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Dignity in Death- Shared Decision making and promoting realistic Medicine

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Introduction: Shared decision making and respecting patients/ parents wishes regarding direction of care and more importantly 'place of care' is a key concept of realistic medicine. Admission to a paediatric intensive care unit is often both aggressive and invasive, with an aim for restorative therapy. Despite this, there is inevitably a small cohort of patients where re-orientation of care becomes most appropriate and withdrawing invasive treatment is in their best interest. The practice of reorientation of care has evolved through the years and involves close collaboration with a multidisciplinary team and with parents.

Objectives: To review current literature regarding re-orientation of care at home for children at the end of life, with an aim to develop a local guideline for implementation and practice for our local PICU.

Methods: An initial literature search was performed to identify UK current practice of re-orientation of care and acknowledgement of any existing guidance. A retrospective analysis of deaths that occurred in our critical care unit from 2010-2017 and identification of those who may have been applicable for re-orientation of care out-with the critical care environment was done. Thereafter, in collaboration with the paediatric palliative care team, a guideline and discharge checklist to implement in clinical practice was introduced.

Results: Between 2010 and 2017, throughout our hospital, 18 children utilised a service to allow death out-with the hospital setting; 15 had a haematological or oncological diagnosis, and 3 had a non-malignant diagnosis. Within the critical care unit, there were 76 deaths, 28 of these (37%) were identified as appropriate for re-orientation of care out-with the critical care environment; around 3 per year.

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