ehospice
Palliative care news,
views and inspiration
from around the world

Cancer care is so much more than just about medicine - advocating for psychosocial care

07 July 2015
News | Care

At a meeting hosted by the Institute of Medicine held in March this year Victoria Sardi-Brown speaks to healthcare professionals about the need for everyone to recognise and acknowledge pain and negative psychosocial effects of a cancer diagnosis on children and their families.

Victoria Sardi-Brown is the co-founder, along with her husband Peter, and president of the Mattie Miracle Cancer Foundation founded in 2009 in memory of their 7-year-old son, Mattie, who died as a result of osteosarcoma. At a recent meeting hosted by the Institute of Medicine (IOM) she spoke with conviction and with a knowledge based on personal experience of the great need for all children with a cancer diagnosis and their families to be provided with a minimum standard of psychosocial care.

Her son, Mattie, battled osteosarcoma for 14 months and, amongst other things, endured 9 months of chemotherapy, three surgeries, radiation and experimental immunotherapies.

> *"...while the predominant focus is on medical care and drug development, anyone who has helped a child endure medical treatment knows that there are day to day issues that are just as*

complex and just as heartbreaking to manage." Victoria Sardi-Brown

Victoria speaks of there being 'all sorts of things bombarding his body' and how, after his first surgery, his life was completely transformed from being an active, happy child to one that was never able to function properly and never being able to walk again.

She reminds us that cancer is not just a physical disease and the response to it should be much more than just the provision of medicine. Her son was diagnosed with clinical depression, anxiety and medical post traumatic stress disorder, all of which required him to take psychotropic medications.

She says, 'He was not only fighting for his life, but in all instances I was advocating for his mental health needs and ways to manage excruciating pain.'

Victoria reports that on top of everything, the family were confronted with a healthcare system that wondered if it was possible for him to be in so much pain and they were encouraged to think that he was addicted to pain medication and his refusal to eat was a form of manipulation.

Not once was Mattie ever given a distress thermometer, a psychosocial assessment tool or any other standardised tool to assess his pain or suffering, and neither was she, as his primary caregiver. They later found out that his pain was very real. Six weeks after his chemotherapy the cancer was found to have metastasised throughout his body. She speaks of the torment of watching their son die a traumatic death as he was in so much pain.

Driving force
Their experience with their son's cancer journey and death has been the driving force for the Mattie Miracle Cancer Foundation to focus on the psychosocial needs of other children with cancer. Their vision is to create and implement a national standard for psychosocial care for children with cancer and their families that would ensure to a minimum level of care from the time of diagnosis, throughout treatment, into survivorship or end-of-life and bereavement care.

In her talk, Victoria quotes the IOM Report on Dying in America that emphasises optimal care must include psycho-social care and states that Integrating psychosocial and palliative care are vital along the entire cancer care trajectory for optimal outcomes.

"It stuns me that in the 21st century there is a disparity in the psycho-social care and services offered among hospitals," she states.

Victoria reminds all present that while the predominant focus is on medical care and drug development, anyone who has helped a child endure medical treatment knows that there are day to day issues that are just as complex and just as heartbreaking to manage.

"Cancer care is much more than just about the medicine. It must integrate psychosocial distress and pain management needs of the patient to be effective."

Victoria and Peter would like to be in touch with anyone in any other region or country who is working towards and advocating for a similar standard of psychosocial support for children with cancer. They can be contacted on the email: pbrown@mattiemiracle.com

See more articles in Care