

SHARING YOUR STORY: A GUIDE FOR PARENTS AND CAREGIVERS

Sharing your child's story and medical history

As parents or caregivers of a child or youth with medical complexities, you may be asked to share your child's medical condition or your family's story. Some families call these Pediatric Education Dialogue (PED) Talks. Some examples of PED Talks may include:

- sharing your child's history as part of a medical appointment
- being part of a hospital committee
- participating in a media interview
- acting as a panelist

It can be exhausting, traumatic and triggering to repeat their story because you may feel like you're reliving your child's history.

Understanding trauma and triggers

Having a child with a complex and fragile medical condition has an important impact on parents and siblings on both their mental and physical health. Witnessing your child suffer and experiencing the fear of losing your child, can be traumatic for families. "Trauma refers to experiences that cause intense physical and psychological stress reactions. Experiences can refer to one event, a series of events, or a set of circumstances that is experienced by an individual as physically or emotionally harmful and have lasting adverse effects on the individual's physical, social, emotional or spiritual well-being." (Alberta Health Services)

Triggers (defined by GoodTherapy.org)

- reminders of a past trauma that can cause a person to feel overwhelming sadness, anxiety or panic
- feelings of trauma can be triggered by any one of the five senses (mostly smell, sight and sound)

Understanding resilience

Resilience is our own ability to recover and bounce back from difficult situations. The good news is that we can actually learn to become more resilient over time, with enough practice. We recommend a holistic approach to building resilience - meaning finding a blend of physical, emotional, mental activities that help you safely return to your baseline (or usual self).

Building resilience takes time and practice, but the more you work on it deliberately, the more natural it will be for you.

Sharing your story: a guiding tool

To help you prepare for upcoming events that may trigger you, or cause you to relive past trauma like public speaking events, or medical appointments, we have developed this guiding tool for you to fill out.

Tips while filling out this tool

- Filling out the tool might be triggering, so please fill it out when you have the time and energy to focus on it.
- You can also ask your health professional/coach, (a Social Worker, counselor, psychologist), another parent (peer) or someone you trust to help you brainstorm and fill out the tool.
- Fill out your tool as you see fit, you do not need to complete it all at once. Take some time to reflect, search for resources, explore what works for you, etc.

My go-to contacts

Here you have space to insert the names of three people that are available to support you in difficult times. This will help you to easily access the contact information of your support team without having to scramble through your phone, your documents, etc. Write down their full names, their phone numbers, including extensions and their roles, so you remember who's who. (Examples of these people can be a trusted friend, a family member, a counselor etc.)



Contact 1	Contact 2	Contact 3
Name:	Name:	Name:
Phone number:	Phone number:	Phone number:
Role:	Role:	Role:

Other resources I find helpful (example social media group, APP or helpful website):

-
-
-

My resilience-building activities

It's important to find resilience building activities that are a good match for you and that are helpful. We recommend that you practice these strategies on a regular basis and not only when you are going through a stressful situation. Also consider your relationships and connections that can offer support. We encourage you to practice these activities deliberately in your everyday life so when you feel stressed, you're able to put them into action easily.



Ask a health professional to learn more about these activities.

Resiliency building activities	What I find most helpful
Physical activities Examples: yoga, balanced nutrition, sleep, stretching, breathing, hygiene, walking, working out, body scans, gardening, activating your senses, dancing and running.	
Mental/intellectual activities Examples: journaling, challenge thoughts, explore passions, practice self-compassion, practice self-awareness and colouring.	

Resiliency building activities	What I find most helpful
<p>Spiritual activities Examples: faith, gratitude, meditation, rituals, connect with nature, pray, learn to let go of what you can't control, appreciation and mindfulness.</p>	
<p>Emotional activities Examples: become aware of emotions, validation, CBT, find a safe place to express yourself, regulation strategies, self-compassion, explore uncomfortable emotions and learn to accept/feel your emotions.</p>	
<p>Other activities Examples: Box Breathing, Breathe with your hand on your heart, countdown with the five senses to be aware of your surroundings and visualize your safe space.</p>	

My story reflection plan

Sometimes you will have more time to prepare, for example if you are giving a presentation in a few months. Other times you might only have a few hours to decide if you'd like to share your story, for example if you are asked to do a media interview.



Allow yourself the time that you need for yourself to prepare. Everyone is different. Telling your story might look differently depending on your audience.

Remember, you can always change your mind about sharing your story, say no or ask questions if you are unsure. If you are sharing your story through any of CHEO's channels, you can even ask to review the story before it is published.

Considerations	My thoughts
Do I need to share my child's story or is this voluntary?	
Who am I sharing with?	
Do I want to share my child's and/or family's story?	
Why do I want to share my child's story?	

<p>What parts do I want to share? What parts are off-limits? Consider spouses, siblings, other family members and what they might want.</p>	
<p>What are my triggers? What are the signs that I have been triggered? What helps when I am triggered?</p>	

My event strategy

What do I need to do during the event (interview, panel, committee, meeting, appointment, etc.) to reduce triggers, difficult reactions and to feel best supported? Check off all that apply and write down your strategy.



I require a safety person in the room. Their name is: _____

I require a safety-exit plan (for example: you might want to go backstage to avoid having to talk to participants in the room, where you won't be able to control comments and questions that could trigger you.) My plan is:

I will practice grounding resilience building strategies/activities that work for me. These are:

I will stick to my key words and points. These are:

- 1.
- 2.
- 3.
- 4.

Remember: it's OK for you to say no and to not answer a question- establish with others or facilitators how to pass along a question you feel is better suited for another panelist.

I have planned other helpful strategies. These include:

- 1.
- 2.
- 3.

My event recovery plan

The purpose of this plan is for you to bounce back from the event without causing any harm or using coping strategies that could be harmful to you. Allow lots of self-care to help recover safely and healthily.



Check off all activities you think would help you get back to baseline (to your usual self) after sharing your story or fill in some other activities you would find helpful. There are extra spaces at the end in case something isn't listed here.

- I need to keep my schedule open for the day of the panel/appointment (do not schedule anything).
- I need to activate my resilience building strategies/activities
- I need to plan a telephone call with my safety person. Their name is:
- I need to plan for respite for that day or few days.
- I need to book a therapy or counseling session for the same day.
- I need to practice self-care by doing activities that help ground me. These include:
- I need to treat myself (example: going shopping, having a special treat, taking a relaxing bath).
- I need to express how I feel to my partner so he/she's aware of the plan to take care of kids/others.
- I need to reach out to a Health Professional if my event recovery plan doesn't result in my initial goal to get back to my usual self.
-
-
-
-
-
-

After completing this tool

- Place the tool somewhere you can see, reflect and add to it every day (fridge, bathroom mirror, vision board, etc.)
- Talk to others about your plan and your coping strategies so they're aware of what you're working on. They can encourage you and offer you feedback on their observations.
- This tool can be modified as you see fit. If you feel that something works better or doesn't work well for an event, change it up and explore new possibilities.
- Consider reaching out to a health professional if the activation of your plan doesn't result in your initial goal to recover to your baseline or usual self.

This tool was designed in collaboration with families from the Complex Care Family Advisory Committee.