

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

Explanatory notes

What is the aim of the guidance?

The urgent 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 and has been amended to reflect experience and learning in this area.

It aims to support health care professionals in planning and coordinating the urgent 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 recognised that there is a lot to consider in a successful transfer and as such the paperwork has been produced to ensure each element has been considered appropriately. **It is recommended that each section is completed to ensure a holistic, safe and well thought transfer occurs.**

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.

Urgent 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 an urgent transfer from hospital 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 urgent 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 an urgent 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 /360
Forget Me Not Children's Hospice	01484 411 042 / 040
Martin House Children's Hospice	01937 844 836 / 845 045
St Andrews Children's Hospice	01472 350 908

For Leeds Children's Hospital please contact either the Palliative Care team on **0113 3923507**, 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. Please note, that the Oncology Outreach team can provide help and support, in particular with syringe drivers, including for non-oncological patients.

For Sheffield Children's Hospital please contact **0114 2717633** for the Palliative Nurse Specialist, which in absence is diverted to the Helena specialist nursing team (**0114 22 60600**) [covered 7 days a week 8am-5pm]. The Paediatric Oncology Outreach Nurse Specialists (POONS) number is **0114 2717588**, (ward 6, 0114 2717309, out of hours). They do not generally cover non-oncology patients but would be happy to advise in an emergency.

Guidance notes

Decision making

Introducing the possibility of urgent 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 urgent 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 pot-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 urgent transfer with community and or hospice services before offering the option to the family. These discussions must include parallel planning (see below) in ALL cases.

Ideally this should include access to 24 hour on call advice or care and support in the home. Whilst access to 24 hour support is strongly preferred if it is not available this will not necessarily 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.

Timing of transfer

With good communication and collaborative working it has been possible to complete transfers quickly, even within hours. However, it should also be recognised that appropriate levels of planning including robust parallel planning and ensuring adequate community support, medications and equipment may mean that this process can take significantly longer, often days. Whilst speed is often desired it should never be prioritised over safety and adequate plans. Reflecting on previous cases this has even warranted a change in the name of paperwork from 'Rapid' to 'Urgent' reflecting a recognition that it may be urgent but not always immediate. Families and professionals should be made aware of this fact to ensure a sense of realism and appreciation of what is involved. The stability of the patient, wishes of the family and the risks of delay (or transfer) must all be taken in to consideration and adequately communicated with the family and the professionals involved to ensure informed collaborative decision making.

Planning for transfer

It is important that the Lead treating physician makes early contact with the Community Paediatrician/GP/ community nursing teams/Hospice. Although the death of the child might be expected imminently, it is important that parallel planning is made with the outside agencies (and appropriate specialist teams) 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.

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. Although as mentioned, please consider what would / should happen if the child survives and what medications / equipment should be recommenced including ensuring they are provided (or planned how to source) in the event of survival.

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 4 weeks of life (correct at the time of writing, but please check with appropriate guidance). 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 28 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 urgent 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. It is good practice (and there is space on the paperwork) to agree a cause of death before the transfer, with the obvious caveat that this may change depending upon circumstances following transfer.

Parallel planning

The family should be made aware of the possibility that their child may not die rapidly following discharge from hospital. They should be aware of who to contact for concerns about symptoms in their child. Appropriate plans should be made on how to manage the child in the event of survival. Some examples include feeding, medications to restart, whether readmission to hospital is appropriate and ongoing longer term care options (please include community teams and continuing care in these discussions as early as possible to know what may or may not be possible). Parallel planning is ALWAYS necessary, it is rarely the case where the outcome is absolutely definitive.

Organ/tissue donation

If a family in partnership with the child's physician has requested organ donation; **urgent 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 urgent 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/Limitation of treatment agreement (LOTA)

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. This should be shared with the named local physician and nursing team. The completed original document should accompany the child on discharge and the transport team be made aware of its contents.

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 (allowing for the possibility of escalating symptoms) and potentially longer, particularly if occurring before a weekend / bank holidays.

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.

Practicalities (see also discharge paperwork for other prompts)

Oxygen and HOOF form

This 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 ambulance crew will need copies of the transfer document and the ReSPECT/LOTA form). The Yorkshire Ambulance service aims to provide an urgent discharge service for end of life care within 3 hours. Embrace transfers are scheduled in response to the demand on the service.

Please consider whether an alternative transport service may be more (or equally) appropriate to Embrace. It is worth noting, that Embrace are usually able to facilitate all transfers including those involving ventilated patients. Whilst alternative transport services are likely to only be suitable for non-ventilated palliative patients, as these are run by Patient Transfer Service (PTS) crews and are therefore unable to provide medical intervention during the journey.

Consider and plan (where possible) for someone to join the patient/family on the transfer who know / are familiar with the family. Providing as much support as possible during this difficult time.

Contacts:

- Embrace: **0845 147 2472**
- Palliative Ambulance (Leeds only): **0300 330 0263**
- Palliative Care Ambulance (All other areas run by the Yorkshire Ambulance Service): **0300 330 2000** (This will take callers through to the Reservations Team. YAS also ask that, at the beginning of the call, please advise the call handler that they are making an End of Life booking. This allows the call handler to take the booking through a slightly more straight forward process.)

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 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.

Collaboration / Communication

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.

Smooth and successful end of life transfers are characterised by good collaboration / communication with all appropriate teams.

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.

Please do not forget those professionals who have known and supported the family throughout their life. Even if they are not involved in the transfer itself they will want to be notified and may also be an invaluable support to the family at these difficult times.

Death

Wishes and plans at the time of death

Discuss with the family and document 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.