ON THE COVER

SMALL COMFORTS
Children's hospitals add palliative care

BY JEANNE METTNER

Stepping through the doors of the Kiran Stordalen and Horst Rechelbacher Pediatric Pain, Palliative and Integrative Medicine Clinic at Children's Hospitals and Clinics of Minnesota in Minneapolis is like entering another world—or at least a world far removed from a hospital.

The 10,000-square-foot space features natural materials—Wisconsin wood floors, baseboards made of oyster shells and walnuts, and stone tile. Large photos of Itasca State Park, the North Shore and plants indigenous to Minnesota cover the walls of the waiting area, where kids and parents can manipulate digital images of cascading water and hear the sound of wind and loon calls. The lighting automatically adjusts based on the time of day, and the exam rooms look as comfortable as living rooms.

“We wanted to create a healing environment, and that meant having healing architecture,” says Stefan J. Friedrichsdorf, MD, medical director of the clinic, which opened in January 2015. “The idea is that when children and teens come into our waiting room and exam rooms, they won't be afraid. And that will engage them more in their care.”

The clinic, which combines pain medicine, palliative care and integrative medicine, is named after the founder of Aveda Corporation and Intelligent Nutrients and his wife. It is believed to be the first of its kind in the world. For Friedrichsdorf, who is also medical director of the department of pain medicine, palliative care and integrative medicine at Children’s Minnesota, its opening is a long-awaited step toward bringing more humane care to kids who are suffering. He estimates his team was involved in more than 4,000 patient visits last year.

The clinic at Children's Minnesota may be one of the newest to focus on alleviating pain and distress in children, but it is not the only one. Over the past decade, an increasing number of children’s hospitals in the United States have been incorporating palliative care into their offerings, often including it in their pain-management programs. One study published in the December 2013 issue of Pediatrics found nearly half of the 226 hospitals asked reported having pediatric palliative care available. Children's Minnesota, Gillette Children's Specialty Healthcare in St. Paul, Mayo Clinic, the University of Minnesota Masonic Children's Hospital and CentraCare/St. Cloud Hospital...
are among those that offer pediatric palliative care in Minnesota.

According to estimates Friedrichsdorf compiled using federal data, about 237,000 children in the United States are currently living with chronic pain and discomfort as a result of cancers, metabolic or genetic diseases, neurodegenerative diseases, and cardiovascular and other conditions. Pediatric palliative care is designed to not only alleviate their physical discomfort but also to help both the child and his or her family deal with the stress of illness. “When we talk about managing pain, we are not talking just about physical pain. There are other elements to it—emotional, spiritual and social pain,” says Scott Schwantes, MD, head of the neuropalliative care team at Gillette.

Although pediatric palliative care is becoming more common, families don’t always understand how their children can benefit from it. “A few years ago, the majority of people thought palliative care was synonymous with hospice or end-of-life care,” says Naomi Goloff, MD, a pediatric palliative care specialist at the University of Minnesota Masonic Children’s Hospital and medical director of the pediatric advanced complex care team. “Now, people—providers and patients—are starting to understand that palliative care adds an extra layer of support during a serious illness.”

Friedrichsdorf says their data show that children enrolled in palliative care live longer, have a better quality of life and are more likely to do something that adds meaning to their life. “We want to make sure that children live as long as possible, as well as possible,” he says. MM

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