The Hierarchy of Evidence

The Hierarchy of evidence is based on summaries from the National Health and Medical Research Council (2009), the Oxford Centre for Evidence-based Medicine Levels of Evidence (2011) and Melynyk and Fineout-Overholt (2011).

I   Evidence obtained from a systematic review of all relevant randomised control trials.

II   Evidence obtained from at least one well designed randomised control trial.

III   Evidence obtained from well-designed controlled trials without randomisation.

IV   Evidence obtained from well designed cohort studies, case control studies, interrupted time series with a control group, historically controlled studies, interrupted time series without a control group or with case- series

V   Evidence obtained from systematic reviews of descriptive and qualitative studies

VI   Evidence obtained from single descriptive and qualitative studies

VII   Expert opinion from clinicians, authorities and/or reports of expert committees or based on physiology

Melynyk, B. & Fineout-Overholt, E. (2011). Evidence-based practice in nursing & healthcare: A guide to best practice (2nd ed.). Philadelphia: Wolters Kluwer, Lippincott Williams & Wilkins.

National Health and Medical Research Council (2009). NHMRC levels of evidence and grades for recommendations for developers of guidelines (2009). Australian Government: NHMRC. http://www.nhmrc.gov.au/_files_nhmrc/file/guidelines/evidence_statement_form.pdf

OCEBM Levels of Evidence Working Group Oxford (2011).The Oxford 2011 Levels of Evidence. Oxford Centre for Evidence-Based Medicine. http://www.cebm.net/index.aspx?o=1025

Databases searched:	ø	CINAHL (Ebsco)	ø	Medline (Ebsco)	ø	Pubmed (NLM)	ø	Nursing (Ovid)	☐	Emcare (Ovid)	☐	Other List: _____
Keywords used:	Memory making, parent's perceptions, staff experiences, palliative care, mementoes, bereavement, death, photography, oncology, bereaved											
Search limits:	2000-2020											
Other search comments:	Neonatal and paediatric populations, NICU, PICU, ward											

Guideline Title: Memory Making Guideline
Author(s): Jess Rowe (compiled by Bereavement SIG members across the hospital and the RCH End-of-Life Committee)

Reference (include title, author, journal title, year of publication, volume and issue, pages)	Evidence level (I-VII)	Key findings, outcomes or recommendations
Robinson MR, Thiel MM, Backus MM, Meyer EC, (2006). Matters of spirituality at the end of life in the pediatric intensive care unit. Pediatrics. ;118(3). www.pediatrics.org/cgi/content/full/118/3/e719	IV	Responses from 56 bereaved parents in open-ended questionaires around the importance of spirituality (and access to these supports) during and after the death of their child. 73% acknowledged the benefits they found from these resources being available.
Bloomer et al, (2016), 'Something normal in a very, very abnormal environment' – Nursing work to honour the life of dying infants and children in neonatal and paediatric intensive care in Australia, Intensive and Critical Care Nursing, vol.33, p5-11.	VI	21 (NICU and PICU) nurses in focus groups and interviews discuss their experiences with bereavement. 4 key themes: respect of child, family centred involvment, mementos and planning death.
van der Geest IM, Darlington AS, Streng IC, et al (2014) Parents' experiences of pediatric palliative care and the impact on long-term parental grief. J Pain Symptom Management, 47, 1043–1053	IV	89 bereaved parents of oncological children. Used cross-sectional study with set of questionnaires measuring grief through Inventory of Traumatic Grief. Key feedback: continuity of care, communication, family involvement during palliative care. Discussing meeting parents needs (social, physical, spiritual) and how these associate with long-term parental grief and complicated grief risk factors.
Midson R, Carter B, (2012) Addressing end of life care issues in a tertiary treatment centre: Lessons learned from surveying parents' experiences. J Child Health Care, volumen 14,pp52–66	IV	28 bereaved families participated via telephone, face to face or postal survey. Importance of end of life resources for staff to access highlighted as key theme.
Meert, K.L., Thurston, C.S., and Briller, S.H. (2005) The spiritual needs of parents at the time of their child's death in the Pediatric Intensive Care Unit and during bereavement: A qualitative study. Pediatric Critical Care Medicine, 6(4), 420-427.	VI	33 bereaved parents of children who died in PICUs in UK via semistructured interviews. Connection with child prior, during and after death the key spiritual need of all parents. This done through momentos, talking about child and legacy building projects.
Butler et al (2019), When a child dies in the PICU: Practice recommendations from a qualitative study of bereaved parents, Pediatric Critical Care, vol 20, number 9, 447-451	VI	Key advice from bereaved families (26) of their experience of their child's death in Australian PICUs. Recommendations for improvements of what care is provided during and after a child's death in ICU, including parental involvement with Memento making (especially photography and ink prints).

Reference	Level	Summary
Sprung CL, Maia P, Bulow H-H, et al (2007) Ethicus Study Group. The importance of religious affiliation and culture on end of life decisions in European intensive care units. *Intensive Care Medicine*; 33(10):1732–1739	IV	**Review of 31,417 deaths across European ICUs (paediatric to adult patient group). Religious affiliation impacted discussions, end of life care and was an important consideration for many families.**
Cortezzo, DE, Sanders, MR, Brownell, EA & Moss K (2015). End-of-life care in the neonatal intensive care unit: experiences of staff and parents, *American Journal of Perinatology*, volume 32, pp713-724.	VI	**238 NICU staff and 28 bereaved families reflect on the importance of the end-of-life practices has on their experience of bereavement. Memory making was a key theme for families.**
Bood, C, Caccitore, J. (2014) Best practice in bereavement photography after perinatal death: qualitative analysis with 104 parents. Psychology; 2: 15-25.	VI	**92 of 93 bereaved parents with photos endorsed them, 9 of the 11 without photos wished they had them. Privacy, respect, and education about what this and involves being key factors to the use of this psychosocial intervention.**
Thornton, R, Nicholson, P & Harms, L (2020), Creating evidence: findings from a grounded theory of memory-making in neonatal bereavement care in Australia, *Journal of Pediatric Nursing*, vol 52, pp29-35.	VI	**Grounded theory approach with semi-structured interviews on 18 bereaved families – discusses the findings of the importance of memory-making for the families and affirming their life-long role as a parent and the legacy of their child.**
Carlson, R. (2012). Helping families create keepsakes when a baby dies, *International Journal of Childbirth Education*, vol. 27, no.2, pp86-91.	VII	**Advice and benefits of keepsakes, photography and momentos for family and the grieving process**
Pace, J. C & Mobley, T.S (2016). Rituals at End-of-Life, *Nursing Clinics of North America*, 51, 471-487.	VII	**Discusses the importance of end of life rituals (both spiritual and tangible mementoes) for both the health care provider and the family to help honour and respect the neonate who has died. Discusses the importance of the environment that these processes happen in and how this assist the families long term grief.**
Suttle et al (2017), End-of-Life and Bereavement Care in Pediatric Intensive Care Units, Pediatric Clinical North America, vol.64, no5, pp1167-1183.	VII	**Discusses the needs of the child (pain, non-pain comfort needs, spiritual) and their family (physical, spiritual, ethical) to best reduce the risk of complicated grief. Importance of follow up care.**
Butler, A.E, Hall, H., Willetts, G., Copnell, B. (2015). Family Experience and PICU Death: A Meta-Synthesis, *Pediatrics*, 136, 961-973.	V	**Systematic review of best available evidence, which explore the family experiences of their child's death in PICUs internationally. Reclaiming of parenthood (parent's role during the admission, during the death and parenting after death) was the main theme. Dicusses the importance of the PICU environment, the preparation and discussions about death prior (what to expect) and the parents role during and after the death.**

Riegel, M, Randall, S & Buckley, T (2019), Memory making in end-of-life care in the adult intensive care unit: A scoping review of the research literature, *Australian Critical Care*, volume 21, pp442-447.	V	**Often compares the memory making options of paediatric population versus the adult population. Finger prints for sterling silver jewellery, locks of hair were discussed as possible future mementoes that adult ICUs could look into as they as so welcomed by paediatric populations and something for family members to hold onto.**
Mullen, J., Reynolds, M., Larson, J. (2015). Caring for pediatric patients' families at the child's end of life, *Critical Care Nurse*, vol. 35, no. 6, pp.46-56.	V	**A systematic review of the role of a nurse during the death of a child in PICU, advice of end-of-life communication (phrases to avoid, non-verbal communication techniques, social work involvement ongoing) using evidence based research during discussions and activities during end-of-life care.**
Miller, L, Lindley, L, Mixer, S, Fornhed, M & Niederhauser, V (2014), Developing a perinatal memory-making program at a children's Hospital, MCN, vol 39, 102-109	VII	**Discusses a Memory-making program to help ensure bereaved families were given a consistent support in tangible mementoes and time (time, jewellery, prints, photography) – this needs continual funding to ensure the sustainability and commitment to offer the program ongoing.**
Children's Health Queensland Hospital and Health Service (2014), A practical guide to Palliative Care in paediatrics, https://www.caresearch.com.au/QuoCCA/Portals/6/Documents/A-Practical-guide-to-Palliative-Care-in-Paediatrics.pdf	VII	**A comprehensive palliative care guideline to the care of a child and their family. Includes discussion of the memory making components and how these tangible mementoes can help a family through their grief.**