

Pediatrics study: Involve adolescents in end-of-life medical decisions

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Conversations between adolescents suffering from chronic illnesses and their families about end-of-life wishes well before a serious event occurs won't discourage hope for recovery or cause additional emotional or mental harm to young patients, according to new research from [Children's National Medical Center](#) and St. Jude Children's Research Hospital published in the journal *Pediatrics*.

In the February edition of *Pediatrics*, Children's National psychologist Maureen Lyon, PhD, and a team of researchers used a professionally facilitated program to help adolescents living with HIV work with their families to plan ahead for managing their disease long term and include plans for adverse events that might require end-of-life, or palliative care, decisions.

This study provides the first randomized, controlled trial design for the study of "advance care planning," which, if constructive, family-centered, and aided by a trained professional, can lead to:

- An increase in the level of agreement between the parents and the child about medical decisions and treatments around chronic diseases.
- Better communication between parents and their ill children.

"We've known for a long time that adolescents say they want to take charge of medical decisions about their chronic illnesses," said Dr. Lyon, of the Division of Adolescent and Young Adult Medicine at Children's National. "For many parents and care providers, even thinking about the

possibility of future, life threatening medical events is difficult, let alone discussing those 'what-ifs' with an already sick child or teen. But when led through the steps by a professional as part of a program that plans for long term care, not just a dire, unthinkable scenario, parents and children can have healthy, productive, and thoughtful discussions about this sensitive topic without losing hope or making the child feel as if they have no control over their medical decisions."

Added Lawrence D'Angelo, MD, MPH, chief of Adolescent and Young Adult Medicine at Children's National and senior author of the study: "Our work provides empirical evidence that adolescents can participate in and understand the consequences of decisions about end-of-life care."

Source: Children's National Medical Center

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