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Supporting Children to say Goodbye

Historically children were not permitted to visit sick or dying relatives on the ITU, with the visiting policy stating that no under 12s couldn't visit. Initially there was considerable resistance when we asked to allow a child to visit a dying relative. There were no resources and there was no structured support for families with children. Unit staff, knowing that the SN-ODs had additional skills, would approach us for support outside of the organ donation process. This led us to increasingly identify the need for, and kinds of interventions that could be offered to support children on the intensive care unit.

We have challenged the myths and misconceptions around allowing children onto an ITU, as there is considerable evidence of the benefits this can bring to children who are supported appropriately to do so. It became apparent that referring to the SNODs to help support children was mutually beneficial. As we became increasingly involved in supporting children and families on the unit we were able to formalise the support required and ways in which this could be provided in the form of an SOP.

We are now regularly asked to support children when visiting critically ill or dying relatives and the ethos on the unit has completely reversed.

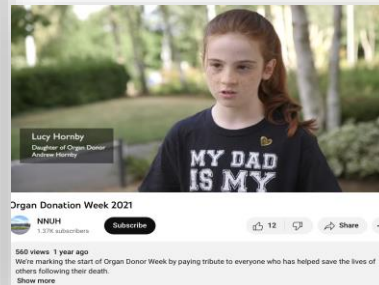
- We have helped create an SOP to support children visiting on the unit.
- Provision of leaflets/literature for parents/guardians.
- We have created resources including lists of support groups/Apps for bereaved children and teenagers and also order and fund all bereavement resources.
- Additionally we have initiated the referral of children to a local organisation for ongoing bereavement support.

We participate in regular teaching on the paediatric study day covering bereavement in children and how, as nurses, we can support them on the unit, as well as organising teaching sessions for the unit from Nelsons Journey and Child Bereavement UK. The provision of this support has allowed the SN-ODs to embed themselves fully as valuable members of the ICU team, not only in the provision of end of life care to donors and their families, but also supporting and teaching others to take on the role of supporting children on the unit.

The consistent referral to the embedded team to support children has resulted in early engagement with potential donor families, forming strong bonds and allowing the family to focus on what is often what is most important to them – ahead of considering organ donation.



Case Study



Lucy was 10 when her Daddy was involved in a fatal accident whilst out cycling. Her mother, Charlotte, asked for help explaining to Lucy that Andy was going to die. Many hours were spent with Lucy, initially in the relative's room then moving to the bedside. So many memories were shared, and new ones made, sharing stories and photographs with the specialist nurse and bedside nurse. Handprints and drawings were completed. Supporting Lucy to spend time with her Dad at the end of his life, and to say goodbye in her own way and in her own time helped Lucy to accept the loss of her father. Supporting his decision to donate is something Lucy is so proud of. Lucy is a huge advocate for Organ Donation and has actively participated in promotional campaigns. She has recorded a short film for organ donation week and will be joining her mother to present at a large Organ Donation study day at her local hospital.

“Lucy was made to feel so very welcome on the unit and she told me her memories of the day are making hand prints with Daddy, choosing a lock of hair and just having precious time with him.”