

Guideline

Transfer of an infant or child to a hospice or home for palliative care

1 Scope

This document is for use within the Paediatric and Neonatal Decision Support and Retrieval Service (PaNDR) in the East of England.

2 Purpose

To provide guidance for the PaNDR team when transferring infants and children with life-limiting conditions to the hospice or home for palliative care.

3 Definitions

EACH East Anglia's Children's Hospices

NGT Nasogastric tube

ReSPECT form – Recommended Summary Plan for Emergency Care and Treatment form

4 Introduction

- Patients must be assessed by a nurse specialist before being accepted by the hospice. This should be arranged by the referring hospital
- Special consideration should be taken when organising the timing of these transfers. For example, some hospices will not accept patients after 17:00 due to changes in their staffing levels and may not be able to take patients over the weekend.
- A nurse from the referring hospital, who knows the family, may travel with the patient if available.
- If not travelling with the team, a member of staff from the hospice will meet the PaNDR team on arrival at the hospice/home. The point at which they take over care should be planned to ensure a smooth transition for the family. If transferring to a hospice the team can stay with the patient/family for a short period if appropriate or remain on site to hold a debrief afterwards. The PaNDR ambulance technicians are also welcome to come into the hospice while the transfer of care takes place.
- A parent will be offered the opportunity to accompany their child during transfer. Due to limited ambulance seating, usually only one parent will

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be able to travel with the team, but if the nurse from the referring hospital does not accompany the infant (or can travel separately) both parents may be able to accompany. This will be discussed on a case-by-case basis.

Consideration should be given as to whether the child needs IV access, particularly if he/ she is on a morphine infusion. It may be that this is removed prior to leaving hospital or upon arrival to either the hospice/ home. A plan must be made by the team at the referring hospital and agreed with the hospice team and the parents. Some patients may have a subcutaneous infusion of morphine. Buccal medication may be prescribed.

- The referring hospital's palliative care team may be involved in the discharge planning and liaison with the hospice
- A ReSPECT form must be completed and signed by a consultant and a copy taken with the patient
- All drugs must be prescribed and dispensed by the referring hospital.
- The referring team must formulate a feeding plan prior to transfer. Adequate NGT and accompanying feeding equipment must be supplied by the referring unit along with compatible syringes (where applicable) and milk.
- Any disposable equipment should be supplied by the referring hospital (such as suction catheters, dressings etc.) and it is the referring units responsibility to arrange transport of this equipment to the hospice or home.
- Conversations regarding the possibility of post mortem examination and the potential for organ donation (if appropriate) should have already taken place at the referring unit.
- The infant/child's GP must be informed of the transfer in advance by the referring team and arrangements made with them (or the GP affiliated with the hospice) to certify the death.
- Prior to departure, the PaNDR team needs to ensure they know how to gain suitable access with the patient to the hospice/ home. For example, if the patient is being transferred home it is unlikely that the transport incubator/trolley will be able to be taken into the house as the majority of front doors have a step leading up to them.
- Prior to departure, the team also need to consider where the ambulance is going to park. If the patient is being transferred home, thought must be given as to whether the road is wide enough to park the ambulance safely.
- Consider whether the patient should be monitored whilst in the ambulance even if this was not being done at the referring unit in order to

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alert the clinical team to any significant changes in their clinical condition. Whilst changes may not trigger any medical intervention, they may alter the course of the transfer and necessitate further communication with the PaNDR consultant and hospice team.

- A plan must be made with parents prior to transfer as to when respiratory support will be withdrawn. It may be that this occurs in the ambulance upon arrival or once the infant/child has reached the hospice/ home.
- A document detailing actions to be undertaken in the event of a cardiopulmonary arrest must accompany the patient on discharge.
- The PaNDR team should discuss the parents' expectations in the event of clinical deterioration and agree on a plan prior to transfer. The team should **not** commence cardiopulmonary resuscitation on the road, though it may be appropriate to provide airway support in the event of acute deterioration to facilitate reaching the hospice.
- If the patient dies prior to the team leaving the hospice / home, the PaNDR doctor, may confirm death and document this accordingly in the PaNDR patient records. The arrangements made prior to discharge for completion of the death certificate will be followed.
- The hospice staff should be provided with a copy of the paperwork from the referring unit and of the PaNDR documentation.

Referral process for all EACH hospices:

- For all EACH Hospice referrals there is a single point of initial contact via the Symptom Management Nursing Service (SMNS) on 01223 815136/ 08454 501053. This applies both within normal working hours and out of hours
- The SMNS will then liaise with the relevant hospice team.

5 The Nook Hospice

Address: EACH, The Nook,
Pigot Lane
Framingham Earl
Norfolk
NR14 7PX

Tel: 01603 967596

Key information:

- For all transfers to The Nook, please liaise with their duty manager.
- The hospice team will not accept any transfers overnight; however, they will be happy to liaise regarding the planning process.

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- The hospice will not accept transfers at the weekend as their staffing levels are not the same during these periods. The team prefer to have a duty manager present for the arrival of a new admission who generally works 09:00-17:00 Monday-Friday. If the team know that a transfer is not coming in until that evening then they will arrange for it to be covered appropriately. In general, if the patient were not ready to leave the referring unit by 17:00 then they would prefer that the transfer is deferred until the following day.
- **Please note:** Intubated patients can be extubated or disconnected from the ventilator either in the ambulance or inside the patient's room. For planned extubations/ disconnections in the ambulance, IPPV can be given until arrival to the patient's room or the infant can just be carried inside without respiratory support. It is important to ascertain parental wishes regarding this prior to transfer.
- Paediatric patients will be transferred into the hospice on the PaNDR trolley and extubated in the patient's room.
- The main entrance to The Nook hospice follows a designated driveway. There is a designated parking space for an ambulance.
- There is a ramp to transfer the incubator/trolley into the main building. Here the duty manager and staff members will greet the team.
- The building is spacious with enough space to manoeuvre the transport incubator/trolley to the patient's room.
- Upon arrival to the patient's room, the team need to be aware that there is only an oxygen port on the wall, no port for air.
- It is encouraged for parents to carry their infant into the hospice. However, they may prefer that a team member assist them. The PaNDR team will ensure their request is facilitated.
- Not all staff in The Nook are trained in IV cannula management. Therefore, it is preferable that the patients have no IV access. Their preference is subcutaneous access or buccal administration of medications. If the patient has an IV morphine infusion, this will need to be changed to subcutaneous or buccal administration.

6 Milton Hospice

Address: Church Lane
Milton
Cambridge
CB24 6AB

Tel: 01223 815115

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Key information:

- For all transfers to Milton please liaise with a member of the leadership team or clinical nurse specialist
- Milton may accept patients overnight and at weekends if the necessary plans/arrangements are in place and there is adequate clinical support. Prior to leaving the referring unit liaise with the hospice team to ensure, they are ready to accept the infant.
- The ambulance can park on the driveway near the main entrance of the hospice. The incubator/trolley can be taken into the hospice via a ramp. The corridors are wide enough for the incubator/trolley to be taken into any of the rooms.
- It is encouraged for parents to carry their infant into the hospice. However, they may prefer that a team member assist them. The PaNDR team will ensure their request is facilitated.
- **Please note:** Intubated patients can be extubated or disconnected from the ventilator either in the ambulance or inside the patient's room. For planned extubations/disconnections in the ambulance, IPPV can be given until arrival to the patient's room or the infant can just be carried inside without respiratory support. It is important to ascertain parental wishes regarding this prior to transfer.
- Paediatric patients will be transferred into the hospice on the PaNDR trolley and extubated in the patient's room.
- Not all staff in Milton are trained in IV cannula management. Therefore, it is preferable that the patients have no IV access. Their preference is subcutaneous access or buccal administration of medications. If the patient has an IV morphine infusion, this will need to be changed to subcutaneous or buccal administration.

7 The Treehouse Hospice

Address: St. Augustine's Gardens
Ipswich
IP3 8NS

Tel: 01473 271334

- Treehouse will consider transfers over weekends following prior completion of a discharge planning checklist by an EACH Symptom Management Nursing Service Clinical Nurse Specialist (SMNS CNS).
- For all transfers to Treehouse, please liaise with their Nurse in charge / SMNS CNS

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- The Ambulance can park outside the main entrance in the designated 'Drop off bay'.
- The corridors are wide enough for the incubator/trolley to be taken into any of the rooms.
- It is encouraged for parents to carry their infant into the hospice. However, they may prefer that a team member assist them. The PaNDR team will ensure their request is facilitated.
- There is piped oxygen and oxygen cylinders on the premises.
- Staff availability and IV requirements would be confirmed prior to transfer being agreed.

8 Little Havens Hospice

Address: Daws Heath Road
Benfleet
Essex
SS7 2LH

Tel: 01702 220350

- This is a 0-19yrs hospice. For all transfers to Little Havens Hospice please speak directly to the care team.
- The ambulance can park outside the main entrance.
- A nurse or member of the team will meet the PaNDR team upon arrival.
- The corridors are wide enough for the incubator/trolley to be taken into any of the rooms.
- It is encouraged for parents to carry their infant into the hospice. However, they may prefer that a team member assist them. The PaNDR team will ensure their request is facilitated.
- There are no on-site doctors, however there are 3 local GPs covering the hospice. Therefore, it is important to communicate with the hospice an expected time of arrival.

8 Keech Hospice

Address: Great Bramingham Lane
Streatley

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Luton
LU3 3NT

Tel: 01582 492339

- This is an adult and children's hospice. Therefore, for all transfers to Keech please liaise with the nurse in charge on the children's inpatient unit.
- Although there is a doctor on-site, it is preferential for admissions to happen on Monday to Friday between 09:00-15:00 (admissions during other times can be facilitated, but this needs to happen with appropriate and early notice).
- The ambulance can park outside the main entrance, accessible to the children's unit. This is situated on the left at the top of Great Bramingham Lane.
- A nurse from the children's inpatient unit will meet the PaNDR team upon arrival. During office hours, the receptionist will alert the hospice team. For out of hours admissions, the PaNDR team will need to ring the bell to gain entry.
- Not all staff in Keech are trained in IV cannula management. Therefore, it is paramount that the patients have no IV access. Their preference is subcutaneous access or buccal administration of medications. If the patient has an IV morphine infusion, this will need to be changed to subcutaneous or buccal administration.

9 Home

- It is important that a member of the hospice team is involved when we transfer a patient to their home.
- It may not be necessary for a nurse from the referring unit to accompany the transfer, but this should be planned in advance with the referring team
- Discussions with the parents regarding accessibility and parking of the ambulance outside their home needs to take place prior to the patient's transfer.
- Thought should be given as to how the child will be taken into the house. For example in neonatal transfers, the transport incubator will not be able to be taken in due to the step up to the front door. In this case parents should decide whether they wish their infant to be carried inside or they could be taken in in a moses basket. The PaNDR team will ensure their request is facilitated.

Please note: As the transport incubator or paediatric trolley may not be able to be taken into the house parents will need to have thought about when they would like the infant to be extubated. This could be done in the ambulance and the infant / child then carried inside, or positive pressure ventilation could be provided using an ambubag until the infant / child is inside the house and extubation be undertaken there.

It would need to be discussed how a larger child can be transferred into the house, such as using a stretcher and how this can be facilitated in a PaNDR ambulance. There needs to be a plan prior to leaving the referring hospital.

10 Monitoring compliance with and the effectiveness of this document

This document is intended for information, guidance and reference when arranging transfers for palliative care patients.

The effectiveness of the document will be monitored by review of any reported incidents via the lead consultant and nurse for risk. These incidents will be shared with the team and consideration given to any amendments if concerns are identified.

11. Equality and diversity statement

This document complies with the Cambridge University Hospitals NHS Foundation Trust service equality and diversity statement.

12. Disclaimer

This document is for PaNDR use only

13. Document management

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