

# Families of children with rare diseases open to advanced care plans with caregiver support

July 31 2019

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A novel palliative care intervention developed at Children's National Health System for caregivers of children and adolescents with rare diseases has shown preliminary success at helping families talk about potentially challenging medical decisions before a crisis occurs.

"Our goal was to find out if the tools we've developed are feasible and not too burdensome for the caregivers of children and adolescents with [rare diseases](#)," says Maureen Lyon, Ph.D., a clinical psychologist at Children's National who leads the Family Centered Advance Care Planning Team (FACE) within the Center for Translational Research at Children's National. "Developing the [tool](#) with their needs in mind was crucial because these families are already doing so much—including many tasks that used to be only done in a hospital-inpatient setting."

The approach was tested in a small sample of families whose children receive [medical care](#) through the Complex Care Program at Children's National. The findings from this preliminary study were recently published in the journal *BMJ: Supportive and Palliative Care*.

The intervention, which was guided by [family](#) feedback including review by the Patient and Family Advisory Council as well as families from the Leukodystrophy and Myelin Disorders Program at Children's National, includes two evidence-based modules:

- A [caregiver](#) needs assessment, based on the validated [Carer Support Needs Assessment Tool \(CSNAT\) Approach](#)
- An advanced care planning discussion, adapted specifically for families of children with rare diseases based on the validated [Next Steps: Respecting Choices](#) curriculum.

The two modules were delivered through four sessions led by two seasoned registered nurses who are familiar with the population. All families rated the sessions as useful and helpful, and while emotionally intense, not harmful in any way. In addition, feedback indicated that the last two sessions would be best served if they were combined into one longer session that coincided with an existing medical visit.

The adapted CSNAT needs assessment allowed the research team to collect some additional important information about the pressing needs and top priorities of the caregivers, which included:

- Knowing what to expect in the future
- Having [personal time](#) to recharge
- Financial challenges

"It's important to strike the right balance of relatability and knowledge so families know they aren't alone in this journey," says Jessica Thompkins, BSN, RN, CPN, research nurse coordinator for the FACE program, who facilitated the CSNAT sessions with families. "Families and their care providers both want to have these conversations ahead of time to avoid having to make important medical decisions in a crisis situation. But we have to first help them address their immediate needs, which will open the door to the right environment for these conversations."

This is the first time these two separate tools have been combined into a single comprehensive program. It is also the first time that the CSNAT, originally designed for caregivers of adults in hospice care, has been

adapted for use in a pediatric population. The team also had to tailor the Next Steps: Respecting Choices curriculum, which was [first applied at Children's National to give adolescents with HIV a voice in their own advanced care planning decisions](#), for use in this context, to make sure the tools speak to these caregivers, who are often the only voice for the needs of nonverbal or noncommunicative children.

"There are few tools developed to tackle these challenging topics for pediatric populations in general. Even fewer look at the serious needs of the people who care for them and how we can deliver important information to help them make the best decisions possible for their families and themselves," says Dr. Lyon. "This preliminary study gives us a good idea of where we need to go next to scale up these tools and give more families and care providers the confidence to have these conversations."

**More information:** Maureen E Lyon et al, Family caregivers of children and adolescents with rare diseases: a novel palliative care intervention, *BMJ Supportive & Palliative Care* (2019). [DOI: 10.1136/bmjspcare-2019-001766](#)

Provided by Children's National Medical Center

Citation: Families of children with rare diseases open to advanced care plans with caregiver support (2019, July 31) retrieved 5 May 2024 from <https://medicalxpress.com/news/2019-07-families-children-rare-diseases-advanced.html>

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