



Teen Cancer America Hospital Services Program

The Need

Approximately 70,000 teens and young adults (TYA) are diagnosed with cancer each year in the U.S. TYA survival rates in some cancers have not improved as significantly as for younger children and older adults. The reasons for this are not clear but it is a reasonable hypothesis that outcomes and survival could be improved if there were a concentration of expertise and the development of research dedicated to this age group. After considerable analysis, prominent medical groups internationally are now focusing attention on the problem of TYA cancer and calling for improved outcomes.

There is an equally compelling and agreed upon need to improve *quality of life* for TYAs with cancer. Studies show higher psychological distress rates among this age group. While developmental psychology recognizes that peer support plays an essential role in TYA development, young people with cancer often experience a double dose of social isolation due to extended absences from school or work, as well as the alienation of facing a life-threatening illness. To date, most U.S. hospitals have done little to address the need for peer support among TYAs. Furthermore the staff skills required to properly support young people and their families are different from both children and adults. By focusing services on them as a distinct group, we can gain a better understanding about how to support them and improve services delivery.

Teen Cancer America envisions a world where leading hospitals deliver the most advanced cancer treatment and supportive care to teens and young adults within the age group 13 to 25, in a high quality functional environment that is designed specifically for young people and that is responsive to their unique needs and concerns.

The Program

Foundation

Teen Cancer America seeks to develop TYA programs in hospitals that share its two core commitments:

- **The *philosophical* commitment that TYAs with cancer require specialized care because of their unique medical and psychosocial needs.** Adopting a patient-centered orientation, Teen Cancer America-affiliated hospitals recognize that TYAs are significantly different from other patient demographics and are committed to providing age-appropriate treatment and care delivered by dedicated multi-disciplinary teams.
- **The *organizational* commitment to change the way TYA cancer care is delivered in an effort to improve outcomes and quality of care.** Teen Cancer America-affiliated hospitals should have a driving belief that TYA outcomes and quality of care can be improved by dedicated facilities and services.

Framework

Based upon the experience of Teenage Cancer Trust in the UK, as well as recommendations from key groups in the U.S., a Teen Cancer America-affiliated hospital program builds upon the Foundation with four elements that establish the framework of the program:

- **A multi-disciplinary team approach:** Patients should be managed by a multi-disciplinary clinical team with both disease-specific and age-specific expertise. The team would incorporate **psychological assessment and counseling**, as well as **onco-fertility counseling**. In addition, the team would likely

include or have access to personnel who offer social support, education and employment liaison and transitional support; smoking, alcohol, and substance abuse counseling; and youth programming.

- **TYA staff training:** Teen Cancer America hospital program staff should be encouraged and given opportunities to pursue specialized training to deepen their understanding of TYA-specific developmental issues and to learn how to communicate most effectively with TYA patients and their families.
- **Best practices and access to clinical trials for TYAs:** Teen Cancer America hospital programs are best situated in hospitals that are experienced in TYA care, that observe best practices, and that offer broad access to TYA clinical trials.
- **Dedicated space for treatment and peer interaction:** Although the particular configuration will vary from one hospital to another, a Teen Cancer America hospital program should include dedicated treatment areas and space for TYA social interaction in both inpatient and outpatient locations. Social areas should be both accessible informally to patients and available for programs that may be organized by youth support staff.

Features

Once it is established that a hospital embraces the foundation and framework, Teen Cancer America works with each hospital partner to design a TYA program to complement its unique assets and resources. One Teen Cancer America program will not necessarily look exactly like another, but should incorporate most of the following:

- **Dedicated inpatient teen rooms:** While receiving inpatient treatment, TYAs should ideally be assigned to rooms that are designed specifically for them. Patients can be assigned to private rooms and in some hospitals this is considered best practice. However young people can gain significantly from socializing; and up to four bed bays have operated successfully with very positive feedback from young people who have preferred this to the isolation of single rooms. TYA rooms should allow for personalization with items from home and should accommodate beds for parents or other caregivers to stay overnight. They should be designed to look as “non-institutional” as possible and should include access to TV, web and interactive communication systems. Enabling young people to communicate with their home/work/education is an essential component of their support, particularly for those that require long periods of hospitalization.
- **Flexible policies to accommodate the TYA lifestyle:** Recognizing that it is important to create as much normality for TYAs as possible, hospitals should adopt flexible inpatient policies regarding waking and bedtimes, mealtimes, visiting hours, and circulation outside the patient room. In successful TYA units for example, it is common to see doctors adjusting ward round routines and timetabling of medication to suit the young people. To the extent possible, hospitals should demonstrate flexibility in scheduling outpatient treatment dates, clinic appointments and procedures in order to accommodate TYA school, social and work schedules.
- **Support programs:** Teen Cancer America hospitals can support psychosocial needs by offering regular peer and family support programs for TYA patients and families both on and off treatment, including outreach to TYAs in the community. These programs should also address the challenges associated with participation in school and work, and offer connection to outside resources, like summer camps and other recreational offerings for TYAs with cancer.
- **Access to computers and social networking:** Recognizing the importance of peer connections, Teen Cancer America hospitals should adopt liberal policies with respect to smart phone, tablet, and computer use, and offer Wi-Fi throughout teen treatment areas to facilitate social networking.

- **Other design aspects:** Teen Cancer America hospitals should offer TYA patients access to kitchen/microwave facilities and, if possible, personal refrigerators, so that they can prepare their own food or microwave food from home when they want to. TYA patients should have access to age-appropriate recreational activities, such as flat-screen TVs, electronic games, music equipment, computers, pool table, etc.

The Case for Teen Cancer America

Why would a hospital collaborate with Teen Cancer America to create a new or expand an existing TYA program, rather than go it alone? What is Teen Cancer America's unique value proposition?

1. The Benefit of Experience

Partnership with Teen Cancer America gives a hospital direct access to Teenage Cancer Trust's 20+ years of experience designing and implementing TYA hospital programs. Teenage Cancer Trust literally wrote the book on TYA hospital programs in its report, *Blueprint of Care*, which lays out the details for creating a quality TYA program. No organization can rival Teenage Cancer Trust for knowledge and experience.

2. Strategic Program Development

Using a proven approach developed by Teenage Cancer Trust, Teen Cancer America will work with each of its member hospitals on a step-by-step basis to create a unique TYA program around the strengths of that particular institution. An invaluable step in the process starts with a comprehensive, medical and environmental assessment, leading to a written "diagnostic" report. The findings are followed by customized staff training at a Teenage Cancer Trust or Teen Cancer America hospital that has implemented a successful TYA program. At the conclusion of the training, and as appropriate, Teen Cancer America and the hospital enter into a mutually developed implementation plan, supported by a detailed *Blueprint for Care*. By walking the hospital through the process, Teen Cancer America can provide valuable support and help address key challenges, such as where the TYA program should be housed, how it can best serve both inpatient and outpatient populations, and how to bridge staffing needs between adult and pediatric patients.

3. Customized Support

Teen Cancer America is equipped to help its affiliated hospitals with operational support in the form of guidance, tools, resources and, in some cases, direct grants, in the following areas: TYA service development; architectural design; marketing/public relations, fundraising; professional training; and (in the future) salary support.

4. Advantages of Association

The Teen Cancer America consortium will create valuable opportunities, both formal and informal, for collaboration across institutions. Teen Cancer America will create forums for its hospitals to share clinical expertise and report on best practices. In addition, Teen Cancer America will promote collaborative research efforts, support TYA cancer registries, and spearhead the development of standardized outcomes measures for benchmarking purposes.

5. Access to Visibility

With its connection to The WHO and other prominent celebrities, Teen Cancer America is already raising awareness about TYA cancer and the importance of improving TYA care. Associating with the Teen Cancer America brand will give affiliated hospitals access to this national platform and heightened visibility for their TYA programs. Moreover, Teen Cancer America can use its web site and other resources to profile and highlight the uniqueness of each affiliated hospital.

6. Acknowledgement of Excellence

An important role for Teen Cancer America will be to establish standards of excellence with respect to TYA care. Using a consensus process, Teen Cancer America's Medical Advisory Group (MAG) may identify gold standard criteria that represent the highest standard of care for TYA programs. Teen Cancer America may also consider creating a "Pathway to Excellence" track that leads to "TYA Center of Excellence" (COE) designation, to be awarded in conjunction with a recognized U.S. medical accreditation body. This status would be awarded only to those institutions that meet acknowledged high standards of TYA care.

COE status will confer special eligibility, such as the right to participate in select research programs, the opportunity to apply for special grants, and consideration for awards that recognize outstanding physician and nurse clinicians and educators. These Centers will be recognized TYA leaders in their community and reach out, as appropriate, to provide guidance to regional care facilities. Additionally, they will be expected to demonstrate a commitment to national and international collaboration to advance TYA research, service delivery, outcomes and survival.