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


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.

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

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
**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 progression, 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.