



FINDING YOUR WAY

WEB SITES

**The National Organization for Rare Disorders Inc.**, P.O. Box 8923, New Fairfield, Conn. 06812-8923; (203) 746-6518; [www.rarediseases.org/index.html](http://www.rarediseases.org/index.html)

**Project Joy and Hope for Texas;** (713) 944-6JOY or toll free at (866) JOYHOPE; [www.joyandhope.org/contact.html](http://www.joyandhope.org/contact.html)

**Department of Symptom Control and Palliative Care**, M.D. Anderson Cancer Center, 1515 Holcombe, Box 08, Houston, Texas 77030; (713) 792-6085; [www.mdanderson.org/departments/palliative/](http://www.mdanderson.org/departments/palliative/)

**End-of-Life Care for Children**, Texas Children's Cancer Center, Texas Children's Hospital, Houston, Texas; [www.childrenoflifecare.org/home.html](http://www.childrenoflifecare.org/home.html)

**Children's Hospice International**, 2202 Mt. Vernon Ave, Suite 3C, Alexandria, Va. 22301; (800) 2-4-CHILD or (703) 684-0330; [www.chionline.org](http://www.chionline.org)

**Pediatric Pain-Science Helping Children**, IWK Grace Health Center, Dalhousie University, Halifax, Nova Scotia, Canada; <http://www.dal.ca/~pedpain/>

**Children's International Project on Palliative/Hospice Services (ChiPPS)**, National Hospice and Palliative Care Organization, 1700 Diagonal Road, Suite 300, Alexandria, Va. 22314; [www.nhpco.org](http://www.nhpco.org)

**The Candlelighters Childhood Cancer Foundation**, 3910 Warner Street, Kensington, Md. 20895; (800) 366-2223; [www.candlelighters.org](http://www.candlelighters.org)

**The Compassionate Friends Inc.**, P.O. Box 3696, Oak Brook, Ill. 60522-3696; (877) 969-0010; [www.compassionatefriends.org](http://www.compassionatefriends.org)

**Growth House, Inc.**; (415) 255-9045; Excellent source for publications and links regarding end-of-life care; [www.growthhouse.org/](http://www.growthhouse.org/)

BOOKS

**"Hospice Care for Children,"** edited by Sarah Zarbock Goltzer and Anne Armstrong-Dailey (Oxford University Press, 1993; \$45)

**"Cat Heaven,"** by Cynthia Rylant (Blue Sky Press, 1997; \$15)

**"Old Turtle,"** by Douglas Wood and Margaret Pike (CenteringCorp, 1992; \$5.95)

**"Cancer Pain Relief and Palliative Care in Children,"** by The World Health Organization (Geneva, 1998; \$16.20)

For more resources, including books, go online to [www.findingourway.net](http://www.findingourway.net)

ABOUT THE AUTHORS

Dr. Bruce Himelstein is director of Palliative Care Services at the Children's Hospital of Wisconsin and an associate professor in the department of pediatrics, Division of Hematology/Oncology at the Medical College of Wisconsin. He is co-investigator for a National Institute of Health grant to research parental beliefs in pediatric oncology and is a member of the Children's Oncology Task Force on End-of-Life Care, and the Bone Tumor Strategy Group. Himelstein is board certified in Pediatric Hematology and Oncology and by the American Board of Hospice and Palliative Medicine.



Dr. Joanne Hilden is the chair of the Department of Pediatric Hematology/Oncology and Children's Oncology Group and a responsible investigator at the Cleveland Clinic Foundation in Ohio. She founded and co-chairs the COG Task Force on End-of-Life Care. Hilden is a 2001 Soros Scholar in the Project on Death in America, and she is a certified trainer for the American Medical Association's EPEC project to educate physicians about end-of-life care.



# When a child is dying

## Smallest patient offers biggest lesson

BY BRUCE HIMELSTEIN AND JOANNE HILDEN

Jennifer Phelan knows it's possible to survive the unthinkable. She knows because her 7-year-old daughter showed her how.

Phelan's education started in June 1999, when her only child, Georgiana Antonopoulos, was diagnosed with lymphoma, a cancer of the blood. It ended last November, as she watched the little girl she called Georgie, surrounded by friends and family, die peacefully on the oncology ward in the Children's Hospital of Philadelphia.

From the moment Georgiana was diagnosed, all Phelan could think about was losing her daughter. She didn't talk about it, though, "because I was told it was normal to feel that way. ... And I don't know if I feared more her dying than I did a relapse. Sure enough, that came true.

"When she relapsed, I knew she wouldn't make it. I didn't want to feel that way, but I did. I didn't tell anybody that, because I was afraid I would get yelled at, having to say something like that or feel something like that, so I did whatever (my doctor) wanted to do as far as the chemo(therapy)."

When the disease failed to respond, her primary care oncologist, Dr. Susan Rheingold, mentioned pediatric palliative care as an option.

What Phelan and her daughter would experience for the next two months is a quietly growing medical specialty that includes the smallest dying patients and their families in critical medical decisions. Teams of specialists work together to tend to the emotional, psychological, practical and spiritual needs of the patient and family — and then stay with the child as he or she moves through the health care system.

Child life specialists, psychologists, hospice professionals, social workers and spiritual counselors are called in to help the family say their goodbyes and prepare for what lies ahead.

In the last few months of her life, Georgiana was getting the kind of comprehensive palliative care not widely incorporated into the mainstream medical system for children with life-threatening illnesses — mainly because no one wants to deal with the fact that children die.

Advocates battle the perception that once a child is put under palliative care, doctors have given up, and a search for a cure stops. It's a perception Jennifer Phelan faced squarely.

"I must stress how much I hated having to experience palliative

care, as I know you know this all too well," Phelan wrote in an e-mail to a team member after Georgiana died. "But the team was so comforting and so very compassionate. I think that is so important because I, as many other parents, was given the worst news imaginable."

Or, as Steve Simms, the psychologist who worked with the family, put it, "Palliative care meant death and letting go. It meant that Jennifer was going to lose her daughter. It was the shattering of the myth that (the hospital) would find the cure. She dreaded the day you would darken her door."

Once Georgiana was admitted, her hospital room immediately was transformed into a homelike setting. Her parents brought her teddy bear and "baby blanket," which she had slept with every night since she was born. Georgiana hated the hospital-issued pajamas and socks, so she brought in her own "funky" footwear. Helping her get to sleep was a wind-up music box that played "Winnie the Pooh" and a bright green frog light.

The team treated and spoke to Georgiana daily, while conferring with her two sets of parents — Jennifer and her husband, and Georgiana's father and his wife.

Unlike her parents, Georgiana quickly came to terms with her condition.

Team members caring for dying children frequently recognize the depth of their patients' perception and awareness. Children often know when they are dying.

Phelan describes it simply: "I see the doctor. My mommy leaves the room. I come back in crying. She put it together. You can't hide it from them. They're going to figure it out on their own."

As Georgiana got sicker, her mother recalls her asking, "Mom, am I going to die?"

"And I couldn't answer her. I said, 'I don't know.' I said, 'That's what we were all afraid of because the medicine didn't work.' And she cried. And that was it — she stopped and went to do whatever she was doing."

Afterward, Georgiana spoke openly with her primary nurse about how snowflakes and ladybugs could come together in heaven. She drew a smiling self-portrait of herself in heaven just a few days before her death.

"I also think it was important that Georgiana had (a child psychologist) talk to her and I think she helped her a whole lot," said Phelan. "She knew why this woman was coming in to talk to her. After a few times she looked forward to it. ... I guess because she thought that she was (just) going to talk to her and it wasn't all talk — it was through play. I guess



COURTESY OF THE PARTNERSHIP FOR CARING

Drawing was an outlet for 7-year-old Georgiana Antonopoulos.

### A picture of hope

Just before she died at Children's Hospital of Philadelphia, 7-year-old Georgiana Antonopoulos drew a picture in art therapy. Her therapist, Stephanie Rogerwick, describes how the drawing came about:

"One day I stopped by to visit Georgiana and stayed a while as she was drawing. Georgiana drew the picture of the angel. She spent a lot of time on the detail of the girl and paid special attention to her hair (two pig-tails) and her face, especially her big smile. When she was done I asked her to tell me about the picture. She said that the girl was an angel now and she was happy. She then told me she drew the picture for me. I asked if she wanted to keep it. She shook her head no and said she was going

to draw another picture.

"She talked about her picture and when she had said enough, she moved on. Drawing was the outlet she needed and talking about the artwork was not as important. I simply provided Georgiana with an opportunity to talk about her picture and for her to control the conversation and express emotions that may be difficult to talk about directly.

"By speaking about 'the girl,' she was able to talk about 'being an angel' without talking directly about herself. Mom and family had already begun the discussion with Georgiana about dying and she may have been feeling that it was OK to talk about it."

— Bruce Himelstein and Joanne Hilden

we found out a lot through that ..."

It took encouragement from the team, however, before Phelan could speak openly with Georgiana about dying. "It was hard, but I'm glad I did it," said Phelan. "Because she said she wasn't scared, and she didn't think about it. I asked her, and it was the way she said it that makes me feel a little better now. Her fear was leaving us. She had said to me, 'If I die, I won't see you anymore.' And I told her she would, because she could watch us from heaven. And then she didn't talk about it again.

"She said that every night when I go to bed she'll come in my room and give me a kiss," Phelan said.

As Georgiana's condition worsened, her doctor and the palliative care team discussed the family's options, including if, when and how to let her die naturally: Stopping the antibiotics. No more trips to the intensive-care unit. Whether

to set up hospice care at home. Saying no to life-support systems. And planning for a funeral.

"When we couldn't get Georgie into remission and the chance of a bone marrow transplant was practically nil, Jennifer investigated the options, but didn't want to put Georgie through more," Rheingold said. "Jennifer's maturity was astounding from the first discussion of palliative care on. Whereas some families want to try anything to prolong their child's life or continue to hope for a cure, not always thinking of the cost to the child and quality of life issues, the quality of Georgiana's life was always first and foremost for Jennifer."

"The hardest decision was stopping those antibiotics," Phelan recalled. "But I knew I didn't want Georgie on a tube (life-support machine). I mean, I don't think I could've seen her like that, because she wasn't going to live anyway

and she wouldn't want to be that way. I think if I had done anything else it would have been for me, not her. That would've been selfish ... I just wouldn't do it."

As death neared, managing Georgiana's pain with morphine became everyone's No. 1 priority.

"I remember at the funeral the priest saying — he was trying to be comforting but so far from knowing what it was really like those past months — that 'now she wasn't suffering anymore,'" recalled Rheingold. "It pissed me off, as Jennifer and we had tried so hard not to make her suffer."

Phelan later wrote to the team: "I can still hear you telling me on Friday, the 24th of November, 'She should pass within the next day or two ...' Sure enough, you were exactly right. I hated the truth, the reality of this nightmare, and I still do, but I appreciated the fact that nobody sugar-coated it."

Phelan remains in contact with Georgiana's nurses, her primary physician, and the palliative care team even now. "I can't even begin to tell you how much I think these contacts are helpful. I developed relationships with these people. They were there for me to talk to and, most of all, they were there for Georgie."

Phelan is part of an online bereavement group and attends support groups at the hospital. She recognizes that she and her husband are grieving differently: "He wants to socialize. I want to be alone." She's also making a picture quilt, a legacy to her daughter.

Phelan has found that because she has been through the unthinkable, she's treated a little too gently — or not at all — by friends and acquaintances. But she has a message for them about acceptance, something else she learned from her little girl.

"I guess people are uncomfortable," she says. "They don't know what to say to me. I get that look, you know, like 'that's Georgiana's mom.' It's all right, it's OK. I'm still here, you can talk to me. Just come up and say hi to me. People ignore you. They don't know what to say. I feel like just saying, 'Hello, it's OK.'"

For Rheingold and the palliative care team, that's the ultimate goal.

"Of my three patients that have died I feel this was the most comfortable for all involved — Georgie, her family and me," she said. "It is always hard to see a child die, but I felt that we worked together as a team to make it the best possible death — if those words can be used together in the same sentence."

For more resources and contacts on end-of-life issues, go to [www.findingourway.net](http://www.findingourway.net).

## Tips for parents coping with the illness of a child

Tips for family members on dealing with the life-threatening illness and death of a child:

Tell the doctors you want an honest answer about your child's prognosis and treatment options.

Keep in mind that if you choose to stop pursuing therapy because the side effects are too severe, it can be a loving choice.

Find a doctor or nurse who is an expert in symptom control. Your child can be comfortable, whether you choose to have her die at home or in the hospital.

Talk about what your child has achieved in his life, no matter how old he is.

Reassure and include siblings.

They are too often neglected, or have unanswered questions and unnecessary guilt.

Find out from the doctors what will happen in the actual time your child is dying so that what you see is not a surprise to you.

While your child is still alive, make memories. Take a lot of pictures, save a lock of hair or finger-

prints, record his voice, have him draw pictures and write for you.

Take care of yourself. Let your friends, family and community help you.

Prepare for the funeral. And let siblings help with that; it is important to them.

Ask the doctors to tell you the

really hard stuff — like the fact that if your child goes on a ventilator, he won't be able to talk to you any more.

Get help from experts in grieving, even if you think you don't need it.

Remember: What you choose as right for your child and family cannot be wrong.