



Checklist

Paediatric End-of-Life Care

- ☐ The Quocca Paediatric Palliative Care project has resources that can inform clinical practice. These will be useful if you are looking after a dying child. You can share this information with your colleagues. <https://www.quocca.com.au/tabid/4688/Default.aspx>
- ☐ The Paediatric Palliative Care website has many useful resources that you can access and use, including family meetings and difficult conversations and some of their resources are in different languages. <https://paediatricpalliativecare.org.au/resource/an-overview-to-family-meetings-and-difficult-conversations/>
- ☐ Actively practice Self Care. Do you have any self-care practices? (See SELF CARE resources) <https://www.caresearch.com.au/tabid/6344/Default.aspx>
- ☐ From the Queensland Government: Palliative Care for Children with Cancer – A Guide for parents: <https://www.childrens.health.qld.gov.au/wp-content/uploads/PDF/brochures/palliative-care-purple-book.pdf>
- ☐ Consider holding regular team debriefing meetings where you can discuss deaths that have occurred or scenarios where a child is experiencing difficult to control symptoms or the team don't agree on treatment approaches. You may want to do this after a particularly challenging death or perhaps at the end of a shift. Sometimes informal support is helpful but sometimes more formalised support is needed such as via Employee Assistance Programs
- ☐ Make yourself aware of the ACSQHC End-of-Life Care Audit toolkit. Find the person in your organisation responsible for QA and bring it to their attention: <https://www.safetyandquality.gov.au/audit-toolkit-home/>

For resources go to the My Toolkit pages in End-of-Life Essentials website: <https://www.endoflifeessentials.com.au/>

Resources

Paediatric End-of-Life Care

Australian Commission on Safety and Quality in Health Care: [National Consensus Statement - End-of-life care](#)

Australian Paediatric Palliative Care website

Quocca Paediatric Palliative Care project

PCC4U has information on [Paediatric Palliative care](#)

WA Cancer and Palliative Care Network [Paediatric and Adolescent Young Adult Palliative Care Model of Care](#)

CareSearch, [Paediatrics](#)

Palliative Care Australia: [Paediatric Palliative Care Policy Statement](#)

From the Queensland Government: [Palliative Care for Children with Cancer – A Guide for parents](#) (1MB pdf) and [‘practical guide to palliative care in paediatrics’](#). (2MB pdf)

From the Australian Centre for grief and bereavement - [After the Loss of a Child: A Resource for Parents of Children in Palliative Care](#)

NSW [Paediatric Palliative Care Programme](#)

From QUT End of Life Law Australia: [Children and end of life decision-making](#)

End-of-Life Essentials: [Glossary of terms](#)

End-of-Life Essentials Able versus Novice: [Which one are You?](#)

Resources

Paediatric End-of-Life Care

Videos, Blogs and Podcasts

CareSearch Blog: Elizabeth Shepherd: [A Rewarding Place to Work: My Personal Perspective on Paediatric Palliative Care](#)

CareSearch blog: Dr Anthony Herbert: [Improving Children's Palliative Care Close to Home in Australia](#)

The video '[Emily's story](#)' is designed to support the learning activities associated with the focus topic '[Caring for children with life-limiting conditions](#)' in PCC4U

Further Reading

Ekberg S, Bradford NK, Herbert A, Danby S, Yates P. Healthcare Users' Experiences of Communicating with Healthcare Professionals about children who have life-limiting conditions: A qualitative systematic review. *J Palliat Med*. 2018 Oct;21(10):1518-1528. doi: [10.1089/jpm.2017.0422](#).

Ghirotto L, Busani E, Salvati M, Di Marco V, Caldarelli V, Artioli G. Researching children's perspectives in pediatric palliative care: A systematic review and meta-summary of qualitative research. *Palliat Support Care*. 2019 Feb;17(1):107-118. doi: [10.1017/S1478951518000172](#).

Bradford N, Rolfe M, Ekberg S, Mitchell G, Beane T, Ferranti K. Family meetings in paediatric palliative care: an integrative review. *BMJ Supportive & Palliative Care*. 2020 July. doi: [10.1136/bmjspcare-2020-002333](#). [Epub ahead of print]

Marsac ML, Kindler C, Weiss D, Ragsdale L. Let's talk about It: Supporting family communication during end-of-life care of pediatric patients. *J Palliat Med*. 2018 Jun;21(6):862-878. doi: [10.1089/jpm.2017.0307](#). Epub 2018 May 18.

Johnston EE, Martinez I, Currie E, Brock KE, Wolfe J. Hospital or Home? Where Should Children Die and How Do We Make That a Reality? *J Pain Symptom Manage*. 2020 Jul;60(1):106-115. doi:[10.1016/j.jpainsymman.2019.12.370](#). Epub 2019 Dec 28.

Mu P-F, Tseng Y-M, Wang C-C. Nurses' Experiences in End-of-Life Care in the PICU: A Qualitative Systematic Review. *Nursing Science Quarterly*. 2019;32(1):12-22. doi:[10.1177/0894318418807936](#)

Atout M. Experience of nurses who work with children with palliative care needs: A mixed-method systematic review. *Palliat Support Care*. 2020 Aug;18(4):473-485. doi: [10.1017/S1478951519000956](#)
