

# Peer support best practice toolkit

A resource for individuals developing and providing peer support programs  
for families of children with medical complexity and other lifelong disabilities

## SECTION 1.0

### Background and models of peer support



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Evidence to Care (EtC) at Holland Bloorview Kids Rehabilitation Hospital is a specialized team of knowledge translation experts supporting the hospital in its commitment to transform care through evidence, knowledge generation, and translation. Through collaborative efforts, EtC strives to make research evidence accessible in promoting evidence-based care in the field of childhood disability.

## Holland Bloorview | Kids Rehabilitation Hospital

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## **CONFLICT OF INTEREST DECLARATION**

The contributing committee members have no conflict of interest to declare.

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## SECTION 1.0

# Background and models of peer support

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# A note from Sonia Facecchia, mother to a child with medical complexity

Caring for a child with medical complexity is a great responsibility, one that brings many physical and emotional demands. As a family begins the early stages of acknowledging that their child has a severe lifelong condition, big changes happen in the family dynamics. Acceptance of this reality is the biggest emotional step of this journey. Meanwhile we have to learn to care for our child with such complexities and strive to make sure we are and will be doing a good job. This process will take much effort.

Caregivers of children with medical complexity are required to begin a journey in a world that most likely they knew nothing about, did not plan for, and quite frankly wouldn't willingly have chosen, but we do it out of love and responsibility. We dedicate ourselves to caring for our child – this is our new role, which includes so many hats ... we must be nurses, doctors, physiotherapists, dieticians, respiratory therapists, entertainers, secretaries, and still be a parent. We have to keep track of appointments, medications, feed schedules, medical condition changes, medical equipment... the list can go on and on. This is a full time job, one that requires all the attention and time available, plus some!

Everyone in the family is affected, including parents, siblings, and even extended family.

Through the process, the main caregivers can start feeling like we no longer belong in the world as we knew it before - life is very different and therefore no longer normal. It is overwhelming to care for a child with high needs when one feels that they need caring themselves. Physical and emotional exhaustion is a constant.

This is why it is so important for peer support for caregivers of children with medical complexity. In the midst of all demands, it is very difficult to find time and effort to navigate and research the possible supports for oneself when we are no longer a priority. Most families would benefit from meeting and talking to others who are experiencing similar circumstances and emotions. It has been my experience and my greatest support thus far. Speaking to others who can relate to your experience can be uplifting, comparing notes can be helpful, and supporting each other reminds us we are not alone and we get each other.

Children with medical complexity and their caregivers may not be a large community but definitely one that needs the most physical, emotional, and financial support!



# Families of children with medical complexity and other lifelong disabilities

Families<sup>1</sup> of children with medical complexity and other lifelong disabilities face physical, financial, social, and emotional challenges associated with providing necessary care (Naramore, 2008; Peer & Hillman, 2014). Depending on a child's level of medical complexity, "service needs have a significant impact on the family unit, specifically time devoted to direct care, frequent provider visits, care coordination, and financial burden" (Cohen et al., 2011, p. 530). Given these extensive care needs, parents and other caregivers must negotiate the role of being the primary care provider while trying to maintain a sense of balance for themselves and the needs of the entire family (Cohen et al., 2011; Peer & Hillman, 2014; Sartore, Lagioia, & Mildon, 2013).

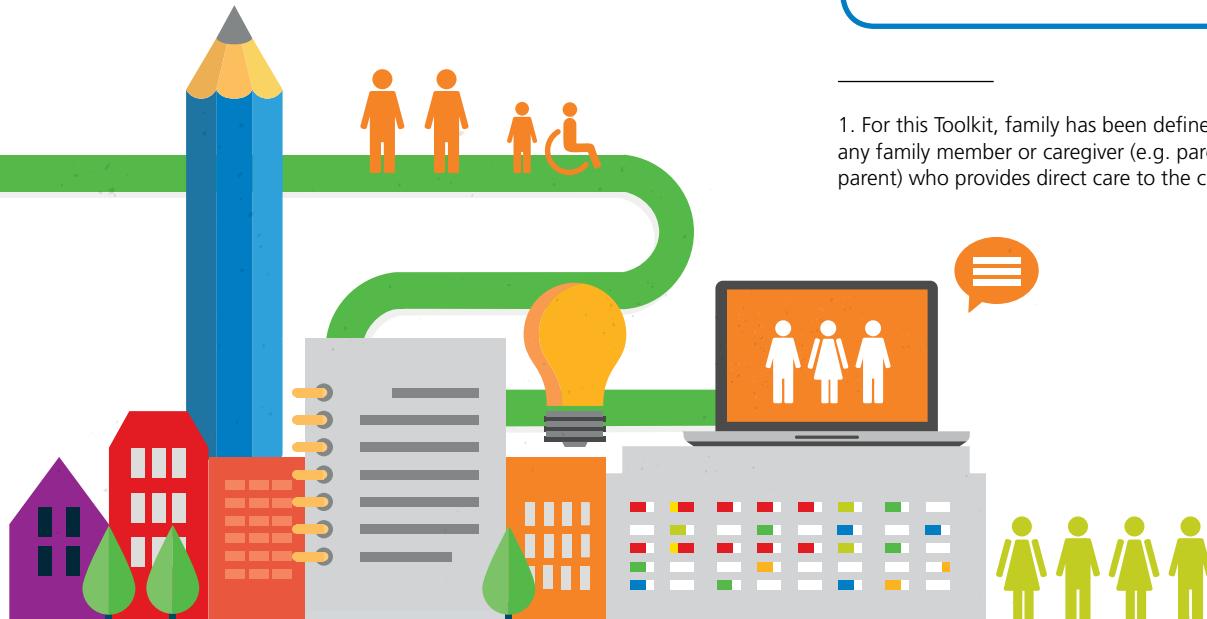
Balancing care with multiple responsibilities can be physically and emotionally demanding for families (Sartore et al., 2013). This can lead to caregiver burden (Nicholas & Keilty, 2007), increased levels of stress, and may result in clinical depression and anxiety (Naramore, 2008;

Peer & Hillman, 2014). This stress can impact the quality of the parent-child relationship and the family's ability to care for and parent their child(ren) (Peer & Hillman, 2014). It is critical to consider ways to address and support families to ensure the health and well-being of all members.

## WHO ARE CHILDREN WITH MEDICAL COMPLEXITY (CMC)?

Children with medical complexity (CMC) represent a small population of children with substantial health needs. These children have severe chronic conditions and functional limitations, often relying on technology for care (e.g. ventilator, feeding tube), and are frequently hospitalized and under the care of many different healthcare providers (Cohen et al., 2011).

1. For this Toolkit, family has been defined broadly to include any family member or caregiver (e.g. parent, grandparent, foster parent) who provides direct care to the child



## Purpose and objectives

One important approach to supporting families is through peer support. The value of unique shared experience has been widely discussed and recognized as an important complement to other professional support services<sup>2</sup> (e.g. Ainbinder et al., 1998; Dennis, 2003).

This *Peer Support Best Practice Toolkit* is a resource for individuals who are developing and/or offering peer support programs for families of children with medical complexity and other lifelong disabilities. The Toolkit includes practical information summarizing:

- peer support models
- research evidence on best practices in peer support
- case studies, templates, and links to helpful resources

There is currently very little research and information regarding peer support specifically for families who care for children with medical complexity. Therefore, this Toolkit will reference literature and examples from pediatric disability more broadly and the term 'disability' will be used throughout the Toolkit. Where possible, case studies of specialized programs and perspectives from family members of children with medical complexity are included to highlight the unique needs of these children and their families.

For this Toolkit, peer support is defined as "*the existence of a community of common interest where people gather (in person or virtually by telephone or computer) to share experiences, ask questions, and provide emotional support and self-help*" (Sartore et al., 2013, p. 2).

## How did we develop the Toolkit?

Through focus groups and a working group, community stakeholders have collaborated with Evidence to Care at Holland Bloorview to support this project. Key meetings were held to identify content and members provided relevant resources.

A rapid review of the literature was also conducted in April 2015 to identify evidence summaries (e.g. systematic reviews, meta-analyses, scoping reviews) on the topic of peer support for families of children with disabilities and complex needs. See the supplementary *Rapid Evidence Review* for a more in-depth overview of the methods and key findings.

Searches conducted via Google and hand searching of other toolkits were also undertaken.

## What does the evidence tell us about peer support?

Although there is a significant amount of literature on peer support, much of this research addresses populations other than childhood disability. For example, peer support has been discussed in the areas of mental health and addictions, breastfeeding, and diabetes (Dennis, 2003; Fisher et al., 2014; Peers for Progress, 2014).



### To watch...

Keep an eye out for an upcoming Cochrane Review on peer support interventions for parents and carers of children with complex needs (Sartore et al., 2013)

2. Note: Peer support does not replace professional support. Families in crises should be referred to a primary care provider or other healthcare professional



## Here are some key reviews that discuss peer support for families of children with disabilities you should know about:

- Peer support for parents of children with chronic disabling conditions: A systematic review of quantitative and qualitative studies (Shilling et al., 2013)
- Internet-based peer support for parents: A systematic integrative review (Niela-Vilen et al., 2014)
- Parent to parent: A synthesis of the emerging literature (Robbins et al., 2008)

### Key takeaways:

- Reviews highlight various models of providing peer support, including: **in-person groups, online and parent matching**
- Within these models, peer support programs are very diverse in their structure and set-up
- A number of articles report positive benefits associated with peer support for families of children with disabilities and complex medical needs, including: ability of families to connect with other families through a shared social identity; receive and provide information and emotional support; enhance coping skills; and other psychological benefits
- Not all studies report positive impacts; however, peer support has not been found to be harmful
- More research is needed on peer support for families who care for children with disabilities and how to best measure its impact on caregivers and children

If you would like to see the full citations for these articles, visit the Reference<sup>3</sup> section.

## Providing support for siblings?

### Here are two systematic reviews that discuss peer support for siblings:

- A systematic review of interventions to support siblings of children with chronic illness or disability (Hartling et al., 2014)
- Intervention and support for siblings of youth with developmental disabilities: A systematic review (Tudor & Lerner, 2015)

### Key takeaways:

- Having a child with a disability impacts family roles and activities
- Support strategies may be helpful for siblings to cope with changes
- Sibling interventions vary in design and purpose, therefore, it is difficult to draw conclusions on overall effectiveness of these programs



3. Note: If you are not able to access some of these articles through Google searching, visit your institution's library or your local library to see if they are available



## Models of peer support

Peer support can be offered in many ways - by various providers in different settings, using both formal and informal approaches (Dennis, 2003). Three key characteristics of peer support are the provision of:

- emotional support (e.g. empathetic, caring interactions)
- informational support (e.g. providing knowledge, advice, suggestions), and
- appraisal support (e.g. providing information to encourage personal decision-making)

Any given peer support program will include a combination of these key characteristics (Dennis, 2013).

The main feature distinguishing peer support from other forms of support is that families have a shared social identity and can relate to one another given their unique caregiving experience (Shilling et al., 2013). Regardless of the type of peer support program, it is important to consider this feature when designing programs.

**... families have a shared social identity and can relate to one another given their unique caregiving experience ...**

This Toolkit highlights three popular models of providing peer support:

- in-person groups
- online
- parent matching

A general overview, key considerations for program development, and links to resources are provided for each model (see Tables 1–3).

Case studies of peer support programs across Ontario are included in Section 2.0 to provide snapshots of the range of programs, while highlighting the facilitators and barriers to peer support in practice.

**Table 1**

## Model: In-person peer support



<b>Overview and key characteristics</b>	<ul style="list-style-type: none"><li>Face-to-face peer support groups involve “voluntary gatherings of people who share common experiences, situations or problems and who offer each other emotional and practical support” (Heisler, 2006, p. 26)</li><li>Peer support groups differ in their purpose, structure (e.g. meeting frequency; duration of program; length of each session; drop-in versus registration; use of curriculum versus open-ended), format, and the engagement of facilitators</li></ul> <p>For example, support groups can be:</p> <ul style="list-style-type: none"><li><b>Professionally-led</b><ul style="list-style-type: none"><li>Engages group leaders who are paid professionals (e.g. healthcare providers)</li><li>Uses educational resources and decision-making processes to guide group discussions</li></ul></li><li><b>Peer-led</b><ul style="list-style-type: none"><li>Engages group leaders who are volunteer members of the group sharing in a common experience</li></ul></li><li><b>Combined approach</b><ul style="list-style-type: none"><li>Professionals and peers work together to facilitate the group</li></ul></li></ul>
<b>Potential challenges for families</b>	<ul style="list-style-type: none"><li>Caregivers may be hesitant to share their personal feelings with others</li><li>There may be limited time and resources to participate (e.g. childcare; transportation; work schedules)</li><li>Potential lack of shared social identity (e.g. child’s condition; parental backgrounds)</li></ul>
<b>Key considerations when developing programs</b>	<ul style="list-style-type: none"><li>Create a relaxed atmosphere where members feel they can share their experiences and provide support to others</li><li>Meeting times and locations should suit the group needs</li><li>Include activities involving information and experience sharing</li><li>Develop criteria (e.g. communication and leadership skills; experience with the support group topic) to screen and select program facilitators (professional and/or peer)</li></ul>
<b>Resources</b>	<ul style="list-style-type: none"><li><b>Comparing Self-Help to Professionally-led Support Groups</b><ul style="list-style-type: none"><li><i>See where your program falls on the continuum of self-help versus professionally-led support groups: <a href="http://selfhelp.on.ca/resource/matrix.pdf">http://selfhelp.on.ca/resource/matrix.pdf</a></i></li></ul></li><li><b>Peer Support Guide for Parents of Children or Youth with Mental Health Problems</b><ul style="list-style-type: none"><li><i>This toolkit has a number of practical tips and resources for starting a peer support group: <a href="http://www.cmha.bc.ca/files/ParentPeerSupportGuide.pdf">http://www.cmha.bc.ca/files/ParentPeerSupportGuide.pdf</a></i></li></ul></li></ul>
<b>References</b>	Best Start: Ontario’s Maternal Newborn and Early Child Development Resource Centre & Ontario Self Help Network, 2005; Harder + Company Community Research, 2012; Shilling et al., 2013

**Table 2**

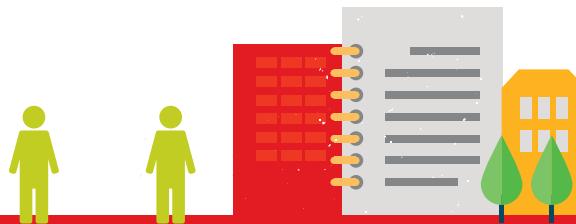
## Model: Online peer support



<b>Overview and key characteristics</b>	<ul style="list-style-type: none"><li>• Online support uses technology to connect peers</li><li>• May provide support in an anonymous and non-judgmental way</li><li>• Typically cost-effective and convenient (e.g. due to living in a remote area; balancing employment and childcare responsibilities)</li><li>• Online peer support can be public (open to all users) or private (password access only)</li><li>• Online peer support can be offered via discussion board, chat, e-mail, live meetings, one-to-one discussion, and open group forums</li><li>• Communication may involve real-time discussion (synchronous) or reading and responding to messages when it is convenient for the user (asynchronous)</li><li>• Peers, professionals or both may be involved in communications</li><li>• Considered a valuable complement to face-to-face communication</li></ul>
<b>Potential challenges for families</b>	<ul style="list-style-type: none"><li>• Access to computers/internet</li><li>• Technical problems (e.g. privacy; security)</li><li>• Receiving a large volume of emails or lack of replies to messages</li><li>• Receiving negative messages or impulsive statements</li><li>• Inability to 'hear' tone of voice or see non-verbal expressions</li><li>• Difficulty establishing rapport, meaningful relationships</li></ul>
<b>Key considerations when developing programs</b>	<ul style="list-style-type: none"><li>• Consider having a designated person as a moderator (e.g. healthcare professional) to facilitate discussions, monitor safety, answer questions, and confirm information accuracy</li><li>• Provide usernames and passwords to maintain confidentiality and security</li><li>• Provide guidelines to assist online support users (e.g. typing in capital letters is considered shouting)</li><li>• Provide training (e.g. skill development) and clear guidelines to facilitators who deliver online peer support (e.g. how to build rapport; how to interpret and reflect on discussions)</li></ul>
<b>References</b>	Baum, 2004; Niela-Vilen et al., 2014; Nieuwboer, Fukkink, & Hermanns, 2013; Paterson, Brewer, & Stamler, 2013; Plantin & Daneback, 2009; Scharer, 2005

Table 3

## Model: Parent matching



<b>Overview and key characteristics</b>	<ul style="list-style-type: none"> <li>Parent matching programs "...offer supports to these parents by matching them with parents who understand the stress by virtue of shared experience (i.e., have a grown or older child with the same or similar disorder)..." (Robbins et al., 2008, p.1)</li> </ul> <p>Experienced parents or mentors who provide support are referred to as a <i>support parent</i> and are matched one-to-one with a <i>referral</i> or <i>referred parent</i> who is seeking support</p> <ul style="list-style-type: none"> <li>Parents are matched based on criteria to ensure the relationship meets the needs of both parents involved</li> <li>These programs are flexible and often vary in their structure and set-up depending on the context</li> <li>Facilitation by a healthcare professional may enhance program effectiveness and aid in monitoring for potential deleterious effects of peer matching</li> <li>Provides the mentor an opportunity to 'give back'</li> </ul>
<b>Potential challenges for families</b>	<ul style="list-style-type: none"> <li>Lack of uptake and sustainability if parents do not feel well-matched with the other parent (e.g. differences in personality; child's condition)</li> <li>Difficult for parents to find a time to connect with one another due to busy schedules</li> </ul>
<b>Key considerations for program development and resources</b>	<p>There are a number of existing resources that can be useful as you develop your program:</p> <ul style="list-style-type: none"> <li><b>Parent to Parent USA</b> <a href="http://www.p2pusa.org">http://www.p2pusa.org</a> Download these free chapters from the Parent to Parent Handbook: <ul style="list-style-type: none"> <li>Matching Parents – Chapter 5: This chapter outlines considerations for matching parents and includes resources for facilitating the matching process</li> <li>Finding and Preparing Supporting Parents – Chapter 6: "This chapter describes specific strategies for recruiting, screening, training, and nurturing supporting parents"</li> <li>Organizing Your Program – Chapter 7: This chapter highlights stories of successful matching programs and evidence-based practices and recommendations</li> </ul> </li> <li><b>St. Jude Children's Research Hospital</b> <ul style="list-style-type: none"> <li>Learn about the PAIR mentor program: <a href="https://www.stjude.org/">https://www.stjude.org/</a></li> <li>Access their training videos here: <a href="http://www.stjude.org/stjude/v/index.jsp?vgnnextoid=a965d6f6d3487310VgnVCM100000290115acRCRD&amp;vgnnextchannel=71dd82edd2be310VgnVCM100000290115acRCRD">http://www.stjude.org/stjude/v/index.jsp?vgnnextoid=a965d6f6d3487310VgnVCM100000290115acRCRD&amp;vgnnextchannel=71dd82edd2be310VgnVCM100000290115acRCRD</a></li> </ul> </li> <li><b>Region of Waterloo Peer Worker Resources:</b> <ul style="list-style-type: none"> <li><a href="http://chd.region.waterloo.on.ca/en/partnersProfessionals/findresources.asp">http://chd.region.waterloo.on.ca/en/partnersProfessionals/findresources.asp</a></li> </ul> </li> <li><b>Mount Sinai Hospital Parent Buddy Program:</b> <ul style="list-style-type: none"> <li><a href="http://www.mountsinai.on.ca/care/nicu/parent-support-1/parent-buddy-program">http://www.mountsinai.on.ca/care/nicu/parent-support-1/parent-buddy-program</a></li> </ul> </li> </ul>
<b>References</b>	Ainbinder et al., 1998; Nicholas & Keilty, 2007; Parent to Parent USA, 2010; Robbins et al., 2008; Santelli, Poyadue, & Young, 2001; Shilling et al., 2013

*Let's hear from some families* about their experience with peer support



# Meet Jennifer and Owen

Owen had multiple, severe disabilities all of his life. Owen was diagnosed primarily with cerebral palsy but they never knew the underlying cause. He was deaf, non-ambulatory, g-tube fed, incontinent and required full support for all aspects of daily living. He died at the age of 12. He was a tremendously happy child and his family did not feel hindered by his needs. They enjoyed all the usual things a family does, including picnics, swimming, camping, skiing, hikes, family outings, vacations and socializing.

Owen's mother, Jennifer, was involved in one peer support parent matching program in the Neonatal Intensive Care Unit (NICU). Her support parent was very kind and tried to be helpful, but felt overwhelmed when Jennifer's son did not do nearly as well as her daughter had (who was about 3 years older). Their relationship fizzled as the parent felt she had nothing to offer Jennifer, since she could not relate to her experience. Although Jennifer's experience was not overly "successful", she feels there is no "bad support" and would encourage parents to consider accepting support if offered.

Jennifer also has advice for facilitators who run different peer support programs:

*"Don't assume that the 'diagnosis' is what makes peer support useful. Over the years, I have developed much more meaningful relationships with parents who share the same physical and emotional challenges – sleeplessness, dealing with bureaucracy, creative ways to foster community connections, forward planning for teen and adult years, equipment management etc. – there was little connection on the basis of diagnosis alone."*

*"Parents with non-inspirational experiences can still be useful, perhaps even more so. Peer supports are often selected because their child is 'out of the woods' and doing well – however, this overlooks parents who may have come to a different degree of acceptance of their child and can offer a mature perspective to a less-experienced parent."*

*"In addition to peer support, facilitators might consider offering mentor/veteran support as well. Peers are sometimes just a few months ahead of the other parent and can be mired in the same issues without quite realizing it. Even if the support parent is a couple of years ahead, they may not have enough perspective to provide guidance to the other parent. If a parent is open and ready to meet an older parent, facilitators should be able to connect them."*

# Meet Darren and Tyler

Tyler is an amazing little boy who is medically complex. He will never talk, walk or eat by mouth, but he has changed the lives of his parents and siblings, Alicia and Bobby, to their very core.

Darren and his family have accessed peer support in many different ways. When Tyler was young, Darren and his wife Helen helped start a parent support group at their local children's treatment centre. The group started with a core group of families that went on to provide peer support for hundreds of families. He has also accessed peer support online through Facebook and groups such as Parent Advocacy Link. From

Darren's experience, online groups like Facebook provide an opportunity for members to become friends who might go out for activities with their kids or grab a coffee.



Linking people who share similar experiences is an element of peer support that has played an important role for Darren and his family. Darren provided these words about the value of peer support:

*"Sometimes we just need to know that we are not alone and that there are others out there living the same experience. You can find people that are very much like you who 'GET IT'. I think that many of our closest friends are families with children who have disabilities. It really is a cultural thing. We live our lives in a very similar, high stressed fashion. Most do not understand what it is like unless they live it. You just want to sit down and talk to people that 'get it.' It does not mean that you don't keep your old friends, but you are certainly not going to discuss the same things with the same level of understanding."*

Engaging in peer support also allows for sharing of new ideas and concepts, and this has been beneficial for Tyler and his family. Darren shared this experience:

*"Our son, years ago was due to have a fundoplication. Another parent suggested a different formula. The formula change not only stopped all issues that Tyler was having where he was throwing up continuously, but he also no longer required surgery. That is just one small instance out of hundreds."*

When it comes to creating peer support programs, Darren had these words to share:

*"If you create a platform that allows for sharing of information and building of networks, then you have a success. Your platform might support four people or four thousand, but you won't know the ripple effect for years to come."*

# Meet Melodie and Matthew

Matthew has Down syndrome and was born with a congenital heart defect called Atrioventricular Septal Defect (AVSD) and underwent open-heart surgery to repair it when he was 5 months old. All of this caused significant delays in Matthew's development. Matthew is non-verbal and has low fine and gross motor skills. Matthew is a happy, friendly, determined young man.

Matthew's mother, Melodie started at Grandview Children's Centre in a Parent Networking Group for parents of babies with Down syndrome. It was the first time she had met another family with a Down syndrome diagnosis. It was her first "Grandview therapy", while she waited for services. Her son Matthew was about 1 year old at the time. The group was to meet for a set number of sessions.

Names and emails were circulated and parents continue to stay in touch to this day. Everyone who was invited to the group had a new Down syndrome diagnosis. She really felt that there should have been some families there who had older children with the same diagnosis. Perhaps even a parent panel. Melodie felt that the group helped her feel as though she was "doing something" while she waited for therapy to start, but she wished it had started sooner, when Matthew was younger.

Melodie is now co-chair of the Family Advisory Committee, a parent mentor, and very active on the Grandview Online Parent Support page. She wants to give back. Melodie provided these words about the importance of peer support to her family:

*"I can't stress enough the incredible benefits of peer support - many I never realized I needed until I started going. It reduces the feelings of isolation with mutual understanding; it helps increase practical knowledge through the sharing of experiences and skills, as well as emotional support. Let the parents take the lead at the sessions but ensure everyone has an opportunity to share. Having new and experienced parents together can have incredible results and create lifelong bonds."*



**Having new and experienced parents together can have incredible results and create lifelong bonds**



# Meet **Stuart and Samantha**

Samantha was a full term birth with difficulties and is now 5 years old. Samantha is undiagnosed, but has been given a working diagnosis of bilateral spastic diplegia and dystonia.

Samantha's father Stuart is a member of many online Facebook support groups, comprised of families with disabled children of many different diagnoses. His experience with online support groups has been very positive. Parenting a disabled child is not easy. He has found all parents in the groups to be extremely supportive and helpful. From Stuart's experience, accessing peer support in the form of counseling organized through doctors or online groups, for example, is important for parents. The knowledge and help gained from peer support is invaluable. Stuart provided these words about how peer support has helped his family:

*"I find the support groups valuable in many ways, from finding and accessing therapies, information on medications, schooling, information on funding and supports available to us that we may not know about, and most*

**Information given during programs should be easy to understand and in plain English; there is already so much going through our heads**

*importantly being in contact with other parents going through similar situations. The support of other parents has very much helped myself and my family navigate this difficult journey. This is not an easy life; peer support very much helps you deal with this difficult time."*

Stuart has advice for facilitators who run online support programs:

*"For online support, the parents must be made to feel comfortable and safe to share their experiences; this would be the same for other peer programs as well. Information given during programs should be easy to understand and in plain English; there is already so much going through our heads."*

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