

ALLIANCE FOR CHILDHOOD CANCER

Principles for Survivorship and Long-Term Follow-Up Care for Survivors of Childhood Cancer

Access to Care

- ◆ Long-term outcomes for children and adolescents with cancer are markedly influenced by comprehensive and accurate initial evaluation as well as treatment. Care for children and adolescents with cancer should be provided at comprehensive pediatric cancer centers by a multidisciplinary team of pediatric cancer specialists, including physicians, nurses, social workers, child life specialists, psychologists, and rehabilitation specialists. Such care should include families' access to education and support services addressing the continuum of care – from treatment to post-treatment monitoring to appropriate long-term follow-up.
- ◆ All children and adolescents treated for cancer must have access and timely referral to pediatric oncology specialists for rehabilitation and post-treatment monitoring for recurrence as well as long-term and late effects of therapy.

Systems of Care

- ◆ Care for survivors should be defined by the “Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers” of the Children’s Oncology Group (<http://www.survivorshipguidelines.org>), which, as frequently updated, will provide guidance for appropriate, quality surveillance and follow-up care.
- ◆ Follow-up care for long-term survivors should be comprehensive and begin during treatment, if necessary. Teams of pediatric cancer specialists and subspecialists with expertise in late effects should develop a care plan for adolescent and young adult survivors so that they can effectively transition from pediatric care to receiving care as adults from internists, oncologists and psychologists knowledgeable about long-term and late effects of treatment.
- ◆ Guidelines should be developed that address issues related to documentation of diagnosis, treatment summaries and physicians involved in the patient’s care, and how to ensure transfer of that information to the childhood cancer survivor. Survivors should have access to and ownership of information related to their diagnosis and treatment.
- ◆ A minimum set of standards should be developed for systems of comprehensive follow-up care that include linking specialty and primary care providers. Systems to provide or arrange care should be included in all institutions treating children with cancer. Comprehensive programs should also include programs for prevention of and intervention for late effects.
- ◆ Opportunities for training programs in late effects for professionals, educational and support sources for families and survivors should be included in comprehensive programs. Information generated through a survivor registry would also serve as an important educational tool for families and survivors.

Insurance Coverage

- ◆ Public and private payers should ensure that coverage for childhood cancer survivors is continuous and flexible enough to recognize their changing health needs, so they have access to appropriate resources and delivery systems for post-treatment monitoring, long-term follow-up and care and treatment of late effects. This is especially important when parents change jobs or employers change insurance plans, as well as when the child enters adulthood.
- ◆ Payers should be required to cover the routine patient care costs associated with participation in clinical trials, including those for clinical trials for supportive care (including services that address physical, neuro-cognitive, psychosocial needs and quality of life), rehabilitation, secondary prevention, hospice and post-treatment monitoring.

Research

- ◆ More research is needed to address the long-term effects and consequences of childhood cancer. Research priorities should include: (1) assessing the prevalence and etiology of late effects during treatment; (2) developing interventions to prevent or reduce late effects; and (3) furthering improvements in quality of care to ameliorate the consequences of late effects on individuals and families.
- ◆ A pediatric cancer survivor registry should be developed to help formulate and guide research and provider education efforts on survivorship and late-effects treatment.