

Terminally ill young adults ID items important to their care

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Adolescents and young adults with life-threatening illness want to be able to choose and record specific information for their end-of-life care, according to a study published online Oct. 8 in *Pediatrics*.

(HealthDay)—Teens and young adults who are seriously ill should have a chance to be involved in end-of-life decisions, and a new planning guide—developed especially for this age group—can help, researchers say.

"It's OK to raise these issues and open up communication," said Lori Wiener, director of the pediatric psychosocial support and research program at the U.S. National Cancer Institute and lead author of a study that helped develop the new guide.

"Adolescents and young adults often stay silent and secret because they

don't want to share their fears—because they don't want to upset their parents. And parents don't bring up end-of-life issues for the same reasons," she explained.

But, for teens, Wiener said, "people really do want to know what you think and what you feel and what your choices will be. Those choices will be different for different folks, but find a way to have your voice heard."

And, for parents, she advised telling your teen or young adult child, "We're going to do everything possible to get you well and for you to survive and live a long and healthy life. But in case something sudden happens, like an allergic reaction, I want to know if there's something special you would want. And, I don't want to do something you don't want. Would you feel comfortable sharing this with me?"

If they don't want to talk about it then, that's fine, she said, adding that you've paved the way for them to bring it up in the future if they want to.

The new study appeared online Oct. 8 and in the November print issue of *Pediatrics*.

Having a serious illness in the teen or young adult years can be especially difficult because, normally, this is when children start to become independent and formulate more of their self-identity. But a serious illness can stall that development. Suddenly, teens and young adults become even more dependent on parents and health care providers. A serious illness can also have a big impact on social development and relationships with peers.

Every year, more than 11,000 teens and young adults between the ages of 15 and 34 die of cancer and other conditions in the United States. Allowing them to have a say in their health care decisions and end-of-

life planning can help them re-establish their autonomy, according to background information in the study.

Wiener and her colleagues had done a previous study evaluating how helpful an advance directive document developed for adults might help this age group. Using feedback from that study, they developed a new guide.

The current study asked 52 teens and young adults living with metastatic [spreading] or recurrent cancer, or an HIV infection, to evaluate the adult guide or the newly developed guide. Participants were randomly asked to evaluate pages from either guide and to suggest any changes in content, design, format or style they felt would be appropriate.

Most of the teens and young adults expressed a preference for the document more tailored to their age group. When adults avoid talking about the impending death, it makes teens feel isolated and anxious, according to the study.

Wiener said that many of the teens focused on whether their life had been worthwhile. They wondered if they would be remembered, and many wanted to know if they could donate their bodies to science so that they might help someone with the same disease in the future.

From this feedback, Wiener and her group developed a new guide called *Voicing My Choices* that's even more tailored to this age group. Topics of the new guide include "How I want to be comforted," "Who I want to make my medical care decisions if I can't make them on my own," "The types of life support treatment I want, or do not want," "What I would like my friends and family to know about me," and others.

Teens and young adults can complete all the sections, or only the ones that are important to them. The only page that Wiener said should be

completed with help is the section on life support.

"This document takes care of the 'what ifs,' and it's a gift for those they leave behind. If parents see something in writing, they feel it has their child's stamp of approval," Wiener said.

An expert whose work revolves around young cancer patients said she wholeheartedly endorsed the guide.

"This is a beautiful study that's really contributing in a significant way to bring a voice to adolescents and young adults for end-of-life care. It's filling an important need," said Dr. Joanne Wolfe, chief of pediatric palliative care at the Dana-Farber Children's Hospital Cancer Center in Boston.

"It's incredibly scary to imagine whether, or even how, to have these conversations with your children, and that comes from a sense of love and protection. *Voicing My Choices* can help them start that conversation," Wolfe said.

"The onus really is on the health care team to sit and listen to different members of the family. Adolescents worry and don't want to upset their parents, and parents don't want to upset their kids, and it's our responsibility to bring those conversations into the open. It can be an incredible relief for everyone once you get past those undisclosed worries," she said.

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