

Introduction

- In the United Kingdom 36% of children die unexpected deaths^[1]
- The possibility of sudden deterioration creates challenges to conduct effective planned palliative care within a highly stressful environment to facilitate the best outcome for the child, parents and medical professionals (MDT)^[2]
- When caring for children, nurses should identify the priorities for the child and the family whilst managing symptoms and withdrawal^[2,3]
- An awareness of key aspects of nursing care guides nurses to achieve a 'good death'.^[4]

Guidance

National frameworks (Royal College of Nursing^[5], National Institute for Health and Care Excellence^[6] and Together For Short Lives^[3]) provide useful resources for palliation in children

However:

- These are not specific to PICU
- Unexpected deaths are not included in the guidance

They can however provide useful resources to guide decision making and highlight key area of care to prioritise

Paediatric palliative care 'embraces physical, emotional, social, and spiritual elements, and focuses on enhancement of quality of life for the child/young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement'^[3].

Together For Short Lives^{Fig Ref [3]}



Unexpected Deaths

- 'A death (or collapse leading to death) of a child, which would not have been reasonably expected to occur 24 hours previously and in whom no pre-existing medical cause of death is apparent'^[7]

Paediatric Intensive Care

- The possibility of sudden deterioration in PICU, or prior to admission, can result in a short period of time between the recognition of futility in treatment to the child's death^[2].

A Good Death in PICU

- The child receives optimal clinical care from a compassionate, respectful, and communicative multidisciplinary staff, and patient and family situational and psychosocial-spiritual needs are identified and met^[8]

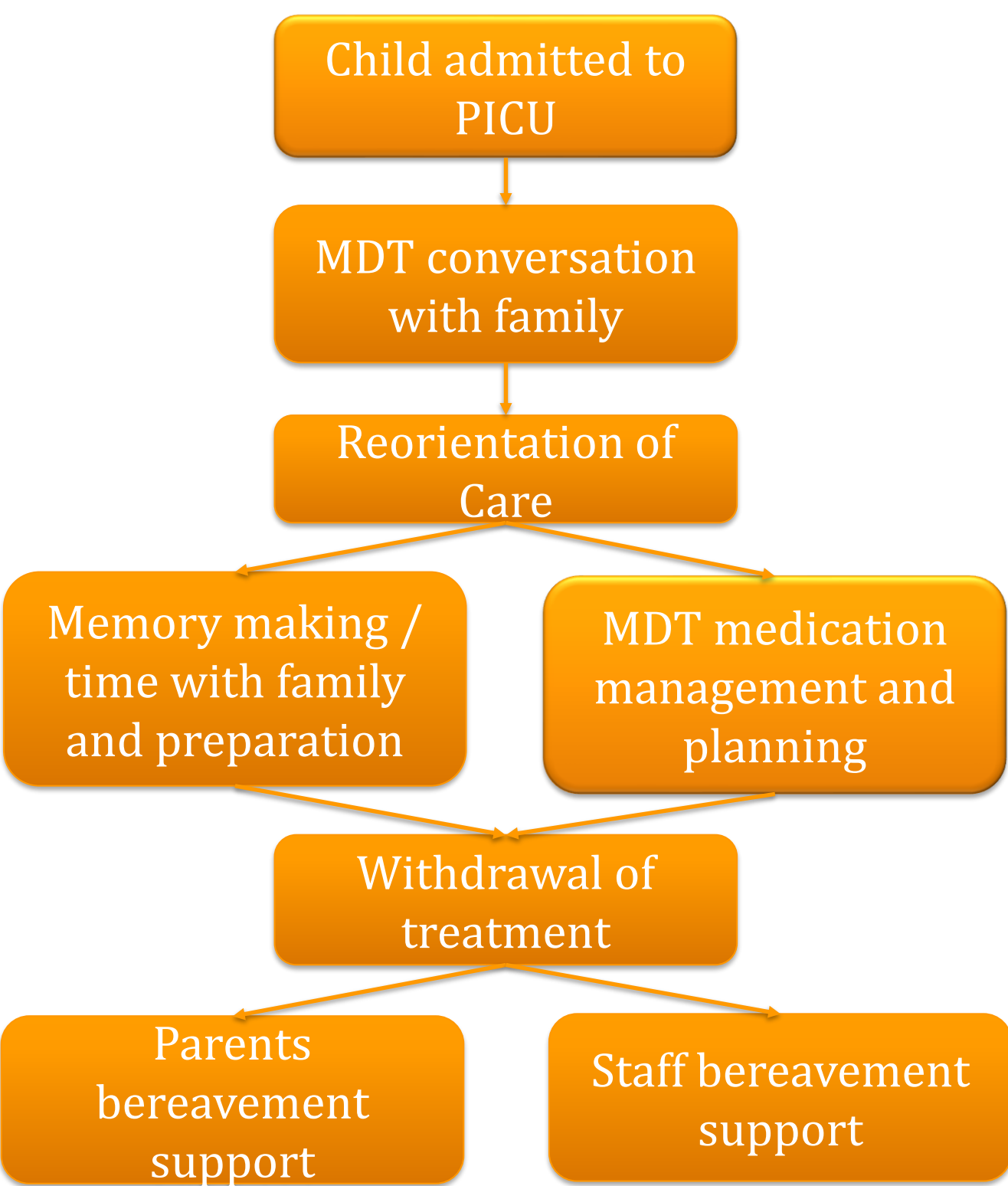
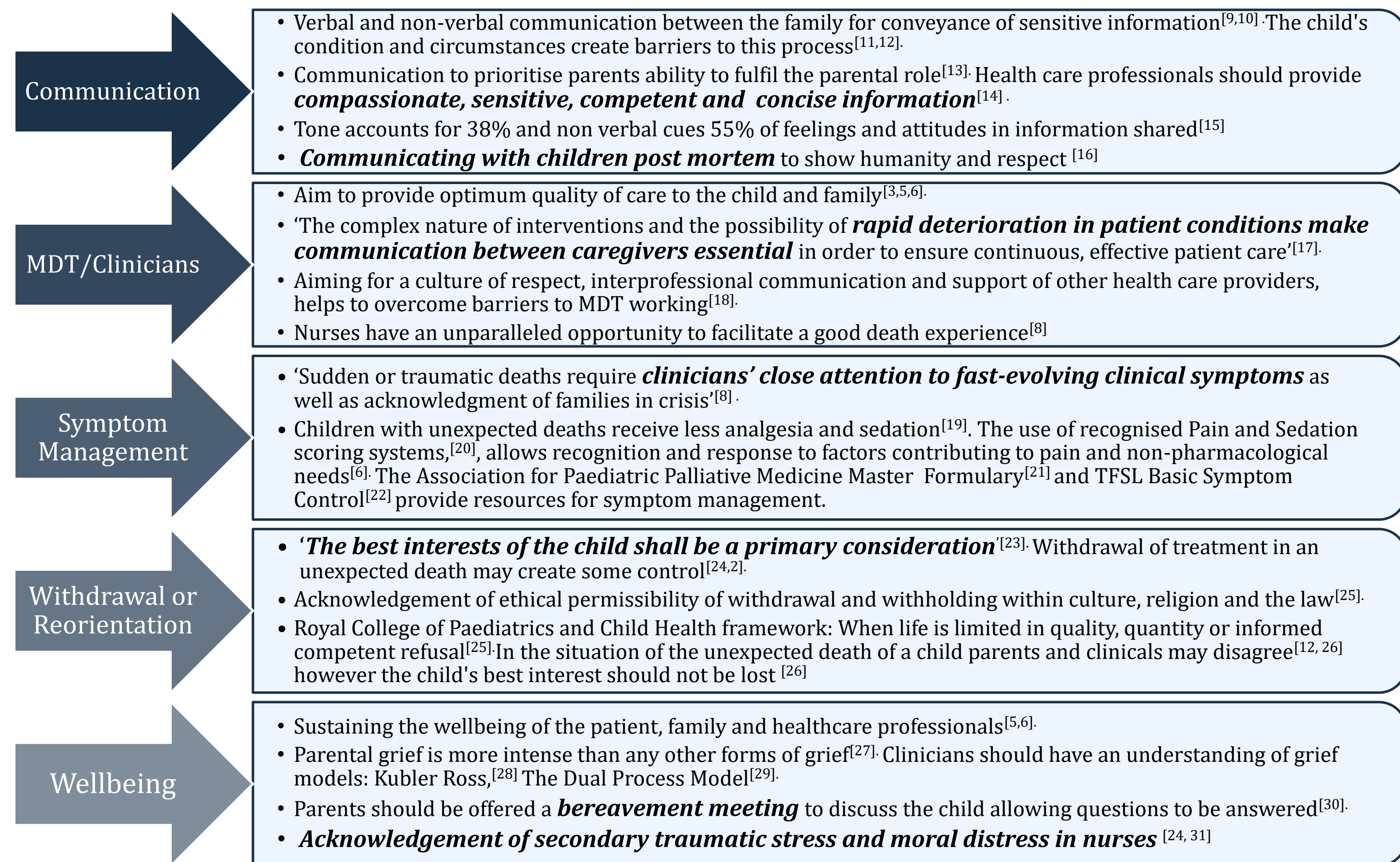
Nurses play a vital role in how the death of a child occurs^[9]

Key Aspects of Nursing Care in PICU

Case Study:

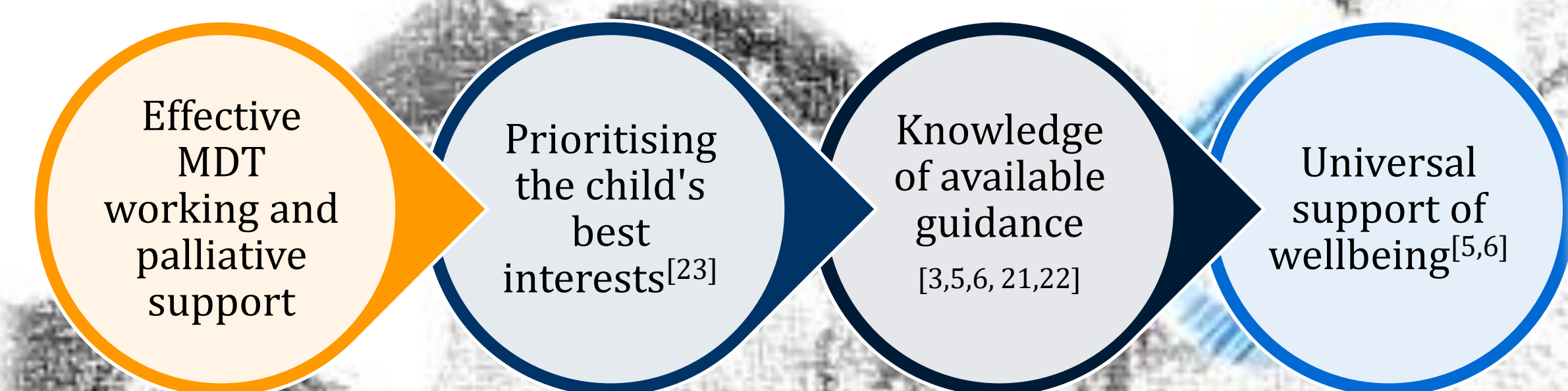
- 12 year old, Previously fit and well
- Atrioventricular Malformation Rupture
- Admitted 0800 to PICU after surgery finding catastrophic brain swelling
- Withdrawal of invasive treatment 1600

The main palliative care priorities for unexpected deaths should focus on the best interests, and needs, of the child and the family supported by key aspects of nursing care:^[2]



Sudden, unexpected deaths emphasise the importance of care continuing into the post mortem and bereavement stages where time is less of a barrier. This allows families time with their child, to process information and begin to grieve. This time also allows for reflection from the MDT. It is important that the key aspects of nursing care are continued throughout the bereavement stage

Implications For Practice



Conclusion

- The unexpected death of a child is challenging for everyone involved
- Prioritising what matters helps healthcare professionals facilitate a good death and gives parents the ability to fulfil the parental role and grieve
- Nurses should utilise skills in developing therapeutic relationships in order to prioritise key aspects of palliative care specific to the child and family unit and recognise the importance of palliative care extending post mortem.

1. Hartley, D., Renton, K., Clarkson, L., McKeating, C., Lyles, L. and Mayer, A. (2019) G468(P) Where children die: a retrospective analysis of child death overview panel (cdop) data. *Archives of disease in childhood* [online] 104 (2), pp. A189. [Accessed 01 April 2022]. 2. Meyer, R.L. (2014) Caring for Children Who Die Unexpectedly: Patterns That Emerge Out of Chaos. *Journal of Pediatric Nursing* [online]. 29 (1), pp. 23-28. [Accessed 12 April 2022]. 3. Together For Short Lives (2018) A Guide to Children's Palliative Care [online]. England: Together For Short Lives. Available from: <https://www.togetherforshortlives.org.uk/changing-lives/supporting-care-professionals/introduction-childrens-palliative-care/> [Accessed 12 April 2022]. 4. Together For Short Lives (2018) A Guide to Children's Palliative Care [online]. England: Together For Short Lives. Available from: <https://www.togetherforshortlives.org.uk/changing-lives/supporting-care-professionals/introduction-childrens-palliative-care/> [Accessed 12 April 2022]. 5. Royal College of Nursing (2018) RCN Competencies: Caring for Infants, Children and Young People requiring Palliative Care [online]. London: Royal College of Nursing. Available from: <https://www.rcn.org.uk/professional-development/publications/pub-007033>. 6. National Institute for Health and Care Excellence (2016) End of life care for infants, children and young people with life-limiting conditions: planning and management [online]. NICE. Available from: <https://www.nice.org.uk/guidance/ng61/resources/end-of-life-care-for-infants-children-and-young-people-with-life-limiting-conditions-planning-and-management-pdf-1837568722885>. 7. The Royal College of Paediatrics and Child Health. (2016) Sudden unexpected death in infancy and childhood, Multi-agency guidelines for care and investigation. [online] London: The Royal College of Paediatrics and Child Health. Available from: <https://www.rcpch.org/uploads/assets/874ae50e-c754-4933-995a804e0ef728a4/Sudden-unexpected-death-in-infancy-and-childhood-2e.pdf> [Accessed 15 June 2022]. 8. Broden, E.G., Deatrick, J., Ulrich, C. and Curley, M.A.C. (2020) Defining a 'Good Death' in the Pediatric Intensive Care Unit. *American Journal of Critical Care* [online]. 29 (2), pp. 111-121. [Accessed 05 April 2022]. 9. Mitchell, S., Spry, J.L., Hill, E., Coad, J., Dale, J. and Plunkett, A. (2019) Parental experiences of end of life care decision-making for children with life-limiting conditions in the paediatric intensive care unit: a qualitative interview study. *BMJ* [online]. 9 (5) pp. e028548-e028548. [Accessed 12 April 2022]. 10. Streuli, J.C., Medeiros, C., Zuniga-Villanueva, G. and Trenholm, M. (2019) Impact of specialized pediatric palliative care programs on communication and decision-making. *Patient education and counselling* [online]. 102 (8), pp. 1404-1412. [Accessed 13 April 2022]. 11. Bloomer, M.J., Endacott, R., Copnell, B., and O'Connor, M. (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 & Critical Care Nursing* [online]. 33, pp. 5-11. [Accessed 10 May 2022]. 12. Marland, E., and Davies, B. (2019) In the child's best interests: should life be sustained when further treatment is futile? *Nursing Children & Young People* [online]. 31(6), pp. 23-27. [Accessed 07 May 2022]. 13. Bennett, R.A., and LeBaron, V.T. (2019) Parental Perspectives on Roles in End-of-Life Decision Making in the Pediatric Intensive Care Unit: An Integrative Review. *Journal of Pediatric Nursing* [online]. 46, pp. 18-25. [Accessed 03 May 2022]. 14. Broten, D., Youngblut, J.M., Seagrave, L., Caicedo, C., Hawthorne, D., Hidalgo, I., and Roche, R. (2013) Parent's Perceptions of Health Care Providers Actions Around Child ICU Death: What Helped, What Did Not. *American Journal of Hospice and Palliative Medicine* [online]. 30(1), pp. 40-49. [Accessed 21 May 2022]. 15. Mehrabian, A. (1981) Silent messages: implicit communication of emotions and attitudes [online]. 2nd edn, Wadsworth, Belmont, Calif. [Accessed 20 May 2022]. 16. Forster, E.M. and Windsor, C. (2014) Speaking to the deceased child: Australian health professional perspectives in paediatric end-of-life care. *International Journal of Palliative Nursing* [online]. 20(10), pp. 502-508. [Accessed 14 May 2022]. 17. Nemeth, C.P., Kowalsky, J., Brandwijk, M., Kahana, M., Klock, P.A., and Cook, R.I. (2008) Between shifts: healthcare communication in the PICU. *Improving Healthcare Team Communication* [online]. pp. 135-153. [Accessed 07 May 2022]. 18. Stocker, M., Pilgrim, S.B., Burmester, M., Allen, M., and Gijssels, W. (2016) Interprofessional team management in pediatric critical care: some challenges and possible solutions. *Journal of multidisciplinary healthcare* [online]. 9 (1), pp. 47-58. [Accessed 11 May 2022]. 19. Ragsdale, L., Zhong, W., Morrison, W., Munson, D., Kang, T.I., Dal, D., and Feudtner, C. (2015) Pediatric exposure to opioid and sedation medications during terminal hospitalizations in the United States, 2007-2011. *The Journal of Pediatrics* [online]. 166(3), pp. 587-593. [Accessed 28 April 2022]. 20. Marco, D., von Borell, F., Ramelet, A.S., Sperotto, F., Pokorna, P., Brenner, S., Mondardini, M.C., Tibboel, D., Amigoni, A., Ista, E., the Analgesation CONSORTIUM on behalf of the Pharmacology Section and the Nurse Science Section of the European Society of Paediatric and Neonatal Intensive Care (2022). Pain and sedation management and monitoring in pediatric intensive care units across Europe: an ESPNIC survey. *Critical Care* [online]. 26(1), pp. 1-13. [Accessed 22 May 2022]. 21. Association for Paediatric Palliative Medicine (2020) *The Association of Paediatric Palliative Medicine Master Formulary 5th Edition* [online]. Association of Paediatric Palliative Medicine. [Available from: <https://www.appm.org.uk/guidelines-resources/appm-master-formulary/>]. 22. Together for Short Lives (2022) Basic Symptom Control in Paediatric Palliative Care [online]. Together for Short Lives. [Available from: <https://www.togetherforshortlives.org.uk/resource/basic-symptom-control-paediatric-palliative-care/>]. 23. The United Nations (1989) The United Nations Convention on the Rights of the Child [online]. The United Nations Treaty Series (1577). Available from: <https://www.unicef.org.uk/rights-respecting-schools/the-rsa/introducing-the-crc/>. 24. Lima, L., Gonçalves, S. and Pinto, C. (2018) Sudden death in paediatrics as a traumatic experience for critical care nurses. *Nursing Critical Care* [online]. 23, pp. 42-47. [Accessed 11 May 2022]. 25. Larcher, V., Craig, F., Bhogal, K., Wilkinson, D., Briery, J., and Royal College of Paediatrics and Child Health (2015) Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice. *Archives of disease in childhood* [online]. 100(2), pp. s3-s23. [Accessed 16 May 2022]. 26. Birchley, G., Gooberman-Hill, R., Deans, Z., Fraser, J., and Huxtable, R. (2017) 'Best interests' in paediatric intensive care: an empirical ethics study. *Archives of disease in childhood* [online]. 102(10), pp. 930-935. [Accessed 27 April 2022]. 27. Butler, A., Hall, H., Willetts, G. and Copnell, B. (2015) Parents' Experiences of Healthcare Provider Actions When Their Child Dies: An Integrative Review. *Journal of Specialist Paediatric Nursing* [online]. 20, pp. 5-20. [Accessed 17 May 2022]. 28. Kubler-ross, E. (2009) *On Death and Dying* [online]. 40th Anniversary Edition ed. London: Routledge. [Accessed 22 May 2022]. 29. Stroebe M, Schut H. (1999) The dual process model of coping with bereavement: rationale and description. *Death Studies* [online]. 23(3), pp.197-224. [Accessed 29 April 2022]. 30. Cook, P., White, D.K. and Ross-Russell, R. (2002) Bereavement support following sudden and unexpected death: guidelines for care. *Archives of Disease in Childhood* [online] 87(1), pp. 36. [Accessed 09 May 2022]