Standard Operating Procedure for Palliative care transfers

Authorised by:

KIDSNTS Clinical practice group.

Applies to:

All KIDSNTS staff

Paediatric Critical Care Network staff

PIC staff BWCH

Palliative care team BWCH

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Aim: To support the seamless transfer of care for babies or children to the destination of the parents' choice for palliative care with compassion. The literature suggests that choice is important to families at the end of life and will help them after the baby/child has died. Many children are admitted to High Dependency or Intensive Care Units have complex life limiting illnesses, and it is often during an Intensive Care admission, that the need for parallel planning for the end of life is realised, and for some, end of life care becomes most appropriate choice.

Definition: It is applicable to all babies and children who require palliative end of life care transfer to either a regional hospital, paediatric hospice or the home environment. This is a non commissioned service which fits with the KIDSNTS philosophy of doing all we can to make the right thing happen for the child.

In this context, technologically complex medical needs are defined as children requiring any or all of the following:

1. Non-invasive ventilation (CPAP/BiPAP/Hiflow)
2. Invasive ventilation (Conventional Ventilation only – i.e. HFOV would need to be able to be converted to conventional)
3. Intravenous cardiovascular support (i.e. inotropes/inodilators)
4. Children not meeting criteria above but who may be unstable during transfer

Current situation: In a review of compassionate care transport 36 transfers between 2015-2017 were requested and KIDSNTS were able to support 78%. Staff surveyed felt it was beneficial for the child and family, it was a positive experience, 88% felt adequately trained, whilst 46% felt inadequate resources was a factor.

Process:

Once the team have reached a consensus that care will be reoriented to palliative:

1. Prior to offering the family a palliative transfer the duty consultant or designated person should refer the patient to KIDSNTS. This will allow the medical feasibility of transfer to be discussed as a team. There will still need to be further discussion regarding logistics once the family's wishes are established.
2. The agreed options will be discussed by the referring multi professional team with the family. These should be presented as possibilities at this stage. Time will be given for the family to consider the options.
3. Update to KIDSNTS team via the referral regarding logistics and timeframes. The call should involve either the family liaison team or palliative care team. It may be necessary to include the community team. This discussion should involve an SJA technician also. If this is a transfer home it will allow them to find out promptly about accessibility. It may be necessary to organise a home visit. If local SJA would attend, if some distance we would ask a member of the community team to attend.

4. Where ever possible the KIDSNTS team will go and meet the parents and discuss the process. This would be in conjunction with a professional known to the family.
5. The PIC team will take responsibility for arranging the logistics of the hospital/hospice/community support and handover. This should include a plan of
    a. Who needs to be in attendance on arrival of the child
    b. What on-going support is needed (care, mediation, equipment)
    c. GP and community teams aware
    d. Who will certify the death
6. The KIDSNTS team will take responsibility for sourcing a team to transfer the child. The team should include an experienced, competent active transport nurse and ANP/registrar and/or consultant. The team composition should be agreed by the KIDSNTS consultant.
7. An agreed management plan and what will happen when and if the patient deteriorates will be discussed with the family by the referring team. KIDSNTS team will ensure the family are clear in this plan. Consider who will need to be contacted if the child dies on route, particularly when crossing borders.
8. A copy of the advanced care plan will be taken on the journey.
9. Establish whether care is going to be withdrawn on arrival to the destination. E.g. Extubation in the Hospice - If so, who is expected to carry out procedure and how long is the child expected to survive (if known). KIDSNTS will be clear how long the team can stay with the child prior and post extubation. Always making sure parents are aware of the plan.

Appendix 1 KIDSNTS referral checklist All this information will be taken in conjunction with the normal demographics and clinical information. This is designed as prompt to consider and document the other steps involved in Palliative care transfers. Please complete and scan or add to data base notes.

Lead clinician: …… Lead nurse organising palliative care ……

Other key people involved (hospice, local hospital, palliative care, GP, BWCH teams) names documented .....

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Designation (if different from home address) …….....

Details around accessibility if a home ……Home visit needed

Language spoken – interpreter needed ……Medication ordered Handover to hospice/hospital or GP by primary team

ACP and rapid discharge checklist completed

Plan for withdrawal

	Completed tick	Comment
Expected time transport team needed.		
Resuscitation plan discussed and signed		
Reason for non-essential medication/equipment being discontinued pain and symptom management		
Who will be at the destination		
Changes in the Child's condition as death approaches Religious/Cultural/Spiritual needs		
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Death in transit		
Awareness of home care bag and necessary equipment		
Wishes around end of life		
How long transport team needed		
Who will sign the medical certificate of cause of death		
Role of post mortem and tissue donation in end of life care		
Who will be responsible for care if child survives		