



# Pediatric Palliative and Hospice Resource List

These resources have been developed by external partners and organizations.

## **Courageous Parents Network**

- <u>How Pediatric Palliative Care Helps</u> This resource hub provides an overview of the benefits of pediatric palliative care for patients, families, and the broader care team.
- <u>Improving the Pediatric Cancer Care Experience with Palliative Support</u> This guide provides an overview of the benefits of palliative care in pediatric oncology.
- <u>Pediatric Cancer Resource Hub</u> This resource hub includes blog posts from parents, videos from physicians, and podcasts hosted by families covering their experiences with palliative care for pediatric cancer patients.



\*All resources are also available in Spanish.

# The Leukemia & Lymphoma Society



- <u>Caring for Kids and Adolescents with Blood Cancer Workbook</u> This workbook is written for the parents/guardians of children up to age 18. It includes information about caring for your child, treatment options, school, nutrition, financial and legal issues, and more. Specific chapters relevant to palliative and hospice care include:
  - o Chapter 4: <u>Treatment Options</u>
  - Chapter 5: Side Effects and Supportive Care
  - o Chapter 14: End-of-Life Care

## **Pediatric Palliative Care Coalition**



- <u>Pediatric Care Plan Book</u> This Care Plan Book was created for families, caregivers and medical professionals, and covers topics like medical history, appointments, medications, and legal topics.
- <u>Caring Conversations Toolkit</u> This toolkit will help families and caregivers ask questions to learn if it is time to start a conversation about palliative care or hospice.
  - There is also a toolkit geared towards medical professionals to start this conversation with a family.
- <u>Self-Advocacy Toolkit</u> This toolkit is designed to help parents, caregivers, children, adolescents and teens on the advocacy journey while receiving care for a complex medical issue.

## **National Alliance for Care at Home**

#### Resources for Providers

- <u>Pediatric Facts and Figures 2023 Edition</u> This report provides an overview of pediatric hospice and palliative care in the United States, including information on pediatric patient characteristics, barriers and facilitators to care, and gaps in services.
- <u>Tips for Caring for a Child When You are an Adult Provider</u> This fact sheet, geared towards providers familiar with adult palliative and hospice care, covers the differences in pediatric palliative care practices.





#### **Palliative Care Network of Wisconsin**

#### Resources for Providers

• <u>Pediatric Palliative Care Fast Facts</u> - These fast facts, covering a broad range of palliative care topics, provide concise, practical, peer-reviewed, and evidence-based summaries geared towards medical professionals.



At the Wisconsin Cancer Collaborative, we are working hard to achieve our 2024-2028 Childhood Cancer Action Plan goals, in collaboration with our knowledgeable and passionate partners.

**Goal #4** is specifically dedicated to improving access to trainings and resources about pediatric palliative and hospice care in Wisconsin.



Read our full 2024-2028 Childhood Cancer Action Plan.



View this resource list on our website (with clickable links).



Join the Wisconsin Cancer Collaborative (for free)!

Are we missing a resource? Let us know at info@wicancer.org.