
Clinical Guidance

Paediatric Critical Care: Palliative Care Transfer to Hospice or Home

Summary:

This guideline is intended for PICU staff who are planning to transfer an infant or child to a hospice or home for end of life care.

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At the end of a child's life, some parents may prefer to spend what is expected to be last hours, days or weeks with their child in a non-hospital setting, surrounded by those they choose. Transfer for ongoing palliative care to a hospice or home provides an opportunity to make this a reality for some families. PICU and Palliative care (PC) should identify responsibilities regarding the following.

Is this appropriate and feasible for the child?

- Meets RCPCH (2015) criteria for treatment limitation¹.
- Involve Palliative Care team (PC) at earliest opportunity.
- Share significant information and answer questions.
- Organ/ tissue donation should be explored. Discuss with SNOD first.
- Discuss with Medical Examiner and Coroner if referral may be required and consider anticipated cause of death.
- Select appropriate children and families to offer end of life care at home or in a children's hospice.
- Discuss pros and cons of hospital/ home/ hospice care.
- Establish family/ child wishes and expectations.
- Reset/ establish reasonable expectations.

Plan for transfer to hospice or home:

- Contact local hospice with parental consent for information sharing – must occur whilst the child is alive in either situation.
- If the hospice is requested, establish if they can facilitate end of life care and confirm preferred date and time for transfer.
- Invite hospice staff to meet family prior to transfer.
- If home is chosen for end-of-life-care, the hospice should be notified in case the parents change their mind and wish for more support or want to use the bereavement suite after death.
- The home environment will need to be evaluated for suitability and access, and the movement of the child within the home considered. Consider a home visit if practical prior to transfer (PC to do if required).
- PC will inform GP of plan to transfer for end-of-life care at the home or hospice.
- The GP will ideally need to meet team and child prior to extubation/ withdrawal of life support and will need to see the child alive before being able to write the death certificate unless there is an alternative agreement in place with PC.
- Encourage family to plan who they would like to be present at time of withdrawal of life support (additional family members or religious leaders).
- PC will plan a timescale regarding compassionate extubation/ withdrawal of life supporting therapy with parents.
- Make a clear plan with parents about information they wish to be shared or kept private during withdrawal of life sustaining support, if others present.
- PC will liaise with children's community/ palliative care nursing teams. Plan to meet them at the home on arrival.
- Infection control issues must be addressed.
- Parallel planning must occur. Approximately one third of children will survive for days, weeks or months so plans must be considered for longer term support for the family.

Important Phone Numbers:

PC Consultant on call name and No:
 Community Nurses name and No:
 GP name and No:
 Hospice location and No:

References:

Larcher V, Craig F, Bhogal K, Wilkinson D, Brierly J. (2015) Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice. Arch Dis Child 100:1-23
 NICE (2016) End of Life Care for Infants, Children and Young People
 Laddie J, Craig F, Brierley J, Kelly P, Bluebond-Langner M. (2014) Withdrawal of ventilatory support outside the intensive care unit: Guidance for Practice. Arch Dis Child 99: 812-816

Paperwork required for transfer:

- Symptom Management Plan – a comprehensive list of anticipated potential symptoms and medications that can be given PRN – written (and prescribed and transcribed onto EPIC) by PC.
- Emergency Care Plan – written by PC and contains parents' demographic details, PC contact details, and a plan of care in an emergency i.e. if child deteriorates on route in ambulance – signed by all parties. Parents can change their mind at any time.
- Do Not Attempt Resuscitation (DNAR) form signed by a consultant and the parents. (PC to do).
- Medical and Nursing notes and drug chart.
- Parents should be given a copy of all paperwork.
- If parents will be giving NG feed or medications, ensure they are trained and signed off as competent. Provide documentation.

Medication:

- Pharmacy need to be contacted to check transcription and doses prescribed, and all medicines prescribed in the symptom management plan need to be dispensed by pharmacy with up to 2-week supply. This all takes time. Request medications early.
- If mum requires milk suppression medication, ensure it has been prescribed by PICU team on outpatient prescription AND supplied by pharmacy.
- The community teams/ hospice will accept the medication and sign for any controlled drugs.

Special Equipment:

- 2 weeks supply of consumables e.g. feed sets must be provided.
- Consider other equipment required e.g. feed pumps. Must be supplied with a return plan when no longer required.
- Take a hospital bereavement pack for family/ bereavement box

Day before planned transfer:

- Identify suitable transfer team – preferably known to family
- Ensure medications request has gone to pharmacy
- Identify medicine collection time
- Book the ambulance for 9am next day (Mon-Fri). Early transfer preferable for availability of GP and community nurses.
- Ensure paperwork is complete & photocopied for transfer
- Confirm travel arrangements for parents
- Discuss any specific parental concerns and talk through emergency plan in case of deterioration on route.

Day of Transfer:

- Establish child's comfort prior to transfer – adequate sedation/ analgesia.
- Rationalise medications, interventions, monitoring on discussion with parents.
- Don't rush any part of the day but we need to be honest with parents about time available – best to set in advance.
- Take time for memory making and find moments of joy.
- Talk to parents before any action to ensure it meets parents' expectations.
- Settle into community environment.
- Try to ensure GP has seen child before withdrawal of life sustaining support (or have back up plan in place).
- Manage extubation and transition from intensive care to comfort care.
- Support bereavement memory making – hand/ footprints.
- Hand over responsibility of care to community team and remote palliative support.
- Document all actions/ interventions.
- Take respectful leave of family when it feels appropriate.