Helpful websites

[Palliative care network of Wisconsin- fast facts Pediatric](https://www.mypcnow.org/?s=pediatrics)  designed to provide concise, practical, peer-reviewed, and evidence-based summaries on key palliative care topics.  This Pediatric Fast Facts collection is dedicated to topics important to clinicians and trainees caring for infants, children, and adolescents with serious illness and their families and caregivers.

[Courageous Parents Network](https://courageousparentsnetwork.org) goal is to empower parents and families who are caring for children with serious illness and educate professionals through video, written material and shared experiences. Excellent resource for parents and professionals.

[*Dana Farber Pediatric Pain and Symptom Management Guidelines*](https://pinkbook.dfci.org/) This booklet is a guide to symptom management in children and a tool for identifying areas for self-study from Dana- Farber Cancer Institute. Pharmacologic options for pain and other distressing symptoms are provided. Use of medications requires adequate knowledge of side effects and drug-drug interactions. These suggestions cannot replace medical consultation.

<http://www.togetherforshortlives.org.uk/assets/0000/1052/Basic_Symptom_Contro_in_Paediatric_Palliative_Care_2011.pdf> Free down loadable basic symptom control manual by **Together for Short Lives,** UK based Palliative care non-profit.

[National Organization for Rare Diseases](https://rarediseases.org/) for parents and professionals with information and education.

[Syndromes Without A Name USA - National Organization for Rare Disorders](https://rarediseases.org/organizations/syndromes-without-a-name-usa/) [*WAN USA (Syndromes Without a Name)*](http://swanusa.org/)  An initiative run by the charity Genetic Alliance UK offering support and information to families of children with undiagnosed genetic conditions.

[Caring Together - Home](https://caringtogether.life/) a free platform based in Canada. designed to educate, support, and empower parents providing care for a seriously ill child and those who are experiencing pregnancy or infant loss.

[National Hospice and Palliative Care Organization/ pediatrics](https://www.nhpco.org/pediatrics/) US based organization that hosts the Children's International Project on Palliative/Hospice Services ( ChIPPS) provides a free newsletter on different topics each time and many resources. Back issues are also available.

For example-Issue 69 Pediatric Hospice and Palliative care in the community or Issue 71 Pediatric Education and training for Pediatric palliative care and hospice providers [Pediatric\_e-Journal\_Index.pdf](https://www.nhpco.org/wp-content/uploads/Pediatric_e-Journal_Index.pdf)

[Palliative Care Pediatric Pain Basics - Hospice and Palliative Nurses Association](https://hpna.digitellinc.com/courses/21/view) Hospice and Palliative Nurses Association members can purchase a short course, webinars and other information is available on caring for pediatric patients.

[Together for Short Lives: Children's Charities - Children Hospices](https://www.togetherforshortlives.org.uk/). .This is a UK-based organization working to improve care and services for children with life-threatening or terminal conditions and their families. They have a list-serve, resources, etc. A free searchable literature database is available.

www.virtualhospice.ca *Canadian Virtual Hospice* resources for families, professional for patients of all ages, with a searchable researcher database, website links and downloadable resources

*Grief Resources*

[Brighter Days Family Grief Center | Grief Center serving Minnesota](https://brighterdaysgriefcenter.org/) focuses on bringing families together after a loss.

.[Caring Together - Grief & Bereavement](https://caringtogether.life/grief-bereavement/) part of the Canadian Virtual Hospice site, includes perinatal and child death

[The Dougy Center for Grieving Children & Families |](https://www.dougy.org/)  on line resources for families and professionals

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