

## Meeting the needs of children with chronic and complex health conditions

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“Ethan” was born extremely premature. With intensive care support, he was able to survive, but he bled into his brain. He is now in preschool, but faces many challenges. He has a feeding tube and has difficulty protecting his airway, resulting in frequent episodes of pneumonia and hospital admissions. He has seizures that require many medications to control. He has severe learning difficulties and needs special attention at school. All this means that Ethan will have a lifelong dependency on the care of many different medical and other professionals, often in many different locations, over long periods of time to keep him as healthy as possible.

Thanks to improvements in medical treatment, more and more children like Ethan and the children featured in the video on this page are now surviving with conditions that might have been fatal 20 or 50 years ago, such as extreme prematurity, severe physical or neurological disabilities, or multiple challenging health conditions. But this means, in turn, that there continues to be a rapid increase in the number of children growing up with chronic, complex medical requirements.

### Introducing Chronic Complex Care

The challenges faced by these children and their families can be enormous. They are very often dependent on medical technology, such as supplemental oxygen or feeding tubes, or they may need one or more assistive devices. They almost always receive a number of different medications, each with its own potential side effects. They may need special education, special feeding, physical, occupational, or speech therapy, help with dressing and moving around, and more. They are likely to be frequently admitted to hospital, where they usually stay longer than children with less complex conditions. They are at higher risk of medical errors, and their families, understandably, tend to be less satisfied with their care. Although these children require a substantial amount of support from the health care system, this care has often been fragmented or lacking. Parents and families are left to take on the bulk of responsibility for care without adequate help and guidance, leading to stress, burnout, and compromised quality of life for both the child and the family caregivers.

### A medical home for children with chronic, complex health conditions

In 1992, the American Academy of Pediatrics published a statement promoting the concept of a "medical home" for all children, meaning that children should be able to access continuous, comprehensive care from a physician or team the family trusts. Unfortunately, this is not always easy to achieve in practice.

Ideally, all families would have a primary-care physician in the community where they live, who could coordinate with other health professionals and hospital-based medical specialists if needed. However, this model of community-based care is not always feasible, especially for children with more complex

needs, due to a lack of time, resources, and specialized expertise in many, if not most community settings. Indeed, many families do not have access to primary care at all. Children with chronic, complex conditions often require treatment at specialized tertiary-care hospitals, and families may come to rely for all their needs on the hospital where their child receives this care. Even there, though, these needs may not be adequately met.

Specialized, multidisciplinary, community-based or hospital-based teams provide coordinated, high-quality care for children with distinct, relatively common conditions such as asthma, diabetes, congenital heart disease, or cancer. However, there are few models of care to serve children with a rare complicated diagnosis or multiple diagnoses; these children may not “fit in” to any available specialized program. Instead, families of children with chronic, complex conditions usually have many different health care providers, each looking after a different aspect of the child’s condition. Even if they are in the same hospital, these care providers may not be in contact with one another. Families must juggle multiple appointments and often need to update care providers about new developments or educate new providers about their child's condition. This lack of continuous, comprehensive care makes for added stress on the child and family.

It is obvious that children who require chronic, complex care are at the top of the list of those who would benefit substantially from a medical home, but it is precisely these children who are least likely to have one.

In view of all these challenges, some hospitals have begun to explore hospital-based care coordination to complement community-based care: effectively, a medical home at the hospital. This model recognizes that regardless of their specific diagnosis, children and families with chronic, complex health conditions have many needs in common and can benefit from the expertise of a dedicated team. This approach offers a “one-stop” approach that helps the child and the family, but also the health care providers. Rather than seeing a multitude of care providers who each treat one isolated problem, families work with a single team whose members are trained to treat the whole child. The team can manage many common problems directly, consult with specialists in other fields if necessary, coordinate the child’s care, share information, and keep the family informed and supported. For children who are often in and out of hospital for emergency treatment, the team can mobilize resources ahead of time rather than scrambling to catch up once the child arrives.

A related model is “shared care.” Under this model, a physician in the child’s community is the child’s primary health care provider. When the child needs to go to hospital, the hospital-based team manages the child’s care. The physician and the hospital team work together to provide coordinated care for the child and family, and the hospital team can help put the community physician in contact with specialized resources.

The goals of both these care coordination models include better care, fewer errors and delays, and happier and more confident patients and families.

### **The Complex Care Team at SickKids**

At SickKids, the Complex Care Team was established in 2006 and includes a small group of medical specialists, two nurse practitioners, and a social worker. For each child enrolled in the program, the

team works with the family to develop an electronic care plan that summarizes the care the child requires and how and when to best provide it. The care plan functions as a medical passport. When the child sees a new care provider or a new setting of care, such as the emergency department, another hospital, or a new school, this care plan is an efficient and accurate tool to bring all health care providers up to speed and ensure that everyone is on the same page.

In the words of one parent who participated in a research study to assess families' and primary care providers' experiences with the program, "The health care that I am getting is more consistent and a better quality than the experience I was having prior.... You have people to support you and it takes less time, I'm able to spend more time with [my son] and I find I get in less of a panicked situation now because I have more people that I can talk to. [It is] great having that support because then I'm not always relying on one family paediatrician all the time, I'm not always calling to bug her, other people are helping out too. It's nice because [the clinic nurse practitioner] is there for you. It's just a better feeling to be part of the clinic." A primary care provider in the same study said, "What a HUGE difference this made for M and her family. We went from a nightmare to a Shangri La!"

The team has six beds in the paediatric ward, and an ambulatory clinic for 80 of the most complex patients to ensure optimal coordination of care. They take the lead in managing hospital-based care for children who see many different providers at SickKids.

The team also works to make alliances with community-based health care providers so that transitions between home and hospital are as seamless as possible. Using a "virtual clinic," families can stay connected to their care providers and coordinators at the hospital, and community paediatricians can contact the team for help and services when needed. The team has also been working with community-based pilot clinics in Orillia and Brampton, where SickKids patients are seen by their local health care provider together with a nurse practitioner affiliated with SickKids. The goal is to provide seamless integration of community- and hospital-based care, and to keep care as close to the child and family's home as possible.

### What does the future hold?

Chronic, complex care is still an emerging field, and we are just beginning to learn the magnitude of the situation: How many children need this kind of service? What are their needs? What works for them? How should care be delivered? There is no doubt, however, that the preliminary data from evolving models of care demonstrates a major impact in decreasing the frequency of hospitalizations and in providing much needed family support to allow children and families to thrive. We hope that with new and improved treatments, many of the medical problems leading to the need for chronic complex care may be alleviated. Until then, the ongoing development and scope of our chronic complex care team will be an essential element in reaching our hospital's vision of "Healthier children. A better world."

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