

# Pediatric Palliative Care in Europe Expands

By Marie Gethins

In late September, the first independently owned pediatric palliative-hospice care facility in Ireland opened. Mary McAleese, president of Ireland, spoke at the official opening, and the €6.5 million spent erecting and fitting the facility was raised entirely through private donations. The Sunshine Home and the Lauralynn Hospice Foundation coordinated fundraising and will continue to raise funds to sustain the service.

Ireland is not alone in facing pediatric palliative-hospice care funding challenges. Despite a long European tradition of government-funded National Health Service, few freestanding pediatric palliative-hospice care facilities receive sufficient, if any, federal funding and must rely on charitable contributions from the corporate and private sectors. However, cost is only one hurdle. Pediatric palliative care training modules for medical specialists and nursing staff have traditionally been scarce. But a slate of new educational initiatives and models of care are emerging across Europe. Three models in particular have taken hold: in-hospital pediatric palliative services, freestanding facilities, and in-home community support services.

## Pediatric Palliative Care Globally

Caprice Knapp, Ph.D., a research assistant professor in the department of health outcomes and policy at the University of Florida in Gainesville, assesses pediatric palliative-hospice care programs globally.

In the March 2011 issue of *Pediatric Blood and Cancer*, Knapp and colleagues systematically reviewed 117 peer-reviewed and non-peer-reviewed articles. More than 65% of countries surveyed had no known activities, almost 19% had capacity-building activities, about 10% had localized provision,

and only about 6% had services that reached mainstream providers. As expected, vast regional variations emerged, with

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best provision generally in the most developed countries. The authors adapted a pediatric-specific four-category typology to categorize country provision based on the OELC (Observatory in the End of Life Care) levels (fig. 1). These categories range from no pediatric palliative-hospice care services to capacity building, some provision of services with funding in place for more, to full-service provision with some integration with mainstream health care providers.

In Europe alone, of the 43 European countries surveyed, 14 had no services, and 24 had some services. Only five have the highest level of services. However, compared with other global regions, Europe is doing well, with the fewest countries at the lowest level of provision and the second-highest percentage of countries at the best level. Knapp notes that in her own local pediatric palliative-hospice program, which is in-home and community based, cancer patients make up a smaller portion of patients than expected. She believes that a combination of high survival rates and hospital-provided palliative care services may explain the low numbers. “Once they have gone through their treatment and surveillance a couple of years, they may not have any more pain management needs or supportive care needs,” Knapp said.

She added that all three types of pediatric palliative-hospice care settings—hospital based, freestanding, or in-home community services—can address patients’ needs at different stages. She notes that the pediatric palliative care team at London’s Great Ormond Street Children’s Hospital includes psychosocial counseling services that also go out into the community. Likewise, in Florida, this need is being met. “Our program is completely community based, and



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we find the number one service they use is counseling,” she said.

Joanne Balfe, M.B., B.A.O., B.Ch., a consultant pediatrician at the Sunshine Home and National Children’s Hospital in Dublin, agrees that some crossover exists between the services, adding that it is too early to determine how many pediatric cancer patients will use the Sunshine Home. “What’s happened in the past with the small number of children that die from cancer in Ireland each year is that because it is such a small number, they get very well known to the staff on the oncology wards. There’s a relationship that has built up and those children have been cared for by that team until very close to end of life,” she said. “The good news is that most children with cancer now do survive into adulthood.”

## Rising Demand

In the UK, demand for pediatric palliative care services has quadrupled in the past 15 years, and approximately 23,500 children are likely to require access to palliative-hospice care services annually, according to the UK Department of Health Statistics.

In addition to hospital services, 44 freestanding pediatric palliative-hospice care facilities are in place. Experts interviewed for this article estimate that 10% of patients using the service have some form of cancer, with most suffering from neurological conditions or other life-limiting conditions.

At Scotland’s two freestanding facilities, the Robin House and the Rachel House,

demand has doubled since 2001. Although respite care, which provides family's with temporary relief from caregiving, makes up a large portion of services, both facilities offer care to grieving families after the child's death. According to Pat Carragher, M.D., medical director at Children's Hospice Association in Scotland, "A significant advantage of referral of a child or young person with a cancer diagnosis and palliative needs [to a freestanding facility] is that additional holistic care is available to that child or young person and their family. Subsequently, this leads to a seamless involvement in bereavement care for parents, siblings, and their extended families."

With improving survival of pediatric cancer patients, recreational-stay palliative care facilities have also grown in Europe. Recreational palliative care facilities offer patients and their families the opportunity to interact in a relaxed setting while having the comfort of medical backup.

In 1994, actor Paul Newman established the first extension of his Ashford, Conn.-based Hole in the Wall Gang Camp in Barretstown, Ireland. As of October 2011, the facility has served 21,000 children, from infancy to age 17 years, and their family members. Sister camps have opened in France, the UK, Italy, and Hungary. Donna's Dream House, associated with the UK Association for Children with Life-Threatening or Terminal Conditions and their Families, and based in Blackpool, England, also offers short-stay recreational palliative care.

### Scarce Funding

Knapp and coauthors of a forthcoming book on pediatric palliative-hospice care global perspectives noted two clear trends across 23 countries: funding challenges and limited access to training. For example, in the U.S., palliative care can be reimbursed only in the last 6 months of life, and a physician must certify that that is the case. "In pediatrics, that doesn't really work. No parent is going to agree to that, to give up any curative treatment to get access to palliative care," Knapp said. "And with cancer, you could be on different clinical trials up until the end of life."

In Europe, support often arises from community concern, generally through private

donations. "I think that's why they have more freestanding hospices in the UK, because the government was not involved. The need was there and the communities created them through private donation," she said. Ireland's Sunshine Home follows this trend, although Balfe highlighted that most funds came from a cancer-affected group. "While the majority of the children we care for at the Sunshine Home have disabilities other than cancer, most of the fund raising for the home came from parents who had children with cancer," she said.

In March 2010, the Irish government issued its first national policy on pediatric palliative care. Based on a needs assessment, the policy recommends that the preferred location of caring for a child with a life-limiting or life-threatening condition is the family home, with parents receiving adequate professional support. Home is also the preferred place of death for their child. However, the policy also states that the state will offer an alternative to inpatient hospital-based care for children who have been appropriately assessed and where a detailed care plan has been established with the input of the child (where appropriate) and parents. The policy makes no provision for freestanding pediatric palliative-hospice care.

### Ramping up Training

An evolving specialty, pediatric palliative-hospice care is attracting more interest across medical disciplines, including nursing, pediatrics, oncology, rheumatology, neurology, and many others. Yet training, particularly for physicians, is rare. "There are very few programs that include this as part of their curriculum, but it is beginning to be picked up and recognized as a subspecialty. Obviously you can't have a subspecialty without training for it," Knapp said, noting that this is a major challenge for less developed regions. "It really causes a chasm for resource-poor countries because they cannot afford to send people to these courses if they are offered in only a few distant places."

The European Association for Palliative Care (EAPC) is addressing pediatric palliative-hospice care standards and training across Europe. In 2007, the Steering Committee of the EAPC task force on palliative care for children and adolescents issued a document highlighting the need for a

comprehensive and integrated approach to pediatric palliative care in Europe. In April 2011, an EAPC task force began a mapping process to collect data and perform a gap analysis. Julie Ling, co-chair of the EAPC task force on educational curricula for health care professionals working in pediatric palliative care, said that it has traditionally been difficult to justify offering training in an area such as pediatric palliative care, which is "fraught with different definitions." Furthermore, access to training varies across Europe. "People have started to see it as an important issue," she said, "But regions are at different levels. England is very well established, but Norway is in its infancy." Ling, also a research fellow at the school of nursing at Ireland's Trinity College, also believes that curriculum development requires a multipronged approach, from nursing education, to undergraduate and postgraduate physician training, to specialist physician training. Ling and the EAPC task force on pediatric palliative care education hope to have a core curriculum by late 2012.

### Preserving Family Choice

Ling also stresses that training and facilities should be geared toward the best patient and family support. "People have a stronger voice than they used to, and we need to listen to what the family wants," she said.

According to Knapp, "I think it is really difficult to put the family at the center of hospital care, while in a hospice you can keep that child and the family at the center of your care. There's a different pace within an acute, busy hospital than in a hospice." Ultimately the goal of pediatric palliative-hospice care staff is to offer families a choice of what services they would like to use: during the illness, at time of death, and through bereavement. As Carragher summed up, "The death of a child has serious and lasting effects on the parents and other family members, effectively for the rest of their lives. Any attempt to reduce symptoms and to improve the quality of life in the final days and weeks must not only be good for the child involved but also, in the fullness of time, be good for those left behind."