

Childhood Cancer and Survivorship

Childhood cancer is relatively rare, accounting for less than 3% of cancers diagnosed each year in the United States.¹⁸ However, cancer is the second leading cause of death (following accidents) in children ages 1 - 14. Improved treatments have led to better childhood cancer survival rates over the past few decades.

However, survivors of childhood cancers may face challenges throughout life due to late effects of treatment, which may include secondary cancers as well as disturbances in every organ system, including cardiovascular, endocrine, reproductive, respiratory, musculoskeletal, nervous, digestive, renal, urinary, visual, and auditory systems. It is also well documented that children previously treated for cancer often suffer from mental health and psychosocial issues.

Some cancer centers caring for adult survivors of childhood cancers offer specialized survivorship care. Long-term follow-up guidelines were developed by the Children's Oncology Group for use by clinicians whose patients are childhood cancer survivors.¹⁹ Special needs of the caregivers of pediatric patients are also complex, since parents may need to spend long periods of time away from the siblings of the patient and may face significant emotional, logistical, and financial stresses.

A recent commitment of \$50 million annually for ten years starting in 2020 was made by the federal government to fund research at the National Cancer Institute through the Childhood Cancer Data Initiative (CCDI). The CCDI is designed to bring childhood research, advocacy, and clinical communities together to use data to meet the following goals:

- Gather data from every child, adolescent, and young adult diagnosed with a pediatric cancer
- Create a national strategy of appropriate clinical and molecular characterization to speed diagnosis and inform treatment for all types of pediatric cancers
- Develop a platform and tools to bring together clinical care and research data that will improve preventive measures, treatment, quality of life, and survivorship for pediatric cancers^{20 21 22 23 24}

