



It's Not Just About the Medicine!

September is childhood cancer awareness month. Mattie Miracle wishes to acknowledge all the courageous children and families affected by this disease. Around 46 children a day are diagnosed with cancer and seven children a day die from the disease in the United States (Surveillance Epidemiology and End Results Cancer Statistics Review/ National Cancer Institute, 2012). However, treating childhood cancer effectively requires a comprehensive approach that addresses both the medical and psychosocial aspects of care.

The goal of psychosocial care is to address the effects cancer and its treatment have on the emotional and social well-being of children, family members, and their professional caregivers. Below are our top 10 facts about psychosocial care.

Top 10 Psychosocial Facts:

1. The Standards of Psychosocial Care apply to all cancer types and treatment centers. The Standards provide evidence based information on the emotional and social support needed to optimize the quality of life for children with cancer and their families from diagnosis, throughout treatment, into survivorship or end of life and bereavement care (Wiener et al., 2015).
2. Childhood cancer threatens every aspect of the family's life and the possibility of a future, which is why optimal cancer treatment must include psychosocial care (Institute of Medicine, 2008).
3. Depression and other psychosocial concerns can affect adherence to treatment regimens by impairing cognition, weakening motivation, and decreasing coping abilities (Institute of Medicine, 2008).
4. The provision of psychosocial care has been shown to yield better management of common disease-related symptoms and the adverse effects of treatment such as pain and fatigue (Jacobsen et al., 2012).
5. For children and families, treating the pain, symptoms, and stress of cancer enhances quality of life and is as important as treating the disease (Institute of Medicine, 2015).

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UPCOMING EVENTS

November, 2019
9th Annual Candy Drive

December, 2019
Annual Holiday Drive

March, 2020
American Psychosocial
Oncology Society
Conference

April, 2020
9th Annual Item Drive

May 17, 2020
11th Annual Walk & Family
Festival



6. Changes in routines disrupt day-to-day functioning of siblings (Alderfer et al., 2010). Siblings of children with cancer are at risk for emotional and behavioral difficulties, such as anxiety, depression, and post-traumatic stress disorder (Alderfer et al., 2003).
7. Cancer survivors in the United States reported medication use for anxiety and depression at rates nearly two times those reported by the general public, likely a reflection of greater emotional and physical burdens from treatment (Hawkins et al., 2017).
8. Symptoms of post traumatic stress disorder are well documented for parents whose children have completed cancer treatment (Kazak et al., 2004).
9. Financial hardship during childhood cancer has been found to affect a significant proportion of the population and to negatively impact family well-being (Bona et al., 2014).
10. Chronic grief from losing a child to cancer has been associated with many psychological (e.g., depression and anxiety) and somatic symptoms (e.g., loss of appetite, sleep disturbances, fatigue), including increased mortality risk (Alam et al., 2012).

For more facts about childhood cancer, click on Learn More.

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Psychosocial Standards are Guiding Practice

Mattie Miracle had the opportunity in April to attend the Association of Pediatric Oncology Social Workers (APOSW) conference in Phoenix, AZ. At the conference, we participated in a plenary with Spencer Moorman, a social worker based in Missouri. This was our first time meeting Spencer, but what we immediately recognized was her passion to help children with cancer and their families and her deep appreciation for the Psychosocial Standards of Care. These historic evidence based Standards of Care were the vision of Mattie Miracle and the creation of an incredibly dedicated core team of

researchers and health care providers from the US, Canada, and the Netherlands.

What Mattie Miracle learned at the APOSW conference, was that Spencer took a deep dive into the Standards of Care. She read the entire 400 page publication, views them as a vital road map for clinicians, and is working on ways to implement these 15 Standards of Care into practice. Spencer told Mattie Miracle that the Standards have assisted her in "categorizing topics, organizational resources, talking points, interventions, and to access baseline psychosocial care delivery." In addition, the Standards validate the science and rigor behind the field of psychosocial care, which in turn enabled Spencer's institution to hire two additional full-time social workers to assist children with cancer and their families.

Mattie Miracle and its core team are committed to seeing the Standards operationalized, so that children with cancer and their families can have access to optimal psychosocial care from the time of diagnosis, throughout treatment, and into survivorship or end of life and bereavement care. Spencer's story illustrates how important it was to create the Psychosocial Standards of Care. As clinicians are already utilizing them to guide practice and are eagerly awaiting the evidence based implementation tools that will be published in 2020.

For more on Spencer Moorman and her perspective on the Psychosocial Standards of Care, click on Learn More.

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6th Year at Curefest

On September 22, the childhood cancer community united as one voice against childhood cancer. Hundreds of people of all ages were in attendance at Curefest on the National Mall. Presentations were made by advocates and childhood cancer survivors, and a three mile walk with the US Capitol and the Washington Monument in the background was completed.

Mattie Miracle had a Foundation tent at the event. We spread our psychosocial message that childhood cancer is NOT JUST ABOUT THE MEDICINE, and encouraged all advocates to join us in expanding the message that comprehensive cancer care must include psychosocial support. Mattie Miracle thanks all our supporters and new friends who visited, and we are particularly grateful and honored that so many families shared their psychosocial stories with us. Curefest is a very memorable event because of the courageous children and families in attendance.

To read about our Curefest experience, click on [Learn More](#).

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Halloween is Just Around the Corner

What do you do with your leftover Halloween candy? How about donating it to us! Join Mattie Miracle as we collect and sort post-Halloween candy during our 9th annual Candy Drive. We are requesting all candy be received by **Saturday, November 9**.

Last year we collected over 15,000 pounds of candy. A good portion of that candy stocked our free Snack & Items Carts at MedStar Georgetown University Hospital (Washington, DC) and Children's Hospital at Sinai (Baltimore, MD). Candy is considered a sweet necessity, helping families manage the long hours of caregiving. Last year, candy was donated to:

1. Children's Hospital at Sinai, Baltimore, MD
2. Children's Inn at NIH, Bethesda, MD
3. Children's National Medical Center - The EVAN Foundation's Treats & Treasures Cart, Washington, DC
4. Hackerman-Patz House, Baltimore, MD
5. HSC Pediatric Center, Washington, DC
6. MedStar Georgetown University Hospital, Washington, DC
7. Pediatric Specialists of Virginia (PSV), Falls Church, VA
8. Ronald McDonald House, Washington, DC
9. Ronald McDonald House, Falls Church, VA
10. Ronald McDonald House, Baltimore, MD
11. Special Love, Winchester, VA
12. Cornerstones, Reston, VA
13. Covenant House, Washington, DC
14. Embry Rucker Community Shelter, Reston, VA
15. Nourish Now, Rockville, MD
16. Sasha Bruce, Washington, DC
17. St. Ann's Center for Children, Youth, and Families, Hyattsville, MD
18. United Community Ministries, Alexandria, VA

Volunteers needed! Please click on "Sign Up" to join our candy sorting parties.

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