KIDS/NTS Palliative Care Transfers

Aim: To facilitate the seamless transfer of care for babies, children and young people to the destination of the parents / child's choice for end of life care.

Scope of care: Applicable across the neonatal and paediatric spectrum up-to the age of 16 years.
KIDS provides palliative care transfer of patients admitted to both the PICUs and HDUs at Birmingham Children's Hospital and Royal Stoke University hospitals (UHNM) for the West Midlands region. It may sometimes be possible to facilitate palliative care transfer from the ward environment also.

NTS offers a neonatal transfer service for babies with palliative care needs from any neonatal unit within the West Midland's Neonatal network to a children's hospice or home.

The referring team should ensure the family are aware that KIDSNTS have the responsibility of delivering acute care transport for the West Midlands region and this will take precedence. This mean there will be the possibility of a last-minute change for any agreed elective transport. However, KIDSNTS will endeavour to carry out elective palliative care transfer once agreed.

Referral:
·Parent team to ensure referral made to palliative care and formalise parallel planning.
·Discuss case with KIDS NTS before offering possibility of KIDS NTS transfer to parents/ family – this should be done via the dedicated KIDS NTS referral line 03002001100.
·If destination of choice for End of Life (EOL) care is a children's hospice, the child should already have been accepted by them, and a rough idea of transfer date known.
· All teams caring for the child and family should consider their particular religious /cultural / spiritual needs and how they can best be met at all stages of the transfer process

Preparation for transfer:
Responsibilities of referring team / Palliative care team

- Complete Advance care plan / RESPECT form with clear documentation of resuscitation status including possibility of cardiac arrest on transfer; Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR), is agreed with family and documented in the medical notes.
  - Links for Rapid Discharge - West Midlands Toolkit - Together for Short Lives
  - Links for Children and Young persons Advance Care Plan Collaborative - RESPECT documents
- Ensure child is registered with a GP - especially important for a neonatal age group child as he / she might not had been registered beforehand.
- Consider and prepare who will take handover of the child at the transfer destination and who will continue to provide symptom management
- Symptom management plan (SMP): The formulation of medications comparative to that in hospital must be carefully considered. This will be written by the palliative care team, who will also source the medications from pharmacy
- TTO medications (i.e. medications not part of the symptom management plan) and discharge summary to be completed by parent team
- Ongoing care needs of the child: Suction, NIV, Oxygen, nutrition/ fluid: plan for who will continue to manage and deliver this. Ensure family understand expectations around this

- **If death is expected**, who will complete the MCCD and ensure the cause of death has been agreed?
- **If HM Coronial process is required** – communicate with HM Coroner office before reorienting the care towards palliation and withdrawal of life sustaining treatment. This is crucial because only certain places of care will be sanctioned by HM Coroner if a post-mortem is required.

- **Tissue donation**: if the family wish for tissue donation - discuss with the NHS Blood and Transplant (NHSBT) national referral centre for Tissue Donation (TD) on 08004320559. TD nurse will assess regarding medical suitability. TD nurse will also determine what logistical arrangements will be needed for tissue donation. It will be the responsibility of the TD nurse to gain consent for tissue donation and to coordinate all aspects of the Tissue donation following the Child's death.

Responsibility of KIDS NTS

- St John's Ambulance (SJA) tech team should be involved in the initial referral call and all following calls to clarify transfer logistics in particular if the child would be going home for EOL care.
- The KIDSNTS team will try to meet the parents beforehand and discuss the process. This would be in conjunction with a professional known to the family.
- The team composition should be agreed by the KIDSNTS consultant.
- In rare cases – KIDS consultant can consider ambulance only service to facilitate palliative care transport of a ward level patient to home / hospice with an experienced staff nurse from the ward who has known the child well in advance. This will be agreed with SJA tech + referring team and or palliative care team / CCN.
- NTS will consider ambulance only service to facilitate palliative care transport for babies from level 2 neonatal units (LNU) and SCBUs in the Network.
- Ensure transport team have contact details of the Children's Community Nurse (CCN) / palliative care nurse/ palliative care rapid response team - who will meet at the address. KIDS NTS to inform CCN / hospice the ETA once the child is on board the ambulance.
- **KIDS NTS offer parents to accompany the transfer – however it may not be possible for both parents to accompany in the ambulance, depending on the team composition. This should be discussed and agreed with parents in advance.**
- Parents must hold the original copy of the ACP (Advance Care Plan).
- Monitoring: Agreement of family and KIDS NTS transport team what monitoring, if any, will be performed on route.
- Symptom Management plan – Ensure appropriate medications, including the bolus and infusion doses likely to be required to achieve optimal comfort for the child during the retrieval process have been agreed between KIDS NTS consultant, palliative care team, retrieval team and parents / carers.
- Clear plan for procedure should the child deteriorate and die on route, ensure family also understand this.
- If the child requires compassionate extubation outside of the hospital environment, this should be undertaken by an experienced doctor/ ANP as part of the KIDS NTS team with effective symptom control needs considered prior to this.
- How the religious /cultural / spiritual needs of the child and emotional needs of the family will be met?
- Ensure comprehensive symptom management plan is understood by the team and who will take over this once KIDS NTS have left the hospice/ home – this will be in conjunction with the palliative care team

If the transfer of a child is planned for home – the referring team / palliative care team and SJA tech team needs to establish following:

- Accessibility road to the house and then up-to the house door.
- Accessibility into the room family wish for the child to be for end-of-life care –how the stretcher / incubator (for NTS transfer) will be moved in and out from the room and house.
- How the parents' and their belongings will be transferred.
- Any specific wish child has that we could facilitate on route?

KIDS NTS Staff wellbeing - It is the responsibility of the KIDSNTS consultant – to look for opportunity and need for both hot debrief and later cold debrief with psychological support.

References:
-KIDS NTS - Standard Operating Procedure for Palliative care transfers. V3 – Nov 2019
-Discharge for End-of-Life Care into the Children's Community Nursing and Palliative Care Team Pathway –Version 3 – January 2022. BCHC policy – ref number – CH 605
-West – Midland Paediatric Palliative Care Network – Rapid Discharge Pathway – April 2011
-WMNTS Palliative Care Transfers, version 3 – November 2015

Further resources:
-West Midlands Palliative care
-The Association for Paediatric Palliative care Medicine
-Child and Young Person's Advanced Care Plan Collaborative

Authors: SM/HO- August 2024