EU Network of Youth Cancer Survivors

(EU-CAYAS-NET)

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SURVIVORS ÖSTERREICH - KINDER-KREBS-ÜBERLEBENDEN-INITIATIVE	SurvivorsAT	10	Associated Partner
Fondation d'Utilité Publique KickCancer	KickCancer	11	Associated Partner
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ASSOCIATION CHILDREN WITH ONCOHEMATOLOGIC DISEASES	ACOD	15	Associated Partner
Krijesnica - udruga za pomoc djeci i obiteljima suocenim s malignim bolestima	Krijesnica	16	Associated Partner
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D3.3 Transition Guideline[1] prepared for submission/publication as open access, including guideline visual summary for advocacy use

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[1] This report presents a high-level overview of the Results that will be submitted as an open access manuscript to a peer-reviewed journal by the end of 2024. Full Results are not included in this PUBLIC deliverable as publication of Results upon approval of the deliverable would constitute prior publication, impeding publication in a peer-reviewed journal. All results will be ultimately available in the public domain via the open access publication, which will also be uploaded to the Platform once published.

1 Executive Summary

There are over 500,000 young cancer survivors, aged 14-39 living in Europe. Thanks to advancements in medical treatments, the survival rate stands at an encouraging 85% in developed European countries. However, there are disparities between European countries, both in terms of survival rates and the way in which post-treatment care is organised. As up to 75% of survivors experience one or more late effects of treatment, lifelong follow-up care is required to monitor their health. As children grow up and become adults, they should be prepared for the transition to the adult healthcare system. The transition process is often disrupted due to the lack of formal programs that leaves many survivors without adequate support, negatively impacting their health-related quality of life.

To address these issues, the EU-CAYAS-NET project developed a comprehensive evidence-based Transition Guideline aimed at standardising and improving the transition process across the EU.

The International Guideline Harmonization Group (IGHG)'s methodology was followed to develop the guideline and used three main knowledge sources to formulate the recommendations:

1. Available scientific evidence
2. Existing guidelines for transition in other chronic disease populations
3. An assessment of needs and preferences of survivors, parents and healthcare providers

In total, 44 strong recommendations were formulated to optimise the transition process, improve the chances on a successful transition from pediatric to adult care systems, thereby ensuring consistent, high-quality support for young cancer survivors, promoting their health and enabling them to make meaningful contributions to society.

The finalised guideline will be compiled into a manuscript for submission to a peer-reviewed journal by the end of 2024. Additionally, a visual summary of the guideline has been created and translated into eight EU languages and published on the Platform (beatcancer.eu) for advocacy purposes.

2 Introduction & Background

In Europe, there are over 500,000 young cancer survivors aged 14-39.[2] Thanks to advancements in medical treatments, the survival rate in developed European countries has reached an encouraging 85%. However, these rates and the quality of post-treatment care vary significantly across the continent.

As many as 75% of survivors experience one or more late effects of treatment, necessitating lifelong follow-up care, also known as long-term follow-up (LTFU) care, to monitor their health. It is crucial to prepare these individuals for the transition from pediatric to adult healthcare systems as they grow older. Unfortunately, this transition often presents disruptions due to the lack of formal transition programs. As a result, individuals transitioning out of pediatric care upon reaching adulthood often discontinue LTFU care. The legal age of adulthood varies across European Union Member States, ranging from 16 to 21 years, leaving many survivors without appropriate support and continuity of care. This widespread absence of transition programs significantly impacts the health-related quality of life for survivors.

Ensuring a seamless transition into adult healthcare not only aids young survivors in maintaining their health but also enables them to contribute positively to society. By providing the necessary support and resources, we acknowledge their potential to excel and make meaningful contributions to their communities. Investing in robust transition programs ultimately benefits both the individual survivors and the broader society.

To address the critical need for improved survivorship care, within work package (WP) 3 *Quality of Life* of the EU-CAYAS-NET project, we developed a comprehensive evidence-based Transition Guideline. The guideline aims to standardise and enhance the transition process for young survivors, ensuring consistent and effective support across the European Union. The development of this guideline built on the efforts of the PanCareSurFup project, which provided a definition of transition that was integrated into the guideline's final recommendations:

Transition of childhood cancer survivors is an active, planned, coordinated, comprehensive, multidisciplinary process to enable childhood and adolescent cancer survivors to effectively and harmoniously transfer from child-centred to adult-oriented healthcare systems. The transition of care process should be flexible, developmentally appropriate and consider the medical, psychosocial, educational and vocational needs of survivors, their families and care-givers, and promote a healthy lifestyle and self-management.[3]

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[2] Vassal, G., Fitzgerald, E., Schrappe, M., Arnold, F., Kowalczyk, J., Walker, D., Hjorth, L., Riccardi, R., Kienesberger, A., Jones, K. P., Valsecchi, M. G., Janic, D., Hasle, H., Kearns, P., Petrarulo, G., Florindi, F., Essiaf, S., & Ladenstein, R. (2014). Challenges for children and adolescents with cancer in Europe: the SIOP-Europe agenda. *Pediatric blood & cancer*, *61*(9), 1551–1557. https://doi.org/10.1002/pbc.25044

[3] Mulder, R. L., van der Pal, H. J. H., Levitt, G. A., Skinner, R., Kremer, L. C. M., Brown, M. C., Bárdi, E., Windsor, R., Michel, G., & Frey, E. (2016). Transition guidelines: An important step in the future care for childhood cancer survivors. A comprehensive definition as groundwork. *European journal of cancer (Oxford, England : 1990)*, *54*, 64–68. https://doi.org/10.1016/j.ejca.2015.10.007

3 Approach

The guideline was created using the IGHG methodology[4], which involves three main phases:

1. Preparation phase,
2. Development phase, and
3. Finalisation phase.

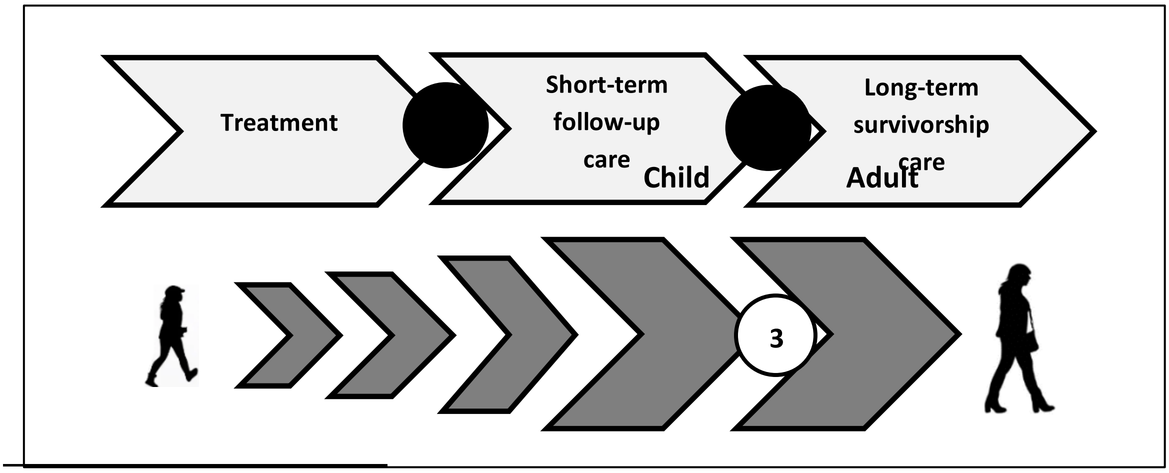
During the **preparation phase**, an effective **guideline panel** was assembled comprising chairs, coordinators, advisors, working group leaders, and members. The panel included a diverse range of disciplines and backgrounds, such as medical doctors, nurses, psychologists, and survivors, with a total of 33 experts from 15 European countries. The coordinators were primarily responsible for the actual development of the guideline. The working group members, both patients and healthcare providers, were valuable contributors by giving their expert opinions when formulating the clinical questions and recommendations, and served as reviewers at key stages.

Additionally, during this phase, the **scope of the guideline** was defined, outlining the aim, target population, and definition:

- **Aim:** To develop recommendations for the transition of child-centred to adult-oriented care for childhood and adolescent cancer survivors treated for cancer up to age 21 years.

  The transition process is connected to three major timepoints of transfer experienced by childhood and adolescent cancer survivors:
  1. From active treatment to short-term follow-up care for adverse effects of cancer treatment,
  2. From short-term follow-up care to long-term survivorship care (5 years after diagnosis), and
  3. From pediatric to adult care service.

This guideline aims to provide recommendations for the transition process that is prior to and shortly after the transfer moments 2 and 3 above. The transition process starts around the first transfer moment from active treatment to short-term follow-up care and ends when the adult age and long-term survivorship care are reached.



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[4] Mulder RL, Brown MC, Skinner R, van Dalen EC, Hudson MM, Kremer LCM. Handbook for guideline development; collaboration between International Guideline Harmonization Group, PanCare Guideline Group and Cochrane Childhood Cancer. 2021

- **Target population**: Childhood and adolescent cancer survivors treated for cancer up to age 21 years >2 years post-treatment.
- **Definition**: Transition of childhood and adolescent cancer survivors: An active, planned, coordinated, comprehensive, multidisciplinary process to enable childhood and adolescent cancer survivors to effectively and harmoniously transfer from child-centred to adult-oriented healthcare systems. The transition of care process should be flexible, developmentally appropriate and consider the medical, psychosocial, educational and vocational needs of survivors, their families and care-givers, and promote a healthy lifestyle and self-management.[2]

In the **development phase**, we began by formulating **clinical questions**, which served as the foundation for a systematic literature search to gather all available evidence. We identified five key questions:

1. What are existing models and what are requirements for the transition of child-centred to adult-oriented care for childhood and adolescent cancer survivors?
2. What are facilitators and barriers to the transition of child-centred to adult-oriented care for childhood and adolescent cancer survivors?
3. What are the needs and preferences of childhood and adolescent cancer survivors and their families for an optimal transition from child-centred to adult-oriented care?
4. What is the effectiveness of transition models in childhood and adolescent cancer survivors?
5. What is the effectiveness of transition models in patients with a chronic condition?

The next step in the development phase was to gather all **available scientific evidence** for the formulated clinical questions. A search strategy in PubMed was designed and executed, initially identifying 1,969 articles. After a thorough and time-intensive screening process based on the inclusion and exclusion criteria.

Following the selection of evidence, the next step in the development phase was to **summarise the included evidence**. Evidence tables were created detailing study and patient characteristics, relevant outcomes and risk of bias, followed by summary of findings tables that highlighted key information for each clinical question. During this step, the quality of the evidence was also assessed using the Grades of Recommendation, Assessment, Development and Evaluation (GRADE) methodology[5], considering factors such as study limitations, result inconsistencies, relevance to the study population, interventions and outcomes, precision of effect estimates, and risks of publication bias.

The next step involved formulating **conclusions of evidence** based on the quality of the body of the evidence. These conclusions served as the initial foundation for the guideline recommendations.

Then we started identifying two **additional knowledge sources**: 1) existing guidelines for transition in other chronic disease populations, and 2) an assessment of needs and preferences of survivors, parents, and healthcare providers.

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[5] Https://www.gradeworkinggroup.org/

For the first additional knowledge source, ten **existing evidence-based guidelines** were identified for the transition from child into adult health care for patients with complex health care needs and specific guidelines on patients with chronic digestive diseases, coeliac disease, liver disease, allergy and asthma, and diabetes. All recommendations from these guidelines were extracted, sorted, and evaluated their relevance for the transition guideline.

The second additional knowledge source was an **assessment of needs and preferences** of survivors, parents and healthcare providers. We aimed to understand the nuanced needs and preferences of young cancer survivors, their families and healthcare providers to reflect the real-world experiences. This process included organising three Peer Visits to leading best practice centres as a part of the EU-CAYAS-NET project: The Princess Máxima Center in Utrecht, the Netherlands (PMC), the Netherlands; Sant Joan de Déu in Barcelona, Spain (FSJD), and the Medical University of Vienna, Austria (MUW).

During these visits, survivors, parents and healthcare providers from 15 European countries observed and experienced the practices and environments of these institutions firsthand. Peer observation forms were used to document their findings, noting both strengths and areas for improvement. This structured method allowed for a thorough examination of existing transition processes, providing valuable insights into what was effective and what could be enhanced. All data from the peer observation forms, the interactive sessions, and an online preparatory workshop were analysed as part of the guideline development process. In total, 170 useful needs and preferences informed the recommendations.

The final step in the development phase was to **formulate the recommendations** based on the conclusions of evidence, existing guidelines and needs and preferences assessment. The initial draft of the recommendations was prepared by the guideline coordinators, advisors, chairs, and working group leaders. Subsequently, the draft was reviewed and discussed with the panel's working group members. The recommendations were graded according to the GRADE methods.[6]

In the **finalisation phase**, we will compile the actual **guideline into a manuscript** that summarises all topics and submit it to a peer-reviewed journal. The guideline is prepared for submission by M26, and with a small delay the manuscript will be finalised (incorporating feedback from the guideline panel members) and submitted for publication no later than Dec 2024 (M28).

Additionally, a **visual summary** of the guideline has been created, which has been translated into eight different EU languages for advocacy purposes. This summary is published on the Platform.[7]

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[6] Alonso-Coello P, Schünemann HJ, Moberg J, et al. GRADE Evidence to Decision frameworks: a systematic and transparent approach to making well-informed healthcare choices. 1: Introduction. BMJ 2016;353:i2016.

[7] https://beatcancer.eu/resources/quality-of-life/article/quality-of-life-project-outputs/

4 Results

76 scientific articles were included as evidence for the guideline (35 articles for Q1, 27 articles for Q2, 14 articles for Q3, 3 articles for Q4 and 12 articles for Q5). Some articles were included for multiple clinical questions. The quality of evidence varied from very low, to moderate. Drawing from the selected scientific evidence, ten existing evidence-based guidelines, and 188 valuable contributions from survivors, parents, and healthcare providers during the needs and preferences assessment, a final set of 44 robust recommendations was developed. The recommendations are organised as follows:

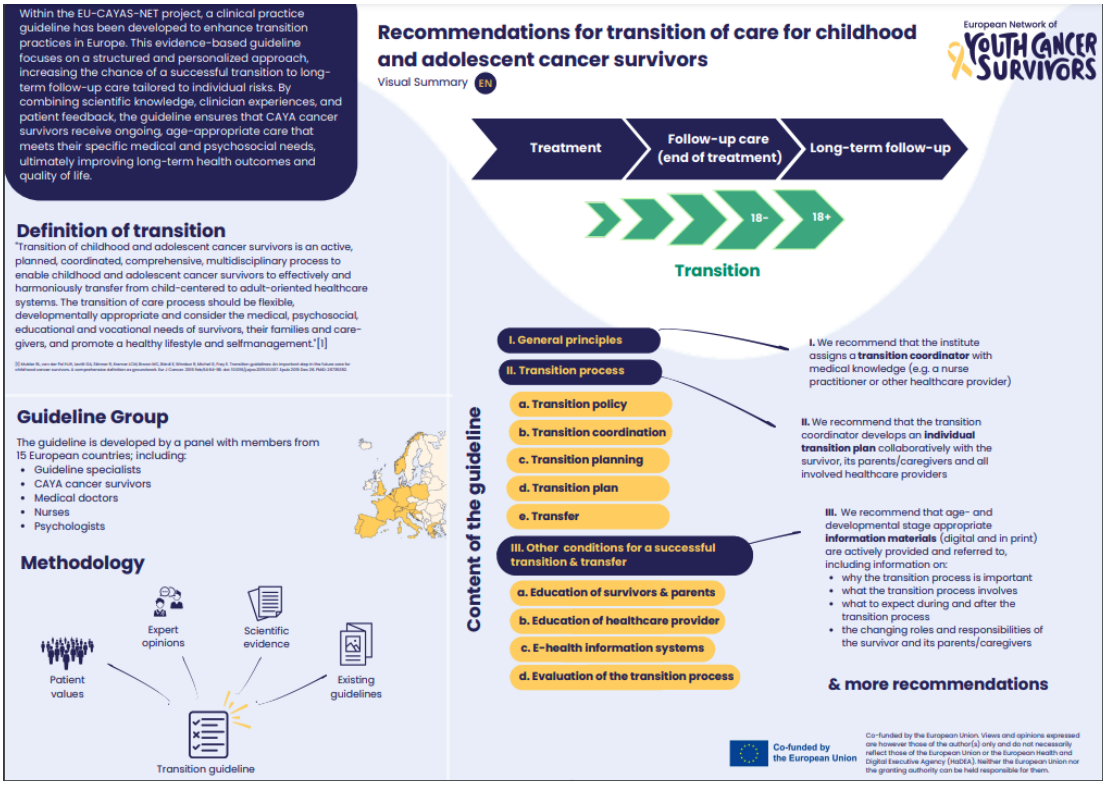
- I. **General principles**
- II. **Transition process**
    - a. Transition policy
    - b. Transition coordination
    - c. Transition planning
    - d. Transition plan
    - e. Transfer moment
- III. **Other conditions for a successful transition and transfer**
    - a. Education and involvement of survivors and their family/caregivers
    - b. Education of healthcare providers
    - c. E-health information systems
    - d. Evaluation of the transition process

The recommendations in **part I. General principles** emphasise that the transition process should be carefully planned, coordinated, and involve a multidisciplinary team to address the complex medical, psychosocial, educational, and vocational needs of survivors. The transition should be flexible and developmentally appropriate, promoting a healthy lifestyle and self-management. In the general principles, it is also recommended to appoint a medically knowledgeable transition coordinator, such as a nurse practitioner, to guide the process. Providers should engage survivors and their families as active partners, offering tailored support and fostering trusting relationships throughout the transition.

The recommendations in **part II. Transition process** emphasise the importance of a structured and personalised approach. Institutions should establish a clear transition policy that involves survivors, families, and healthcare providers from both pediatric and adult care settings. A transition coordinator should be appointed to each survivor to manage the process and create an individualised plan in collaboration with a multidisciplinary team. The plan should address the survivor's unique needs and future goals and be regularly reviewed as they grow. The transfer to adult care should take place when the survivor is ready, ensuring smooth communication between healthcare providers and ongoing support after the transition, with a focus on maintaining continuity of care.

The recommendations in **part III. Other conditions for a successful transition and transfer** emphasise that the transition process from pediatric to adult healthcare should be well-supported and informed. We emphasise providing age-appropriate educational materials to survivors and their families, explaining the importance, steps, and expectations of the transition. Healthcare providers involved in the process should receive specialised training, and their roles in the transition should be formally recognised. The recommendations in this part also highlight the need for efficient e-health systems to support communication and information sharing. Finally, institutions should regularly evaluate the quality of the transition process, incorporating feedback from survivors to ensure their needs are met.

A visual summary of the transition guideline recommendations is available on the Platform, which offers an accessible and engaging overview of the key elements and recommendations of the transition guideline, specifically tailored for young people living beyond cancer. The aim is to provide stakeholders, including healthcare providers, patients, and families, with a clear understanding of the guideline's purpose, main content and some example recommendations.



Within the EU-CAYAS-NET project, a clinical practice guideline has been developed to enhance transition practices in Europe. This evidence-based guideline focuses on a structured and personalized approach, increasing the chance of a successful transition to long-term follow-up care tailored to individual risks. By combining scientific knowledge, clinician experiences, and patient feedback, the guideline ensures that CAYA cancer survivors receive ongoing, age-appropriate care that meets their specific medical and psychosocial needs, ultimately improving long-term health outcomes and quality of life.

Recommendations for transition of care for childhood and adolescent cancer survivors

Visual Summary EN

European Network of YOUTH CANCER SURVIVORS

Definition of transition

"Transition of childhood and adolescent cancer survivors is an active, planned, coordinated, comprehensive, multidisciplinary process to enable childhood and adolescent cancer survivors to effectively and harmoniously transfer from child-centered to adult-oriented healthcare systems. The transition of care process should be flexible, developmentally appropriate and consider the medical, psychosocial, educational and vocational needs of survivors, their families and care-givers, and promote a healthy lifestyle and selfmanagement."[1]

Guideline Group

The guideline is developed by a panel with members from 15 European countries; including:

- Guideline specialists
- CAYA cancer survivors
- Medical doctors
- Nurses
- Psychologists

Methodology

Content of the guideline

- I. General principles
- II. Transition process
  - a. Transition policy
  - b. Transition coordination
  - c. Transition planning
  - d. Transition plan
  - e. Transfer
- III. Other conditions for a successful transition & transfer
  - a. Education of survivors & parents
  - b. Education of healthcare provider
  - c. E-health information systems
  - d. Evaluation of the transition process

I. We recommend that the institute assigns a **transition coordinator** with medical knowledge (e.g. a nurse practitioner or other healthcare provider)

II. We recommend that the transition coordinator develops an **individual transition plan** collaboratively with the survivor, its parents/caregivers and all involved healthcare providers

III. We recommend that age- and developmental stage appropriate **information materials** (digital and in print) are actively provided and referred to, including information on:

- why the transition process is important
- what the transition process involves
- what to expect during and after the transition process
- the changing roles and responsibilities of the survivor and its parents/caregivers

& more recommendations

Co-funded by the European Union

Translations are available in eight EU languages, accessible through the links provided below:

- English: https://beatcancer.eu/wp-content/uploads/2024/08/Summaries-of-Transition-Guideline-_EN.pdf
- German: https://beatcancer.eu/wp-content/uploads/2024/08/Summaries-of-Transition-Guideline-_DE.pdf
- Spanish: https://beatcancer.eu/wp-content/uploads/2024/08/Summaries-of-Transition-Guideline_ES.pdf
- French: https://beatcancer.eu/wp-content/uploads/2024/08/Summaries-of-Transition-Guideline-_FR.pdf
- HR: https://beatcancer.eu/wp-content/uploads/2024/07/Summaries-of-Transition-Guideline_HR.pdf
- Italian: https://beatcancer.eu/wp-content/uploads/2024/08/Summaries-of-Transition-Guideline-_IT.pdf
- Lithuanian: https://beatcancer.eu/wp-content/uploads/2024/08/Summaries-of-Transition-Guideline-_LT.pdf
- Dutch: https://beatcancer.eu/wp-content/uploads/2024/08/Summaries-of-Transition-Guideline_NL.pdf
- Romanian: https://beatcancer.eu/wp-content/uploads/2024/07/Summaries-of-Transition-Guideline-_RO.pdf

5 Impact & Conclusion

With the development of the Transition Guideline, we aim to significantly contribute to the EU-CAYAS-NET project's goal of enhancing the quality of life for childhood, adolescent, and young adult cancer survivors. With its 44 strong recommendations, the guideline aims to standardise and improve the transition process across the EU, increasing the likelihood of a successful transition from pediatric to adult care systems. This ensures consistent, high-quality support for young people living beyond cancer, promoting their health and enabling them to make meaningful societal contributions.

However, merely publishing the guideline will not achieve its full potential impact. A robust implementation plan is crucial. Guidelines require contextualisation, as they are not always directly translatable into practice and policy. Implementing clinical practice guidelines is a complex process influenced by various barriers and facilitators. First and foremost, active dissemination efforts are urgently needed. For this reason, the guideline methodology and recommendations have been/will be shared at several international conferences, including the 30th PanCare meeting (18 Sep 2024, Ljubljana, Slovenia), the 2nd International Pediatric Cardio-Oncology Conference (09 Nov 2024, Cincinnati, United States), and the CCI Europe/SIOP Europe Conference (14 - 17 May 2025, Budapest, Hungary), with the possibility of presenting at additional meetings. Furthermore, until the project end date in June 2025, additional efforts to disseminate the guideline will include prominently referencing it in the upcoming joint WP3 position paper (D3.5) on quality of life. In addition to disseminating the guideline, the results of the workshop (Task 3.4.1) and Peer Visits (Task 3.4.2) will be incorporated into an academic publication focusing on the needs and preferences of survivors during the transition process.

In essence, while the project has succeeded in developing a high-standard clinical practice guideline for the transition of care for young cancer survivors and creating a straightforward summary for advocacy use, this work needs continuation. New efforts for optimal implementation of the guideline are essential to optimally improve care and thereby enhance the quality of life for young cancer survivors.