How should we talk with parents of children with cerebral palsy about advance care planning?

Principal Investigators: Dr Andrea Hoffman
andreahoffman@hollandbloorview.ca
Dr. Adam Rapoport
arapoport@sickkids.ca

Centre for Leadership: Child Development Program

Have you considered advance care planning?
Considering participating in a research study about this topic.

What is this study about?
This study is about understanding what parents of children with cerebral palsy (CP) think about having advance care planning conversations (ACP) with their health care providers. ACP may help families better understand their child’s diagnosis and prognosis and then use that knowledge to think, talk and plan for possible future educational, participation, financial, health and medical issues that may arise.

The purpose of this research is to help us understand what parents think about having ACP conversations and to guide clinicians about what should be discussed, when these topics should be raised, and with whom they’d prefer to have these conversations.

Who can participate?
We are looking for...
- Parents or bereaved parents of a child with CP (any level of motor involvement)
- Parents of a child/children with CP who are able to read/write in English and who have access to a computer and the internet

What’s involved?
This study involves an online questionnaire.
- One or both parents will complete a questionnaire that will take about 30 to 60 minutes.

Potential Risks and Benefits
We do not expect that participants will experience any risks or harm by participating in this study.

We hope that the information gained from the study will help us find ways to guide how doctors, nurses and other health care professionals talk with families with children who have CP about these issues.

Participants will receive a small token of appreciation to thank them for their time.

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