

# OVERALL CONCLUSIONS

DECEMBER 2020 • CHILDHOOD CANCER AND FUNCTIONAL IMPACTS ACROSS THE CARE CONTINUUM

## FUNCTIONAL IMPACTS OF CANCER AND ITS TREATMENT

- 1. During recent decades, the incidence of childhood cancers has increased at a modest rate, and the survival rates for many cancer types have improved. The result has been a growing number of survivors of childhood cancer who, starting from the time of diagnosis, are adversely affected by cumulative physical, cognitive, and psychosocial functional deficits, whose severity may increase over time, as a result of the cancer and its treatment.**
  - Despite improved overall survival, certain specific cancers, including certain hematologic malignancies with adverse genetic features, some central nervous system (CNS) and solid tumors with metastatic disease, or tumors that recur after primary therapy, have distinctively poor prognoses.
  - The functional, social, and psychosocial impacts of all childhood cancers on both the affected children and their families are significant, beginning at the time of diagnosis, continuing through treatment, and often lasting into survivorship.
  - The interruption of normal childhood during critical developmental stages by the diagnosis and treatment of a childhood cancer can be particularly debilitating and result in long-term adverse effects.
  - Although many survivors of childhood cancer experience persistent adverse physical, cognitive, and psychosocial effects from the cancer and its treatment, CNS tumors and some leukemias place survivors at especially high risk for cognitive deficits, and solid tumors are often associated with physical impairments and medical complications.

## ADVERSE EFFECTS OF TREATMENT

- 2. Treatment of childhood cancers generally includes individual or combined use of different modalities (e.g., surgery, radiation, chemotherapy), each of which can precipitate a range of acute, chronic, and late-occurring impairments.**
  - Adverse physical, functional, cognitive, and psychosocial effects can occur regardless of treatment modality.
  - Acute effects of treatment can elicit impairment during both the treatment course and a period of recovery following its completion.
  - The adverse effects of pediatric cancer therapy may also continue well past the end of treatment, can be cumulative, and may become more severe over time.
  - It is important for survivors of childhood cancer to receive lifelong surveillance and appropriate interventions for treatment-related physical, cognitive, psychological, and emotional long-term and late effects.
  - The severity of adverse effects can vary depending on cancer type; tumor location; presence of metastases; type of surgery received; treatment modality employed; duration of treatment; and such patient characteristics as age, genetics, and underlying preexisting conditions.
  - Increasing understanding of the biology and pathogenesis of cancers is resulting in a growing number of targeted treatments that hold promise for less serious acute and long-term adverse effects.

## OCCURRENCE AND PERSISTENCE OF FUNCTIONAL IMPAIRMENTS

- 3. Functional deficits resulting from cancer and its treatment can improve over time, but many may persist or worsen, or even have onset at a later time, resulting in long-term functional impairments whose effects include restrictions on participation in the educational, vocational, and avocational arenas.**
  - Cognitive sequelae, especially among children treated for central nervous system (CNS) tumors and those who receive certain types of chemotherapy, may begin at the time of diagnosis or initiation of treatment, but often persist and may progress in severity over time. Specific cognitive deficits (e.g., a decrease in processing speed related to radiation treatment) may begin well after treatment has concluded or may become evident at a later developmental stage associated with differing functional demands.
  - Long-term psychosocial effects are especially common among the following subgroups of children: those who undergo pretreatment prior to hematopoietic stem cell transplantation, those with CNS tumors, and those who experience significant physical late effects.
- 4. Many survivors of childhood cancer do not achieve an age-equivalent degree of independence in one or more of several domains, which may include mobility; endurance; activities of daily living; and cognitive, social, or communicative skills.**
  - Although rehabilitation services may improve the level of independence with respect to functional activities among survivors of childhood cancers, survivors may never achieve the full level of educational and vocational participation expected for their age or developmental stage.

## TRANSITION FROM ADOLESCENCE TO ADULthood

- 5. The transition from adolescence to adulthood is particularly challenging for adolescents diagnosed with cancer, as well as for survivors of childhood cancer.**
  - The change in the U.S. Social Security Administration's disability determination process during the transition from adolescence to adulthood introduces challenges for determining disability and sustaining benefits across the 18-year-old threshold.
  - Complexities in the transition from pediatric to adult cancer care and follow-up may lead to disengagement in care, which can result in more severe adverse outcomes in adult survivors of childhood cancers.
  - Attrition at the point of transfer from pediatric to adult cancer care cannot be explained solely by issues of access. Special support is necessary to keep survivors of childhood cancers engaged in the health care system into and throughout adulthood.

## PARTICIPATION IN CLINICAL TRIALS

- 6. Clinical trials advance the standard of care for patients with childhood cancers and are critical to improving survival while also reducing toxicity, late effects, and subsequent neoplasms. Because of the small number of pediatric patients with cancer, trials would not generate meaningful results without a high rate of trial participation, which is generally considered the standard of care for childhood cancers.**
  - Regulatory agencies have implemented changes to enable early access to novel therapeutic agents and to facilitate the participation of adolescents and young adults and pediatric patients with cancer in clinical trials.

- It is important to increase the participation of adolescents and young adults in clinical trials, as their participation rate is typically much lower compared with younger children.
- Increased engagement of patients, especially those from underrepresented groups, and their advocates in the development of clinical trials is important to enable representation of the patient and family perspective, including quality of life, tolerability of side effects, and goals of treatment, in the trial design.

## AVAILABILITY OF PEDIATRIC CANCER CARE PROVIDERS AND SERVICES

**7. The availability of and access to pediatric cancer treatments, clinical trials, follow-up care, and rehabilitation and psychological services can be limited by geography and other factors, such as the availability of experts in pediatric cancer and survivorship care, as well as specialized technology.**

- High-quality care for pediatric cancers relies on effective coordination among a highly specialized team across a broad range of disciplines.

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