

ALLIANCE FOR CHILDHOOD CANCER

Core Principles for Comprehensive Quality Cancer Care For Children and Adolescents

1. Outcomes for children and adolescents with cancer are markedly influenced by comprehensive and accurate initial evaluation as well as treatment. Modern risk-based therapy often depends upon biologic testing of diagnostic material. Therefore all children and adolescents suspected of having cancer must have access and timely referral to pediatric oncology specialists for high quality screening and diagnostic testing, treatment, rehabilitation and post-treatment monitoring for recurrence as well as long-term and late effects of therapy.
2. Care for children and adolescents with cancer should be provided at comprehensive pediatric hematology/oncology 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.
3. The majority of pediatric cancer patients are treated in the context of clinical trials, making participation in clinical trials the standard of care. Insurers' denial of children's access to high quality clinical trials is tantamount to the denial of standard care.
4. To ensure access to clinical trials, payors should be required to cover the routine patient care costs associated with participation in clinical trials. Access to and coverage for cancer care should encompass the continuum, from diagnosis, treatment, supportive care (including services that address physical, neuro-cognitive, psychosocial needs and quality of life) to rehabilitation, hospice and post-treatment monitoring.
5. Insurance coverage for children and adolescents with cancer and their families should allow portability in cases where parents change employers and continuity in situations where a plan changes providers or benefits. Such continuity should apply to all services across the continuum of care.
6. Survivors should have access to comprehensive long-term follow-up care from pediatric cancer specialists and sub specialists with expertise in late effects. Teams providing follow-up care should develop a plan to transition young adult survivors so that on reaching adulthood there should be effective transitioning of care to internists, oncologists and psychologists knowledgeable about long-term and late effects of treatment experienced by childhood cancer survivors.
7. Underlying each of these principals is the need for sufficient research funding to support basic, translational and clinical research to advance knowledge of and improvement in the care of children and adolescents with cancer, as well as critical resources and programs for the recruitment, training, mentoring and retention of skilled pediatric cancer specialists.

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