



Educate

Childhood cancer impacts everyone in the family. The Psychosocial Standards are now available. The Standards highlight many of the psychological and social issues that can arise throughout treatment, into survivorship or end of life and bereavement care. If you and your family are feeling overwhelmed and have psychosocial concerns, please know you are not alone. Download the Standards and see which ones apply to you. The Standards may assist you in communicating with your healthcare team about psychosocial issues. The healthcare team is available to address your family's concerns and open communication with the team will help to create a well-rounded treatment plan.



Empower

Receiving the news that your child has cancer is devastating and it can make you feel like you have lost control over your life. However, the family is a vital part of the overall treatment team, as no one knows your child better than you. This knowledge is empowering as it helps you advocate for your child, your family, and access to supportive services.



Equip

Psychosocial support is needed throughout the cancer experience. Not just at diagnosis. With the help of your healthcare team, supportive services can be identified to assist you and your family.

15 Standards of Care

(1) Psychosocial Assessment, (2) Monitoring and Assessment of Neuropsychological Outcomes (3) Psychosocial Follow-Up in Survivorship, (4) Psychosocial Interventions and Therapeutic Support, (5) Assessment of Financial Burden, (6) Standards of Psychosocial Care for Parents of Children with Cancer, (7) Anticipatory Guidance and Psychoeducation, (8) Procedural Preparation and Support, (9) Providing Children and Adolescents Opportunities for Social Interaction, (10) Supporting Siblings, (11) Academic Continuity and School Reentry Support, (12) Assessing Medication Adherence, (13) Palliative Care, (14) Bereavement Follow-Up After the Death of a Child, (15) Communication, Documentation, and Training Standards

Implementation of Standards

A team of researchers, clinicians, parent advocates, and payors are strategizing how to implement the Standards nationwide. Research is underway to develop an evidence based checklist and guidelines to assist treatment centers with the implementation of the Standards. In addition, the team is working to understand the resources needed to deliver the Standards and address barriers to implementation.

Standards were funded and the vision of:

The Mattie Miracle Cancer Foundation

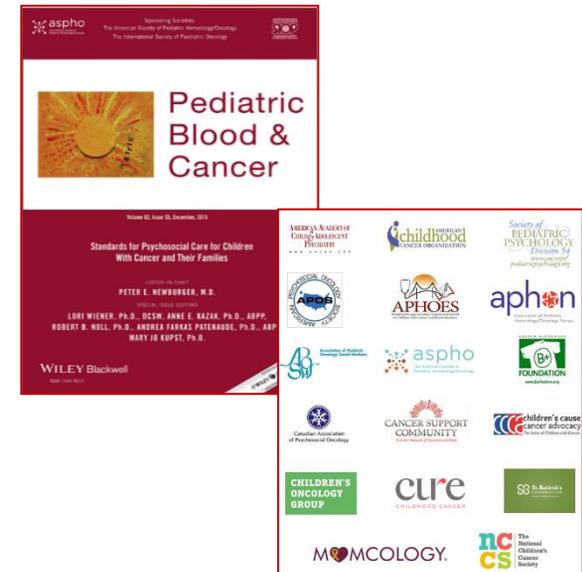
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Free access to Standards:
mattiemiracle.com/standards



Psychosocial Standards of Care Endorsed by 17 Organizations



Why Standards are Needed

- ☀ Comprehensive cancer care is **NOT JUST ABOUT THE MEDICINE™**
- ☀ Standards provide a psychosocial **ROAD MAP** for families and healthcare professionals
- ☀ **PSYCHOSOCIAL CARE** should be provided throughout the cancer experience
- ☀ Optimal psychosocial care is needed for effective treatment **OUTCOMES** and **QUALITY OF LIFE**

MISSION OF STANDARDS

A three-year-long rigorous research process was undertaken by over 80 healthcare professionals in the United States, Canada, and the Netherlands to develop **15 evidence based Psychosocial Standards of Care** for Children with Cancer and Their Families.



These Standards apply to all cancer types and treatment centers where care is provided. The Standards are intended to be a road map that provides informational and practical types of emotional support that can make a significant difference in the quality of life for the child with cancer and their family members.

PSYCHOSOCIAL CARE

After a child is diagnosed with cancer, a family's life will change. These changes can affect the overall quality of life of the child and the family. **Psychological, social, and emotional concerns naturally arise during the entire cancer journey.**

Standards have been created to guide the optimal level of psychosocial support that should be



provided throughout this process. **Families have the right to address psychosocial issues** with their healthcare team as this will help the team tailor supportive services that best meet your child's and family's needs. Treatment centers are encouraged to implement the Psychosocial Standards of Care for all children with cancer, as optimal psychosocial care is associated with adherence to treatment, more effective outcomes, and a better quality of life.

SOCIAL

Peer interactions are an important part of socialization. However, children in treatment are often limited in participating in social activities which in turn can lead to **isolation, feeling disconnected, and different from peers**. Many treatment facilities have a child life specialist. Child life specialists can help children cope with isolation, increase medical knowledge about procedures, and provide distraction activities.



FINANCIAL

It is common for families to face financial difficulties throughout the treatment process. These difficulties may have negative consequences on a family's well-



being. Families are encouraged to talk with the social worker at your child's treatment center to obtain referrals to organizations to **reduce financial burden**.

SCHOOL

Returning to school can be stressful for children with cancer. **School re-entry services can ease adjustment** back to school by providing information to school personnel about your child's medical, emotional, and educational needs. Hospital based educational specialists and/or your child's social worker can assist with communication among the school, the healthcare team, and the family.



SIBLINGS

Given the changes in family routines, siblings of children with cancer can be **at-risk for emotional and behavioral difficulties** such as anxiety and depression. With the assistance of the healthcare team, families can find ways to anticipate and meet siblings' needs.



SURVIVORSHIP

Childhood cancer survivors are at high risk for **medical late effects** following treatment. It is important that survivors receive **long-term follow up care** that includes screening for both the physical and psychosocial late effects. Psychosocial late effects include adverse educational and/or vocational progress, social and relationship difficulties; distress, anxiety, and depression; and risky health behaviors. Follow up care should be discussed with your healthcare team before the completion of treatment.

PALLIATIVE CARE

Palliative care can be beneficial **from the beginning** of your child's treatment. Palliative care providers help manage pain and distressing symptoms associated with cancer to reduce suffering and improve your child's quality of life.

BEREAVEMENT

After the death of a child, parents may want continued connections with your child's healthcare team. These connections can provide support and **assess your bereavement needs** as well as help identify resources that may help you and your family cope with this forever loss.