Communicating with Children and Adolescents with Life-Limiting Conditions

A forum sponsored by the Health Advocacy Program at Sarah Lawrence College and the Westchester End-of-Life Coalition on November 4, 2003.

The following is a summary of the forum's proceedings by Nathan Ionascu, MD, a retired pediatrician and bioethicist, who chairs the WEOLC Committee on Children and Adolescents with Life-Limiting Conditions, and Dr. Alex Okun. Inquiries or comments regarding the forum or related issues can be addressed to him at **nionascu@westchesterendoflife.org**.

BACKGROUND

This forum grew out of discussions among WEOL Coalition members about the difficulty many professionals have talking to children who have life-limiting conditions. The difficulties a physician experiences are compounded by the need to respect these children's own knowledge and desires as their autonomy emerges. The forum drew together a panel of clinicians, researchers, parents and advocates representing a range of academic, medical, and social practice fields and life experiences. Dr. Nancy Green, Medical Director of the March of Dimes, a Pediatrician and Pediatric Hematology-Oncologist, moderated the program. The audience of more than 50 people also reflected a range of disciplines and included a variety of professionals, as well as a number of Sarah Lawrence College students.

PANEL PARTICIPANTS

Nicole Asselta, CSW, Social Worker, Visiting Nurse Service of N.Y. in Nassau County, L.I. and Chairman of the Outreach Program of the Parent Resource Center in Port Washington, NY.

Fred Epstein, MD, Founding Director of the Hyman-Newman Institute of Neurology and Neurosurgery, Beth Israel Medical Center. Author of If I Get to Five (Henry Holt & Company, LLC, New York, NY; 2003).

Kenneth Gorfinkle, PhD, Assistant Clinical Professor of Psychology and Psychiatry, Columbia University College of Physicians and Surgeons and New York-Presbyterian Medical Center. Author of Soothing Your Child's Pain: From Teething and Tummy Aches to Acute Illness and Injuries (PUBLISHER, YEAR).

Maggie Hoffman, Advocate, Co-Director of Project Delivery of Chronic Care, a family-centered, community- based pediatric training program that focuses on the impact of chronic illness and/or disability on individuals and their families.

Linwood Lewis, Psychology faculty, Sarah Lawrence College, with special interests in the effects of culture and social context on the conceptualization of health and illness; his research includes adolescents with HIV/AIDS.

Alex Okun, MD, Associate Professor of Clinical Pediatrics, Albert Einstein College of Medicine/Children's Hospital at Montefiore (CHAM), and Medical Director of the LINCS Program (Linking Individual Needs of Children with Services) at CHAM

Michael Rowe, PhD. Associate Clinical Professor of Sociology at Yale University School of Medicine's Department of Psychiatry, and Co-Director of the Yale Program on Poverty, Disability, and Urban Health. Author of Book of Jessie (The Francis Press, Washington DC, 2002).

Tania Shiminski-Maher, Pediatric Nurse Practitioner, Hyman-Newman Institute of Neurology and Neurosurgery, Beth Israel Medical Center. Co-author of Childhood Brain and Spinal Cord Tumors: A Guide for Family, Friends, and Caregivers.

Penny Wolfson, Creative writing faculty, Sarah Lawrence College. Author of Moonrise: One Family, Genetic Identity, and Muscular Dystrophy (St. Martin's Press, NY, 2003), detailing her thoughts and the family's experiences across the years as well as her research efforts for a better understanding of the disease.

DISCUSSION TOPICS

The theme of the meeting, "Communicating with Children and Adolescents with Life-Limiting Conditions", encompassed a wide range of topics discussed by members of the panel and audience.

The major topics and the comments are summarized in the following:

Communication. Parents appreciate help talking with their sick children about what is wrong. When their children's disease is life-limiting, parents often welcome advice as to whether, when and how to communicate this. They can be reassured that careful, active listening is essential, and that simple, straightforward answers are often best. The child's developmental and maturity levels are major determinants of the depth to which these discussions will go.

Often, children will open a dialogue with members of the health care team with whom they feel comfortable. Child life specialists, music therapists, and occupational and physical therapists help children express fears, concerns and other feelings through play, song, art and rehabilitative work.

Support Services. There is a great need for support services for children and families beyond that provided by the medical team. The devastating blow of a life-limiting illness in a child can be even more overwhelming for families struggling with poverty, single parenthood or limited support from relatives. Families with limited English proficiency may have less access to available services and are more likely to suffer with unanswered questions about their children's care and prognosis. Parent-to-parent support systems are invaluable and may be available at certain children's hospitals, disease-specific foundations and other community-based organizations.

End of Life Care. Some dying children cannot go home. Communication among members of the health care staff and between them and family can be even more challenging and confusing in these circumstances. There is little a hospital environment can offer these patients and their families to facilitate a death with dignity, surrounded by the love of those the child holds dear. Families whose children spend the ends of their lives in intensive care units may face additional barriers to valued intimacy and family unity.

Dr. Joelle Mast, Pediatric Neurologist and Medical Director of Blythedale Children's Hospital, mentioned efforts under way to provide palliative and hospice care for these children, even in an ICU, to thus alleviate their isolation and profound suffering.

Depression. The subject of depression in children with life-limiting conditions, and especially in adolescents, was discussed at some length. Many of these children do not want to talk about death and dying; they just want to live as normal a life as possible, for as long as possible. Some children handle bad news, for example, that their disease is progressing, better than adults. They may be better able to concentrate on the here and now, to try to accomplish what matters to them in that moment or hour, or on that day.

Many children and adolescents appear to be able to hold onto two realities: they know they are going to die, and yet they can also live an ordinary and fulfilling life; in this way children often seem to be very pragmatic. This is well expressed by Ansel, Penny Wolfson's son in her book about his Duchenne muscular dystrophy "Moonrise" (page 226):

"I don't know why I 'm having so much trouble," he says to me. "Do you think I'm just tired? Why should I be so tired?"

"I don't know, Ans. It may just be the disease. It's getting worse, I guess. That's really crummy, isn't it?"

He doesn't say anything.

I ask him at another time, "Do you think about the fact that you may not have as many years as other people?"

"No, Mom. I just want to be happy."

Stigmatization. Children with life-limiting conditions may be stigmatized, particularly in school, because of their illness or its disabling effects. Many schools address differences among children in the early grades. This area is not emphasized in the curricula for older students. Adolescents in remissions who can attend classes and who wish to be in school may be intimidated to do so for fear of being ostracized by their peers.

Project DOCC, with Advocate Maggie Hoffman, has run a very helpful program whereby middle school students who were sick or disabled formed a panel that went to talk to their peers in other schools and to sensitize them to these problems.

Teams. A number of panelists mentioned the benefits and limitations of the team approach to care for children with life-limiting illness. Teams can be experienced as another form of fragmentation. In some situations, it may seem that there is no one to coordinate the care, no "captain of the ship". Penny Wolfson said that the primary care doctor should be the one to do this for families, but that in many situations they are only peripherally involved, at best. While many families and caregivers feel intensely involved with members of the team while their child is sick and dying, they feel abandoned by the same professionals after the child dies. Teams committed to interdisciplinary work offer the strengths and perspectives of different health care fields to the child and family and may be able to organize richer forms of care and support.

Education. Educating health professionals about how to care for children who are near the end of their lives needs to start early. It should concentrate on the health professionals' responsibility to become involved, sometimes very closely, in the lives of their patients and families. Some health care staff members have a more difficult time than others facing the death of their patients or communicating other bad news to patients and families. Most would welcome additional education and support for their own professional development. Support systems for professionals are crucial throughout the child's illness, as well as during the bereavement process.

Hope. Throughout the evening, people often raised the subject of hope. Professor Michael Rowe said that hope should not be tied to "outcome." His feeling is that there is no such thing as false hope. Physicians must be very careful not to encourage unrealistic expectations on the level of physical healing, lest the patient and loved ones feel shattered when this hope proves unjustified. Enabling them to accept the situation will allow the institution of more supportive and palliative interventions.

When families or professionals wish to continue virtually ineffective chemotherapy, for instance, in the hope that "the tumor may shrink", honest appraisal and communication of the limited benefits and likely burdens of the chemotherapy is essential. Parents and professionals can always hope for additional quality time, palliation and comfort, while wishing that temporary improvement of the primary disease, even fleeting, may occur. To elicit the child's understanding and wishes concerning therapy, a nurse, child therapist or social worker might be needed. Occasionally, some families will persist in requiring continuation of therapy, as they have not yet reached the "acceptance" stage, and chemotherapy may have to be used for a certain length of time.

But an attitude of hopefulness is possible even in the darkest times. While many children want to know the truth and appreciate honesty, no one should be left without hope.

The Coalition continually follows the field of Children and Adolescents with Life-limiting conditions and welcomes comments from the medical profession and the general public. Comments and questions may be addressed to **nionascu@westchesterendoflife.org**.