

Story Angles / Evidence (Page 1 of 3)

“The # 1 wish families want more than anything is a cure for their child. Second is to catch up on sleep, so they can handle the next challenge...and the one after that.”

Jonathan Cottor
Proud Dad, Founder/CEO

Story Angles	Evidence/Source
<p>“Respite” may not be a familiar concept</p> <p>Respite care allows primary caregivers the opportunity to sleep, regenerate their reserves, destress, and experience some sense of normalcy for a brief period. Out-of-home respite offers advantages for families such as providing an opportunity for a complete rest from the responsibility of caring and the chance to spend time with other family members or for some leisure activities.</p> <p>Respite, or “short breaks” are an essential component of children’s palliative care to allow the parents and family members some relief of caregiving responsibilities.</p>	<p><u>Sources:</u> Whitmore KE, Snethen J. Respite care services for children with special healthcare needs: Parental perceptions. <i>J Spec Pediatr Nurs.</i> 2018;23(3):e12217. doi: 10.1111/jspn.12217 [doi]. Murphy M, Hill K, Begley T, Brenner M, Doyle C. Respite care for children with complex care needs: A literature review. <i>Compr Child Adolesc Nurs.</i> 2021:1-10. doi: 10.1080/24694193.2021.1885523 [doi].</p> <p><u>Sources:</u> Gibson-Smith D, Jarvis SW, Fraser LK. Place of death of children and young adults with a life-limiting condition in england: A retrospective cohort study. <i>Arch Dis Child.</i> 2020;106(8):780-785. doi: archdischild-2020-319700 [pii]. Ling J, Payne S, Connaire K, McCarron M. Parental decision-making on utilisation of out-of-home respite in children's palliative care: Findings of qualitative case study research - a proposed new model. <i>Child Care Health Dev.</i> 2016;42(1):51-59. doi: 10.1111/cch.12300 [doi].</p>
<p>Families with children on life-limited journeys face overwhelming mental stress</p> <p>Children with medical complexities (CMC) have even greater family stress often caused by the medical conditions of their children, the increased care requirements, financial burdens, marital strains, and diverted time from their other children</p> <p>When parents’ wellbeing is taken into consideration and being addressed, the wellbeing of a child with life-limiting conditions improves.</p>	<p><u>Source:</u> Lindly OJ, Chavez AE, Zuckerman KE. Unmet health services needs among US children with developmental disabilities: Associations with family impact and child functioning. <i>J Dev Behav Pediatr.</i> 2016;37(9):712-723. doi: 00004703-201611000-00004 [pii].</p> <p><u>Source:</u> Murphy M, Hill K, Begley T, Brenner M, Doyle C. Respite care for children with complex care needs: A literature review. <i>Compr Child Adolesc Nurs.</i> 2021:1-10. doi: 10.1080/24694193.2021.1885523 [doi].</p>
<p>Respite is a critical service for families with medically fragile children.</p> <p>Respite is a critical service for families that provides temporary relief to caregivers. As part of a continuum of home- and community-based services (HCBS), respite can improve families’ quality of life and help improve outcomes, including promoting more stable living situations.</p> <p>Essential respite care, especially when provided out-of-the-home, gives parents a chance to sleep, spend time with other family members, and care for themselves which in turn gives them more energy and patience resulting in improvements in the level of care they can then provide to their child.</p>	<p><u>Sources:</u> https://nashp.org/state-medicaid-approaches-to-respite-care-for-children-and-youth-with-chronic-and-complex-needs/</p> <p>Edelstein, H., Schippke, J., Sheffe, S., Kingsnorth, S. “Children with medical complexity: a scoping review of interventions to support caregiver stress,” <i>Child Care, Health and Development</i>, 43(3): 323-333, 2017, https://archrespite.org/bibliography/children-with-medical-complexity-a-scoping-review-of-interventions-to-support-caregiver-stress/</p> <p>Suzuki, S., Kamibeppu, K. “Impact of respite care on health-related quality of life in children with medical complexity: A parent proxy evaluation,” <i>Journal of Pediatric Nursing</i>, Nov-Dec 2022. DOI: 10.1016/j.pedn.2022.07.009</p> <p>Centers for Medicare & Medicaid Services. “Alternatives to Psychiatric Residential Treatment Facilities,” Accessed May 2024. www.medicare.gov/medicaid/long-term-services-supports/alternatives-psychiatric-residential-treatment-facilities</p> <p>English, K., Lieman, R.B., Fields, S., Schober, M. “Services in Support of Community Living for Youths with Serious Behavioral Health Challenges: Respite Care.” The TA Network, 2017. www.pacarepartnership.org/uploads/TA_Network_RespiteBrief-2017-v2.pdf</p> <p><u>Source:</u> Murphy M, Hill K, Begley T, Brenner M, Doyle C. Respite care for children with complex care needs: A literature review. <i>Compr Child Adolesc Nurs.</i> 2021:1-10. doi: 10.1080/24694193.2021.1885523 [doi].</p>

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<p><i>There is a Severe Lack of Respite Providers Available in the U.S.</i></p> <p>Parents may become overwhelmed with the ongoing caregiving needs of their children and can struggle finding qualified caregivers capable of providing them a break from these 24/7 responsibilities.</p> <p>Caregivers of children with chronic and complex needs report that respite is not sufficiently available.</p>	<p><u>Sources:</u> Whitmore KE, Snethen J. Respite care services for children with special healthcare needs: Parental perceptions. <i>J Spec Pediatr Nurs.</i> 2018;23(3):e12217. doi: 10.1111/jspn.12217 [doi].</p> <p>https://nashp.org/state-medicaid-approaches-to-respite-care-for-children-and-youth-with-chronic-and-complex-needs/</p> <p>Hirt, E., et al. “Fitting the Pieces Together: The Experiences of Caregivers of Children with Medical Complexity,” <i>Hospital Pediatrics</i> 13(12): 1056-1066, 2023. https://doi.org/10.1542/hpeds.2022-007112</p>
<p><i>Parents Struggle with even knowing they need Respite</i></p> <p>Needing respite care is something with which parents struggle. Many parents report being unfamiliar with the idea, not knowing of its existence, being unaware of how it could help their family, or the thought of temporarily relinquishing responsibility for their child’s care seems unthinkable and creates an emotional barrier of anticipated guilt.</p>	<p><u>Source:</u> Murphy M, Hill K, Begley T, Brenner M, Doyle C. Respite care for children with complex care needs: A literature review. <i>Compr Child Adolesc Nurs.</i> 2021;1-10. doi: 10.1080/24694193.2021.1885523 [doi].</p>
<p><i>Parents must Trust a Respite Provider before they allow them to care for their child.</i></p> <p>Parents need to have trust and can be hesitant and reluctant to relinquish their child to respite care if they are not feeling assured that their child will be safe, receive the appropriate care and monitoring, and have a good experience. Children with life-limiting conditions have very complex medical needs that require parents to care for their children throughout the day and night, sometimes including very technical levels of care such as suctioning that if not managed would lead to death.</p>	<p><u>Sources:</u> Whitmore KE, Snethen J. Respite care services for children with special healthcare needs: Parental perceptions. <i>J Spec Pediatr Nurs.</i> 2018;23(3):e12217. doi: 10.1111/jspn.12217 [doi]. Ling J, Payne S, Connaire K, McCarron M. Parental decision-making on utilisation of out-of-home respite in children's palliative care: Findings of qualitative case study research - a proposed new model. <i>Child Care Health Dev.</i> 2016;42(1):51-59. doi: 10.1111/cch.12300 [doi].</p>
<p><i>Significant Nursing Shortages and Low pay is a major barrier preventing desperate families from accessing respite services</i></p> <p>Respite can be challenging for families to access given the significant workforce shortages. Increasing reimbursement rates can incentivize providers to deliver respite services, which can help expand and sustain respite service availability.</p>	<p><u>Source:</u> https://nashp.org/state-medicaid-approaches-to-respite-care-for-children-and-youth-with-chronic-and-complex-needs/</p>

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<p style="text-align: center;"><i>Respite gives light to siblings and helps them thrive</i></p> <p>When children with life-limiting conditions and their families receive respite care, the siblings benefit because for a short time they become the sole object of their parent’s focus who can then attend to their needs, and together even go on a vacation or have visitors to their home that would not otherwise be able.</p>	<p><u>Source:</u> Murphy M, Hill K, Begley T, Brenner M, Doyle C. Respite care for children with complex care needs: A literature review. <i>Compr Child Adolesc Nurs.</i> 2021;1-10. doi: 10.1080/24694193.2021.1885523 [doi].</p>
<p style="text-align: center;"><i>Adult healthcare facilities are not appropriate for children’s care because kids are not little adults.</i></p> <p>A key difference between adults and children with life-limiting conditions is that a child’s life path is often more difficult to project, are more resilient and can live longer than expected, and therefore need more support for longer periods of time.</p> <p>Caring for children requires different and usually more resource-intensive services which is why hospice programs that traditionally provide adult palliative care are often unprepared and ill-equipped to appropriately handle care for a population with different needs than their usual patients.</p>	<p><u>Source:</u> Siden H, Chavoshi N, Harvey B, Parker A, Miller T. Characteristics of a pediatric hospice palliative care program over 15 years. <i>Pediatrics.</i> 2014;134(3):765. doi: 10.1542/peds.2014-0381 [doi].</p> <p><u>Source:</u> . Gans D, Hadler MW, Chen X, et al. Cost analysis and policy implications of a pediatric palliative care program. <i>J Pain Symptom Manage.</i> 2016;52(3):329-335. doi: S0885-3924(16)30116-6 [pii].</p>
<p style="text-align: center;"><i>Community-based pediatric centers reduce dependence on Children’s Hospital resources, with significant savings</i></p> <p>PICU resources are more frequently used by children with CCC’s (Chronic complex medical conditions). PICU patients who were readmitted within 12 months of hospital discharge accounted for 20% of all hospital bed days and added an additional \$3.7 billion (21.5%) to total healthcare costs.</p> <p>Costs in a PICU (Children’s Hospital) are approx. \$6,023* for 24-hour care, compared to a range of \$1,845-\$3,100** at a community-based children’s respite home.</p> <p><small>*Includes Clinical, Supplies, and Room/Board/Other, but <u>NOT</u> including Physician Laboratory, or Pharmacy Expenses, nor Pediatric Palliative Care Services and Support</small></p> <p><small>**Includes Pediatric Palliative Care Services and Supports; Nursing, Child Life Specialist, Medical Director oversight, Emotional/Psychosocial, etc.</small></p>	<p><u>Source/Assumptions:</u> 2016-2017 Retrospective Study of 52 Children’s Hospitals ;N=239157 x 27.5% avg increase for today’s cost https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7892293</p> <p><u>Source/Assumptions:</u> 2016-2017 Retrospective Study of 52 Children’s Hospitals ;N=239157 x 27.5% avg increase for today’s cost https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7892293</p> <p><u>Source:</u> NCPPCH Cost Analysis and 2024 Budget Detail for Crescent Cove (MN), based on 3 levels of child acuity</p>

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