



# Caring for Children with Serious Illness

## What is pediatric palliative and hospice care?

Pediatric palliative and hospice care focuses on enhancing quality of life for the child and family; preventing and minimizing suffering, optimizing function, and providing opportunities for personal and spiritual growth. Pediatric care can begin before birth and continue through young adulthood. Below is a breakdown of age groups:<sup>1</sup>

- **Perinatal:** before birth
- **Neonatal:** birth to 1 month
- **Infancy:** 1 month to one year of age
- **Childhood:** age 1 to 12
- **Adolescence:** ages 13 to 17
- **Young adulthood:** age 18 years and over

Diagnosing children's illnesses and prognosticating the outcome of the illness is difficult as children tend to have rare diseases while also being incredibly resilient. Children do not tend to follow a linear disease progression; they will move between highs and lows throughout course of the disease.

## What is concurrent care?

In 2010, the Patient Protection and Affordable Care Act (ACA) enabled children who were enrolled in Medicaid or Children's Health Insurance Program (CHIP), and living with a serious illness, to continue to receive disease directed treatment along with hospice care. This policy allowed families to avoid the terrible choice of deciding when to stop disease directed treatment for their child's illness and instead to choose care only focused on comfort. With concurrent care, pediatric patients must still meet the six-month prognosis, but they no longer must discontinue the care that may extend their life. Concurrent care treatments are any therapies, medications, equipment, or modalities related to the child's serious health condition.

Concurrent care differs from the Medicare hospice benefit in that when Medicare beneficiaries elect hospice, they must waive their rights to payments for any treatment for their terminal illness, outside of hospice care. Each state was charged with implementing concurrent care which has resulted in varied policies and execution. These variances have caused confusion for children, families, and providers. As

of 2018, concurrent care for children was mandated for children on TRICARE, the healthcare program for uniformed service members, retirees, and their families around the world. In addition, some private insurance companies provide concurrent care coverage for children but it may require individualized education and advocacy from providers and is not guaranteed.

## What are the barriers to accessing these services?

Pediatric palliative and hospice care providers are faced with similar issues as adult providers but at a heightened level. Providers have highlighted the lack of pediatric trained personnel, competing organizational priorities, and lack of funding/reimbursement as key issues to providing care.<sup>2</sup> These struggles have resulted in pediatric programs closing and downsizing, leading to children and families being unable to access these necessary services or being required to use adult services not set up for children.

### ONE PARENT DESCRIBED

"...the hospice staff as 'wonderful people,' [but] they were not adequately prepared for a 10-year-old. Their equipment was sized for adults, not children."

1. U.S. Department of Health and Human Services, (2023). NIH style guide: Age. [https://www.nih.gov/nih-style-guide/age#:~:text=Adolescents%20\(13%20years%20through%2017,adults%20\(65%20and%20older\)\\*](https://www.nih.gov/nih-style-guide/age#:~:text=Adolescents%20(13%20years%20through%2017,adults%20(65%20and%20older)*)

2. 2023 Edition: Pediatric Facts and Figures. Alexandria, VA: National Hospice and Palliative Care Organization, [https://www.nhpc.org/wp-content/uploads/NHPCO\\_Pediatric\\_Facts\\_Figures\\_2023.pdf](https://www.nhpc.org/wp-content/uploads/NHPCO_Pediatric_Facts_Figures_2023.pdf).

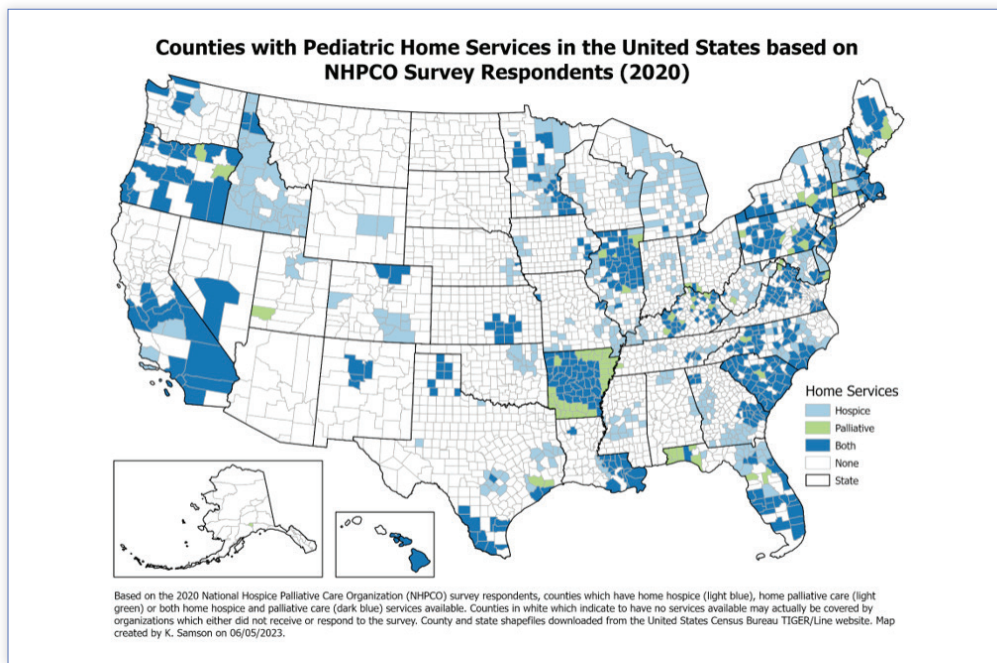


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In addition, there is a lack of data regarding the impact of concurrent care on the care children and families receive and how each state has implemented the requirements of concurrent care.

## Do children have access to the services they need?

Access to the services children need when facing a serious illness will vary based on where in the U.S. they live, whether there is an adequate workforce to care for them, and whether there are providers familiar with providing concurrent care. Below is a breakdown of pediatric palliative and hospice services in the U.S. based on the 2020 NHPCO Needs Assessment.



### For more information:

- **For comprehensive data** on the state of pediatric palliative and hospice care, review the 2023 Pediatric Facts and Figures at [www.nhpc.org/palliativecare/pediatrics/pediatrics-professional-resources/](http://www.nhpc.org/palliativecare/pediatrics/pediatrics-professional-resources/)
- **For more in-depth information** on a variety of issues in pediatric palliative and hospice, review over 20 years of pediatric e-journal issues at [www.nhpc.org/palliativecare/pediatrics/chippis-pediatric-e-journal/](http://www.nhpc.org/palliativecare/pediatrics/chippis-pediatric-e-journal/)
- **For more information** on the implementation of concurrent care by state, review the University of Tennessee, Knoxville Pediatric End-of-Life Research at [pedeolcare.utk.edu/state-concurrent-care/](http://pedeolcare.utk.edu/state-concurrent-care/)