

Considering care for caregivers of children with special health care needs



What is this study about?

Many individuals play an important role as caregivers in the wellbeing of family members with special healthcare needs. Home caregivers can be parents, siblings, other family members or even friends. Being a home caregiver can mean experiencing stressors that take a toll on personal health and wellbeing.

Stressors are anything that causes extra pressures such as planning medical and home health visits, keeping track of medications, or managing medical technology. Home caregivers risk exhaustion, face financial issues, can have troubles at work or in their relationships, and are at a higher risk of stress-related illness. While being a home caregiver can be challenging, the right supports can help. But what kinds of aids can best help with different types of stressors and different caregiver needs?

Who are 'children with medical complexity'?

Children with medical complexity are a distinct group among children with serious, long-term health conditions. They have physical and developmental disabilities and are considered to be medically-fragile, meaning they depend on medical technology (feeding tubes, ventilators, heart monitors) and need round-the-clock care.



To answer this question, a scoping review focused on the needs of home caregivers of children with medical complexity was carried out to look at available aids. The research shows that these families are at great risk of caregiver stress.

What is a 'scoping review'?

A scoping review looks at many types of studies to better understand a topic. It may include published (e.g., journal articles) and unpublished work (e.g., posters, presentations, other documents).



What did the study find?

The review identified 6 aids that can be helpful to caregivers:

Care and Service Planning Supports

- Professionals such as a social worker or care coordinator can help with planning services, offering information on services that are available or might be needed, and information on funding to apply for

Respite Supports

- Organizations offering respite care such as camps or weekend stays, allows parents and siblings breaks from caregiving duties to deal with other parts of their lives

Caregiver Supports

- Taking part in peer and emotional support programs, like a parents' group, connects caregivers with others who know about a child's condition and can suggest different resources and creative solutions

Technology Supports

- Access to technology such as tele-medicine or remote vital sign monitoring allows families to access expert care from home, saving time and simplifying the day without the need to travel to and from appointments

Funding Supports

- Workplace benefits such as health insurance or paid leave can lessen worries about money and costs of care, and the need to take time away from work to care for their child

Equipment and Service Supports

- Access to special equipment or health services in the home such as mechanical lifts, day and night nurses, or accessible transportation

While studies only looked at one type of stressor and aid at a time, understanding how best to organize aids to help with multiple stressors at the same time is important to help families as whole.



What this means for caregivers

Here are some tips from families at Holland Bloorview for home caregivers:

- Work** with your/your child's healthcare team to find out what supports are out there for you
- Identify** who on the healthcare team can help you to:
 - Find resources (including financial support)
 - Identify training or learning opportunities
 - Direct you to peers or support groups
 - Learn what to advocate for and how
- Ask** if there are caregiver groups that you can attend while your child is in a session
- Ask** if your healthcare team uses technology for appointments or to share information to reduce the need to travel for in-person visits
- Look** for respite options that you feel comfortable with. Think about:
 - How often you will need it
 - If you prefer in-home or outside of the home care
 - Who you would want to offer respite (family member, healthcare professional, individual vs. group)

From a caregiver who read this review:

Everyone deserves self-care. Supports for people caring for others with complex needs are extra important since the demands on them/us are so high. The right supports can reduce stress. Get the best available support for you and your family. Be there for you and be there for your child.



Tips for speaking to your healthcare provider:

Stuck on where to start? Consider completing the following sentences:

- An educational opportunity that I would like is _____
- My key contact(s) for support is _____
- I would like respite for _____
- Funding sources available to me are _____
- Technology supports in my area include _____
- Equipment or service supports I could use are _____

Check out the [Care for the Caregiver](#) Hub at Holland Bloorview to help caregivers find the support they need.



For more information

Find the [abstract here](#), or visit your local library:

Edelstein, H., Schippke, J., Sheffe, S., & Kingsnorth, S. (2017). Children with medical complexity: A scoping review of interventions to support caregiver stress. *Child: care, health and development*, 43(3), 323-333.

- View [Dr. Kingsnorth's researcher profile](#)

