

Rapid transfer for end of life care for children and young people guidance notes (including compassionate extubations outside of PICU/NNU)

Explanatory notes

What is the aim of the guidance?

The rapid transfer for end of life care for children and young people (including compassionate extubations outside of PICU/NNU) guidance has been written by a working party from the Yorkshire and Humber Children and Young Peoples Palliative Care Network. It brings together two previously published network documents – the Rapid Discharge Pathway for End of Life Care and the standard operating procedure for Compassionate Extubations Outside of PICU/NNU.

It aims to support health care professionals in planning and coordinating the rapid transfer of children and young people (CYP) from hospital to home or hospice in the last hours or days of life. It is a framework to guide care and decision making.

It is designed to be used alongside individual advance care and end of life care plans. It exists to facilitate choice in place of care in the last hours and days of life for CYP with life limiting / life threatening illness when their family have expressed a wish for their child to die at home, in a hospice or other hospital.

The documentation is intended to be used for children and young people aged 0-18 years of age who are likely to die within the next few hours or days and for those who may be considered for compassionate extubation outside of the critical care setting.

Throughout the guidance the term child / children refers collectively to infants, children and young people aged 0 to 18 years of age.

It aims to guide and document decision making and plans. It should not be a substitute for effective direct communication between professionals and family members.

Who is it for?

The guidance and documentation is designed to be used for children where a consensus decision has been made by a child's family and the multi-disciplinary team that a child is likely to die soon and if the family wish for them to die at home, hospice or other hospital. Some families may have identified their preferred place for end of life care through prior advance care planning.

Rapid transfer may not be an option if a Coroner's post-mortem is likely to be required (this should be discussed with the coroner), major organ donation is requested, or if the MDT judge that a child's deterioration may be too fast to ensure safe and effective transfer to the families preferred place of care (this should be explicitly discussed with the family)

When should it be used?

This guidance should be considered as soon as it is clear that death is likely to occur soon or if a decision has been made with the family for the child to be compassionately extubated. The recognition of dying is complex; irrespective of previous diagnosis or history. The diagnosis of dying should be made by the MDT and the decision to consider a rapid transfer from hospital should be identified as urgent care and will need a fast response from the MDT in hospital, community, hospice or local hospital.

Prior to discussing choices with the family it is essential to liaise with other agencies (specialist palliative care services; community nursing; hospice; local hospital, and transport teams) to discuss the possible options for rapid discharge. This should include whether or not end of life care at home is an option and if there is access to 24 hour support locally. Children's hospices may be the preferred option for end of life care if there is

limited community support, if a child has complex health needs, or if the child and family are already known to the hospice.

It is important to be realistic about the time frame needed to organise a rapid transfer for end of life care, particularly when care is complex. The family need to be involved and kept informed about all decision and plans of care, including any changes that are made to that plan.

Additional support and advice

Additional support and advice in completing this document or for palliative care and symptom management advice can be obtained from any of the 4 children's hospices in the region.

Bluebell Wood Children's Hospice	01909 517 369
Forget Me Not Children's Hospice	01484 411 042
Martin House Children's Hospice	01937 844 836
St Andrews Children's Hospice	01472 350 908

For Leeds Children's Hospital please contact the Children's Haematology & Oncology Outreach Team **0113 3922323**, or page the Children's Oncology Macmillan Nurse Specialist on call via switchboard or ward L31.

Guidance Notes

Introducing the possibility of rapid transfer to the Family.

This should ideally be done by the child's Lead Consultant but may be introduced by the medical team caring for the child when end of life is imminent. It is the responsibility of the Lead Consultant to ensure that the responsibility for coordinating the discharge is handed over to a lead professional, this may be the senior nurse on duty, specialist nurse, specialist children's palliative care services where they exist or the children's community nurse.

The health professional coordinating the discharge should ensure good communication occurs and that at each stage the family, community/hospice staff are kept up to date.

For children who will have compassionate extubation discuss with the family who will extubate their child and the timing of this following transfer.

The documentation once completed should be copied and kept in the patients notes. The original is given to the family and a copy sent to the principal care team.

Decision to plan for rapid transfer

It is essential that there is clear documentation of the multi-disciplinary decision for end of life care. This must be recorded by the lead treating physician who must clearly document if there is a need for a Coroner's post-mortem and whether or not the child is a potential organ donor.

Prior to discussing with the family, it is essential to identify the level of end of life care support that is available locally. Discuss options for rapid transfer with community and or hospice services before offering the option to the family.

This should include access to 24 hour on call advice or care and support in the home. Whilst access to 24 hour support is ideal if it is not available this will not prevent discharge. Families, however, must be made aware of this and understand what support will be provided.

Document all demographic details of the child and family, the community team, hospice, GP, AHP's and other support services that are or will be involved with the child and family on discharge.

Offer referral for support from the hospital chaplaincy service

Planning for transfer

It is important that the Lead treating physician makes early contact with the Community Paediatrician/GP or Hospice. Although the death of the child might be expected imminently, it is important that parallel planning is made with the outside agencies for the continuing care and support of the child and family in case the child survives. A lead professional responsible for the discharge process should be identified.

Communication with the family

When communicating with the family it is important the following information is shared with the family, so they fully understand and are in agreement with the plans being made.

Limitation of treatment agreement / ReSPECT Ensure that the family are aware of the plan for their child's care and treatment. This should be documented on a Limitation of Treatment Agreement (LOTA) or ReSPECT form.

Death in transit. The family should be made aware of this possibility and the plan for what should happen. If being transferred by ambulance the team need to be aware of where the child should be taken - home/hospice.

Non-essential medication/equipment discussed and discontinued. The aim of care to ensure that comfort and dignity as a priority for the child should be discussed with the family, and that it may be appropriate to reduce or stop monitoring, remove lines and discontinue some drugs.

Pain and symptom management A plan to manage symptoms should be discussed and agreed with the family. This may have previously been documented in an advance care plan. This plan should be documented and shared with all professionals involved in the care of the child. The responsibility in developing the plan will be influenced by the teams involved in care. This may be a specialist children's palliative care team in the hospital or community, hospice services or the treating physician.

The anticipated symptoms as death approaches. The family should be offered the opportunity to discuss how they may expect their child to die and how they may change over the next few hours/days as death approaches. This could include how they may look, change in colour, changes in breathing pattern, possible noisy breathing, secretions, agitation etc and how these symptoms would be managed.

Local team to support family. The family should be made aware of the professionals who will be available to support them once leaving the hospital. Contact telephone numbers must be recorded in the pathway paperwork and given to the family at discharge.

Who will verify the child's death. It is important to clarify who will be available to verify the child's death, particularly if the death occurs out of hours. Where possible, it should be someone known to the family.

Who will certify the child's death. The Medical Certificate of Cause of Death can only be completed by a doctor who has looked after the child during their last illness. This is usually interpreted as a doctor who has seen the child within the last 2 weeks of life. The doctor who completes the medical certificate of cause of death does not have to see the child after death if the death has been verified by another professional. If no doctor has seen the child in the last 14 days then the coroner must be informed. He or she may authorise the issue of a death certificate or initiate further investigations.

In order to facilitate certification of death following rapid transfer home it is essential that, prior to discharge, **a senior doctor is identified from the hospital who is willing to issue the certificate of cause of death**, if the child dies before they have been seen by a doctor at their discharge destination. This doctor's name and contact details must be documented on the documentation. It is the responsibility of the team caring for the child at home to notify this named doctor as soon as possible after the child's death.

Prior to discharge the named doctor at the discharge destination (GP / Community Paediatrician / Hospice Doctor) should be contacted. This person should be asked to review the child following transfer to facilitate

optimum care of the child and family and to take over the responsibility of verifying and issuing the certificate of cause of death when required.

Role of post mortem/tissue donation

Organ/tissue Donation

If a family in partnership with the child's physician has requested organ donation; **Rapid Discharge for EOL care cannot occur.** For some children organ and tissue donation may not be possible because of a child's underlying diagnosis. Advice and support can be sought from the Organ Donation Service 0117 975 7575

If a family in partnership with the child's Physician wishes to request tissue donation; a discussion with The National Blood Service (NBS) on call Tissue Donation Nurse on 0800 432 0559 is essential in assessing if tissue donation is an appropriate option after death. The assessment will identify medical suitability as well as determine the logistical arrangements that will need to be made in order to retrieve donated tissues after the child has died. It will be the responsibility of the NBS Tissue Donation Service to gain consent for tissue donation and to coordinate all aspects of the tissue retrieval following the child's death.

Post mortem:

If there is any concern expressed around the cause of death from either medical staff or the child's family, the coroner must be informed as soon as possible in order to identify the type of post mortem and any specific requirements. **This may be a limiting factor for rapid transfer for end of life care to occur.**

If a family or the child's physician in partnership with the family has identified the need or request for a post mortem following a child's death, this will normally be a hospital post mortem and the coroner does not need to be informed. The arrangements for PM and consent need to be obtained and organised prior to discharge. It will also be necessary to organise transportation back to the hospital.

Sharing information

ReSPECT/LOTA. This should be shared with the named local physician and nursing team. The completed original document should accompany the child on discharge.

End of life and symptom management plan. This should be agreed and documented prior to discharge. This should be shared with the named local physician and nursing team. In some instances the local service may be responsible for generating the plan. If this is the case this should be shared with the hospital team.

Current and anticipated drugs should be provided and an administration prescription for them should be completed. The prescription and medications should accompany the child home. A minimum of 48 hours supply should be dispensed.

Nutrition and feeding plan. If required an agreed feeding plan should be completed and shared with the family. This should be shared with or faxed to the named local physician and nursing team. The completed original document should accompany the child on discharge. An initial supply of feeds and administration equipment should accompany the child on discharge.

Oxygen and HOOF form needs to be completed and faxed/emailed to the appropriate supplier or completed via the oxygen company's online portal. Consent to share information with the supplier must also be sought from the family. The HOOF must be completed following the guidance notes on the document. If the child is being transferred to a hospice this should be discussed with the hospice team first.

Equipment

Plan early with the Community or Hospice service and clearly document who is responsible for supplying what. The hospital would normally be expected to send home enough supplies for a minimum of 48 hrs and ideally 72 hrs. Be aware of week-end and Bank holidays when community/Hospice teams will struggle to get supplies. Pharmacy will also need to be informed as soon as possible to enable them to get drugs ready for discharge

Transportation

Plan as early as possible if the Yorkshire Ambulance or Embrace Service is involved. The service should be made aware of the child's DNACPR status and equipment requirements. The Yorkshire Ambulance service aims to provide a rapid discharge service for end of life care within 3 hours. Embrace transfers are scheduled in response to the demand on the service.

Contact telephone numbers

YAS	0845 120 3192
EMBRACE	0845 147 2472
Palliative Care Ambulance (Leeds only)	0300 330 0263

Transport in an ambulance: Before transfer the ambulance crew will need copies of the transfer document and the ReSPECT/LOTA form.

If a child dies in transit

A plan of action in the event of the child dying in transit should be agreed. This must be recorded on the transfer documentation. This should be discussed and agreed with the family. If the child is to be transferred by ambulance it is essential that this plan is agreed and shared with the ambulance service. Normally the child should be transported home to the planned destination. The GP/Community Paediatrician should be contacted to verify death. The arrangements made prior to discharge for completion of the death certificate should be followed.

In the event of death in transit the responsible coroner in these circumstances is the coroner for the district where the child actually died. This may be different to the coroner for the intended discharge destination. Ideally the death should be notified to the registrar in the district in which the child actually died. However if this is very inconvenient it is possible to notify the death to the most convenient registrar's office but this may result in a delay in processing the relevant documentation.

Family Support

Key professionals involved in the care of the child and family. Please record all key individuals involved with the child and family. It is important that working hours, contact details and any out of hours numbers are recorded.

Community Teams; Continuing Care Services and Hospices require as much notice as possible to set up services to support a child dying at home/hospice. It is important to discuss with the Community Team/Continuing Care Services/Hospice what they can offer the family in terms of support. Early contact with outside agencies will help to speed up the process of discharge

Good liaison will prevent the family having unrealistic expectations of what the Community will do to support them and help them make a decision regarding where they want to be discharged too.

Wishes and plans at the time of death

Discuss with the family and document any specific plans and wishes they may have at the time of their child's death. This may include place of care, cultural or religious practices, preferred funeral director, and tissue donation

Support at the time of death. If known record who will support the family at the immediate time of death. Any details of agencies who will be responsible for providing bereavement care and follow up should be documented.