

Sharing Your Experience to Impact Change: A Tip Sheet for Caregivers



This tip sheet is for caregivers who share their story in advisory roles, on committees, as speakers or in written formats, with the goal to shape positive change in the health and social care systems. It was co-developed by caregivers to offer practical suggestions and proven approaches for sharing stories with confidence, purpose and impact.

Ground rules for sharing your caregiver experience

- **Honour and respect your family member's story:** Remember your caregiving journey is also their story. Get permission before sharing any details of their story publicly.
- **Understand your why:** Think about what change you want to influence. Knowing why you want to share your experience will guide what you say and keep your story focused.
- **Know your boundaries:** This is your story – you choose what to share and what to keep private. This can change depending on the purpose, audience and format (e.g. written story vs. verbal presentation; meetings that are confidential vs. recorded).
- **Prepare for emotions:** Caregiving is emotional. Everyone has a different comfort level with showing feelings. Plan ahead for what you'll do if you feel overwhelmed (e.g., pause, acknowledge emotions or stop sharing).

Sharing your experience effectively:

Making choices

Develop strong messages

- Have a clear purpose – what change are you trying to impact?
- Keep it simple and concise – less is more.
- Highlight the emotional impact – to help others empathize with your experience.
- Make it relatable – personal stories help people connect.
- Link your experience to data or stats – this shows how broader trends impact real people.
- Tailor what you share to the audience and/or meeting, setting or topic.

Find common ground

Before participating in a meeting, event or project, take time to review the agenda and purpose. Think about the people who will be there and their roles. Then choose the parts of your story that connect with the topic. By preparing and reflecting ahead of time, your input will be more focused and impactful.

Ask yourself:

- Why does understanding the caregiver experience matter to this group?
- What change do I want them to make? Think big and small.
- How can my story help the listener/reader improve the caregiver/patient experience in their roles?
- What challenges or barriers could they see differently after hearing my experience?

Link your experience to data

“Data makes you credible. Stories make you memorable.” ~ Elizabeth Bailey, Patient Advisor

Caregiver stories put a human face on data. When possible, link your story to related data or statistics. This strengthens your message and shows how your experience is more than one story and represents the wider context.

You might say:

- “This isn’t just my experience. Research shows...”
- “My story is one example of a bigger trend...”
- “This reflects what studies have found about caregiver experiences...”



Chronological order isn't always best. Choose the parts of your story that are relevant to the audience. You don't always have to share your entire story.

Think about your caregiver experience as an iceberg. Identify the parts of your story that are most relevant to the meeting, situation or topic and only share (surface) those parts.

Practice being succinct. Try telling a part of your story in just a few words. For example, here are two stories told in six words: “Waiting for rounds. Some questions answered.”; “Healing paths travel backwards and forwards.”

Use pictures or images when possible. A picture is worth a thousand words.

Tips for delivery:

These approaches will help you feel prepared and more confident, whether you're in a small meeting, speaking to a committee, participating in a large event or writing an email, social media post or for a publication.

Keep in mind - shorter is usually better and easier for people to digest and remember.

Writing Tips

- Start with the most important information so people see your key message first.
- Use attention-grabbing statements to keep people interested.
- Use headings, bullets and/or bold text to make key points stand out for the reader. (This is also helpful for slide presentations).
- Proofread with purpose - good writing is refined by rewriting.

Speaking Tips

- Take a breath before you start. Take your time.
- Use simple, plain language.
- Pause or repeat key points to give the audience time to process what you are saying.
- Use body language, eye contact and tone of voice to engage your audience.
- Ask questions to draw people in.

Prepare and Practice

Share your experience with a friend or family member to help refine different parts of your story.

- Record yourself and listen back.
- Practice out loud in front of a mirror.
- Handwrite your story to help you remember how you want to share it (order and details).

When caregivers share their experiences, they bring understanding, compassion and nuance to important discussions that can impact real change. Your story carries wisdom that no chart or report can capture. Lived experience is expertise. Thank you for adding your expert voice to shape meaningful change.



Consider categorizing your story into parts and create a reference sheet (i.e. a Story Bank) that you can draw from at any time.

Don't know the latest data or trends? Ask the Ontario Caregiver Organization or the group you are collaborating with for data, trends or research that aligns with your story.

Remember, it's your story. You always have the final say on what's shared. You can change your mind at any time, even if you initially said yes.

Trust your instincts. If sharing your experience doesn't feel meaningful or safe, you can pull back. Caregiver stories are complex and it's okay to make last-minute changes.