care form is a document recognised by the referring and receiving hospitals and the ambulance service to ensure that resuscitation is not commenced inappropriately. If this form is not completed, and the baby deteriorates the ambulance personnel are required to resuscitate.

3.2 Advanced Care Planning and Rapid discharge

The Child and Young Person's Advance Care Plan should be completed for any baby being transferred to home or hospice for end of life care. The ACP must be discussed with parents and completed for any baby being transferred to home or hospice for end of life care. Both documents have been a collaborative development by the North West Children & Young People's Palliative Care Clinical Network (NWCYPCCN) and North West Ambulance Service (NWAS). A clear plan for management of deterioration or death in transit needs to be documented.

All local hospices have agreed to use the NWNODN Neonatal palliative care document for transfer, and will then update documentation as required. However receiving teams may request a specific ACP to be completed therefor early liason with local teams is essential.

4.0 Transfer process

When requesting an ambulance for this type of transfer (and it does not involve Connect NW or NWTS, and there is no clinical member of staff accompanying baby), please inform ambulance control of active plan of care, and Advanced Care Plan in place during booking. A speciality palliative crew will be dispatched within a two hour window (see 2.1).

The North West Ambulance Service (NWAS) require the paramedic crew to discuss the plan of care, documentation and the baby's condition with the parents and the referring consultant before transfer. As this may cause further distress to the parents, they should be informed of this by the referring team. They should be advised not to travel ahead of the ambulance. If parents cannot be present at the time of transfer, ambulance control must be informed at booking.

Paramedic vehicles should be used for any palliative baby, no matter how stable the baby may be, as per NWAS guideline. (Please discuss with NWAS when booking ambulance)

If a baby is expected to require respiratory support and the assistance from Connect NW or NWTS, then this should be discussed at least 48 hours in advance in order that appropriate arrangements can be made. Transfers supported by Connect NW will normally take place during weekdays, to ensure that the correct staffing is available.

4.1 Parent/carer Accompanying Transfer:
One parent/carer may travel in the ambulance with their baby. He or she must understand that they are not to interfere with care provided and that if their baby deteriorates, the plan of care will be followed. The accompanying parent should complete the parent behaviour contract. If the mother is accompanying her baby, she must be safe to travel and fully discharged from obstetric care.

The transport team and/or NWAS crew have to right to refuse transfer of the parent if deemed necessary at any point.

4.2 Deterioration during transfer:
If deterioration is likely or expected during the transfer, or if concerns are raised by any individual, a senior doctor who knows the patient should accompany the Transport Practitioner and baby. If deterioration is not expected during the transfer, the baby is stable and the transport team and the referring consultant are all in agreement, then a Transport Practitioner may transfer the infant alone. If team caseload is acceptable, a second Transport Practitioner may attend for support.

The transport staff will discuss and agree with the family prior to departure what action should be taken in the event of a deterioration during transfer, aiming to follow the end of life care plan where possible but also to facilitate some time at at the hospice and avoid a death in transit. Any changes to the plan which are applicable during transfer should be documented.

Normal road speed should be observed. Lights and sirens are used at the discretion of the paramedic crew.

The baby should be transferred to the predetermined receiving site, preferably closest to where parents live. No diversion to alternative destinations should be made, unless part of the agreed plan of care.

4.3 If death occurs during transfer:
Verification of death is completed at receiving site by appropriate person. Death certification will need to be done by a medical practitioner who has cared for the baby in the last 14 days.

In case of death in the ambulance before arrival, the case may need to be discussed with the coroner.

5.0 Ongoing Care

The Paediatric Palliative care team at Alder Hey should be informed of the transfer for Mersey transfers.
Local hospices will have arrangements for medical cover, this will normally be through the GP, or community paediatric consultants supervising ongoing care. If death occurs prior to the local medical practioner seeing the baby, it will be expected that the referring consultant will complete the Death certificate (MCCD). Please refer to Coroner Notification guideline Oct 2019, if case also needs to be discussed with the coroner.

For further advice following the guidance for symptom management in this guideline. (Guidance for symptom control also available through the NWODN palliative care webpage http://www.neonatalnetwork.co.uk/nwnodn/palliative-care/

All contact details for children's hospices for the Northwest can be found in the Children's North West Palliative Care Services Directory http://www.childrenspalliativenw.org.uk/

6.0 Getting home

It is more gentle a transition to go home from a hospice than from hospital, as there are hospice to home teams. If however, parents feel strongly that they wish to take their baby home for end of life care this is possible with support from local hospices, GP and the community paediatric team, and paediatric palliative care nurses in some areas.
They should all be contacted to facilitate transfer home. The same transfer considerations need to be made as documented in '**How to transfer'**

7.0 Checklist for Hospice Transfer

Check list for hospice transfer		
Referral accepted by hospice		
Drugs prescribed for transfer with baby to hospice (TTO) **In addition to normal medication:** **A one week course of:** • **Paracetamol 10 mg/kg/dose PRN OG/NG (6-8 hourly/max 4 doses in 24hrs)** • **Morphine Sulphate 50 micrograms/kg/dose PRN OG/NG (4 hourly/max hourly) [12 hrly for pharmacy dispensing]** • **Buccal midazolam 100 micrograms/kg/dose PRN (4 hourly/max hourly) [12 hrly for pharmacy dispensing]**		
How to transfer • **If the baby does not need respiratory support :** • **Parents own vehicle, Hospice vehicle, Rainbow Trust or NWAS** ○ **If hospice staff will do the transfer, parents can travel with them. We/parents may need to provide a car seat - check with hospice staff.** • **If the baby does need respiratory support:** ○ **Ambulance (one parent can travel with them). Need to discuss with ConnectNW/NWTS transport team *before* discussion with family.**		
Ambulance contacted if they are doing transfer		
Hospice staff aware of need for transfer		
Transwarmer needed for transfer in own/hospice vehicles (consider for babies <2.5Kg)		
Documentation to be completed: **NWNODN Advanced Care Plan (ACP)** **NWNODN Guidance on referral & transportation of Palliative care babies.**		
The Child and Young Person's Advance Care Plan discussed with parents and completed		
The Paediatric Palliative care team consultant at Alder Hey should		

be informed of the transfer(Mersey transfers only)	
GP and community paediatric consultant informed if involved with ongoing care	
Are all neonatal consultants aware of transfer and that they may be contacted to provide secondary level clinical advice until transfer of care to other professional.	