



## About the Centre:

Support House's **Centre for Innovation in Peer Support** provides wellness based, peer-led self-help and social connections programming to community members; and support to organizations who have peer staff, through training in peer-support program implementation, capacity-building, evaluation, research, knowledge brokerage, and quality improvement.

Growing from its original identity as a Consumer Survivor Initiative in 1999, then known as TEACH (Teach, Empower, Advocate for Community Health), the need for the support and training of agencies providing authentic peer support was identified. As a result, the Centre has evolved to become a "Benchmark of Excellence" in peer support and the meaningful engagement of lived experience and family/caregiver co-design. The Centre for Innovation in Peer Support has been engaging and supporting 11 Mississauga Halton LHIN funded & accredited Health Service Providers (HSPs) plus regional, provincial, national, and international collaborators. The HSPs include hospital psychiatric inpatient units, addictions residential treatment, supportive housing programs, central access, employment support programs, justice, community mental health and addiction providers, and self-help education and support groups.

The Centre's Provincial, Systems & Partner stream is focused on building capacity of People with Lived Experience & Family/Caregivers, People Engaging in Services, Peer Support Workers, Peer Support Supervisors, Health Service Providers, Regional Mental Health & Addiction Systems, and Provincial Healthcare Systems. System transformation is key.

The Centre's Direct Service (Peer Programming) stream offers quality regional programs that are designed, developed, implemented and evaluated by people with lived experience. This stream is focused on both peer-led psychosocial rehabilitative programming plus the Volunteer and Peer Mentor Training & Internship programs. Together, we build community and connection through creating safe spaces to heal and grow for people navigating mental health and substance use/addiction challenges, as well as the supporters/families.

The Centre continues to ensure that the lived experience of people and the values (fidelity) of peer support work are viewed as assets that facilitate the journey of individuals to what they see as health and good quality of life. (Life worth living). With those values and priorities, the Centre continues to champion social and healthcare change that fosters person-directed care to ensure every person will be recognized, appreciated and respected for the unique person they are on their unique journey; and to ensure that care provision is adaptable to the fluctuations in peoples' wellness and needs.

The Centre knows that the roots of equality & inclusivity are found through engaging the people who know ‘what it’s like’, and how that can promote values driven/person directed service delivery, inform quality improvement, co-create service provision, inform policy change, encourage cultural humility and transform organizations and systems.

### **The Centre’s QI Lens, Provincial Footprint and Awards:**

The Centre’s leadership has been trained and coached extensively in quality improvement with the Excellence through Quality Improvement Project (E-QIP) for 2 cohorts. Leadership are also certified in LEADS Healthcare Leadership and are certified in Lean Six Sigma Green Belt. The Centre has been identified as a Promising Practice by Provincial System Support Programs (PSSP) Evidence Exchange Network (EENet) @ Centre for Addiction & Mental Health (CAMH), has co-authored on the 2017 Health Canada-Drug Treatment Funding Programs (DTFP) Performance Measurement in Peer Support, and was featured in the Ontario Excellence through Quality Improvement Report – An inspiring look at Quality Improvement in action.

The Centre has been the recipients of the 2017 Ontario Peer Development Initiative (OPDI) Lighthouse Innovators Award, 2017 Recipients of the Addictions & Mental Health Ontario (AMHO) President’s Shield Award and 2016 Association of General Hospital Psychiatric Services (AGHPS) Summit Award. The Centre partnered with Evidence Exchange Network (EENet) @ Centre for Addiction & Mental Health (CAMH) to identify core elements of peer support programs across different health sectors such as mental health and addictions, diabetes, chronic disease and cancer; positioning this work to support breaking down healthcare silos.

### **About Support House:**

Support House is directed by our core values. They guide our agency’s decisions and actions, unite our staff, define our brand, and inspire our culture. We put people first – our supports are person directed. We connect and engage and start conversations to build and maintain relationships. We focus on health and wellness practices to inspire our culture. All employees are required to adhere to our Oath of conduct tied to our values.

## How to Use This Toolkit

This guide reflects the combined knowledge of leaders from the Centre for Innovation in Peer Support (Centre) and key provincial documents related to lived experience public speaking and lived experience and/or family/caregiver advisory committee participation. It is our hope that you will be able to use this guide to help you build your knowledge capacity and inform your own journey as a lived, living experience and/or family/caregiver advocate within your community.

## To Cite this Document

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## Legal

The views represented herein solely represent the views of the Centre for Innovation in Peer Support. Information in this document should not replace your own research and due diligence. The information used to create this guide draws on the experience of the Centre and public sources, referenced throughout. The materials in this guide are general guidelines only. This guide is not intended to provide legal advice. If there is a discrepancy between this document and any applicable legislation, the legislation will always prevail.

**We would like to thank those involved in creating this document. The determination and dedication to those worked diligently to create systems and frameworks for lived experience voice to be represented across all areas of our health care system with within our communities in both empowering and inspiring. Special acknowledgement to Betty-Lou Kristy, Christina Jabalee, Cheryl Kozell, Alyssa Gremmen, and Richard Adair for assembling this learning toolkit.**

**If you have questions about this resource please contact**

**[centreinfo@supporthouse.ca](mailto:centreinfo@supporthouse.ca) | [www.supporthouse.ca](http://www.supporthouse.ca)**

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There is a growing role for people who have engaged with healthcare services to share their 'stories' (life journeys) to help guide the discussion toward healthcare transformation. This evolution of patient, client, lived & living experience, family, caregiver, resident and citizen voice (expertise) is an essential link in a growing conversation to drive meaningful change.

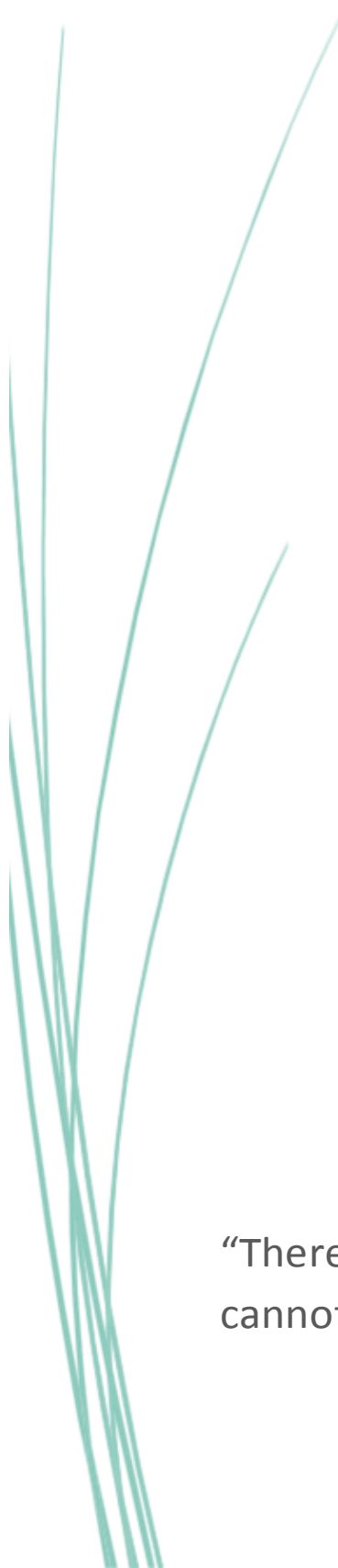
A large piece of this change is well beyond healthcare parameters and more about social change. It is where healthcare intersects with the broader determinants of health and what people need to find their wellness (whatever that looks like for each and every person). There is a need to humanize, to model recovery/wellness and highlight resiliency but also speak to the significant system and service barriers, the unmet needs, and the litany of harms that have resulted due to discrimination and judgement (stigmatized).

Advocacy (giving voice) and Experiential Expertise can have enormous positive impact across the continuum of care by providing a broader perspective grounded in the reality of what truly happens to people (both good and not so good). The nexus of change all throughout history has been those people who can speak up and speak out in meaningful & effective ways.

This guide is a resource to co-create safer space and an opportunity to champion change through sharing your life journey in a way that others can learn. It provides a cultural shift from storytelling to evidence. It ensures the involvement of people with lived experience (patient) and family (caregiver) into all aspects of our evolving healthcare, and the ability to champion social and systems change.

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**\*This resource has been structured to include multiple parameters of engagement that involve sharing your personal lived experience (patient) and/or family (caregiver) experience for public disclosure. There is an emphasis on developing and planning what to share, and how to safely share in ways that are effective and meaningful. Opportunities to engage can look different and one opportunity usually leads to many others (speaking at events, being on a panel, media, narratives, video, writing, blogs, vlogs, research, quality improvement etc). It also involves working with a multitude of different people from different walks of life. It is a skill and a craft. But most of all it is your life.**



“When allowed full and equitable political and social power with meaningful involvement in healthcare governance, policy development, planning, delivery, and evaluation, people with lived & living experience, family members/caregivers and peers can provide unique and relevant context upon which to work with and base decisions on.

The lived experience of people, families and peer support is shaping the cultural shift from ‘storytelling’ to evidence. It provides a road-map to affirmative change”

- Betty-Lou Kristy, Chair Minister’s Patient & Family Advisory Council

“There are many truths of which the full meaning cannot be realized until personal experience has brought it home.”

-John Stuart Mill

## Patient Declaration of Values for Ontario

(LIVED, LIVING AND/OR FAMILY, CAREGIVER EXPERIENCE, RESIDENT AND /OR CITIZEN)

The values important to patients, families and caregivers developed by the Minister's Patient and Family Advisory Council (PFAC). Updated: October 15, 2019. Published: February 19, 2019



### Respect and Dignity

1. We expect that our individual identity, beliefs, history, culture, and ability will be respected in our care.
2. We expect health care providers will introduce themselves and identify their role in our care.
3. We expect that we will be recognized as part of the care team, to be fully informed about our condition, and have the right to make choices in our care.
4. We expect that families and caregivers be treated with respect and seen as valuable contributors to the care team.
5. We expect that our personal health information belongs to us, and that it remain private, respected and protected.

## **Empathy and Compassion**

1. We expect health care providers will act with empathy, kindness, and compassion.
2. We expect individualized care plans that acknowledge our unique physical, mental and emotional needs.
3. We expect that we will be treated in a manner free from stigma and assumptions.
4. We expect health care system providers and leaders will understand that their words, actions, and decisions strongly impact the lives of patients, families and caregivers.

## **Accountability**

1. We expect open and seamless communication about our care.
2. We expect that everyone on our care team will be accountable and supported to carry out their roles and responsibilities effectively.
3. We expect a health care culture that values the experiences of patients, families and caregivers and incorporates this knowledge into policy, planning and decision making.
4. We expect that patient/family experiences and outcomes will drive the accountability of the health care system and those who deliver services, programs, and care within it.
5. We expect that health care providers will act with integrity by acknowledging their abilities, biases and limitations.
6. We expect health care providers to comply with their professional responsibilities and to deliver safe care.

## **Transparency**

1. We expect we will be proactively and meaningfully involved in conversations about our care, considering options for our care, and decisions about our care.
2. We expect our health records will be accurate, complete, available and accessible across the provincial health system at our request.
3. We expect a transparent, clear and fair process to express a complaint, concern, or compliment about our care and that it not impact the quality of the care we receive.

## **Equity and Engagement**

1. We expect equal and fair access to the health care system and services for all regardless of language, place of origin, background, age, gender identity, sexual orientation, ability, marital or family status, education, ethnicity, race, religion, socioeconomic status or location within Ontario.
2. We expect that we will have opportunities to be included in health care policy development and program design at local, regional and provincial levels of the health care system.

*Note: The purpose of this Patient Declaration of Values, drafted by the Minister's Patient and Family Advisory Council in consultation with Ontarians, is to articulate patients' and caregivers' expectations of Ontario's health care system. The Declaration is intended to serve as a compass for the individuals and organizations who are involved in health care and reflects a summary of the principles and values that patients and caregivers say are important to them. The Declaration is not intended to establish, alter or affect any legal rights or obligations, and must be interpreted in a manner that is consistent with applicable law.*

## Peer Support Values

The Centre for Innovation in Peer Support built out our peer support and engagement work from the Mental Health Commission Canada’s Peer Support Values. A foundational base of core values and putting those **values into action**. Through innovative Quality Improvement processes, these actionable (and measurable) values are both the overarching and underpinning of the expectations people can have for the person-directed services/trainings they receive from us; and how we interact with each other.

## The Core Values




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Self-Determination

Hope and Recovery

Health & Wellness

Empathetic & Equal Relationships

Dignity, Respect & Social Inclusion

Integrity, Authenticity, & Trust,

Lifelong Learning & Personal Growth

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(Mental Health Commission Canada–Peer Support Values)

## Support House Values

Support House's Centre for Innovation in Peer Support became "Change Champions" for Support House continuing to build out the values throughout our organization.

**diversity**  
**integrity**  
**respect**  
**quality improvement**  
**advocacy**  
**collaboration**  
**self-determination**  
**effective communication**  
**lifelong learning**  
**mutual trusting relationships**  
**accountability**  
**safety**  
**personal growth**  
**hope**  
**equity**  
**accessibility**  
**inclusivity**  
**belonging**  
**innovation**

## Notes about language.

### Lived Experience

When referring to lived experience we are intending to be inclusive of a broader scope of descriptors that people often use such as patient, family, caregiver, resident, citizen, community member etc. It references someone who has direct personal experience with the specific subject matter (E.g. When looking at caregiver supports someone with lived experience would be someone who supports a loved one who struggles with mental health concerns. When looking at direct service to people who use substances that would be someone with lived experience who has, or has had, their own substance use concerns.

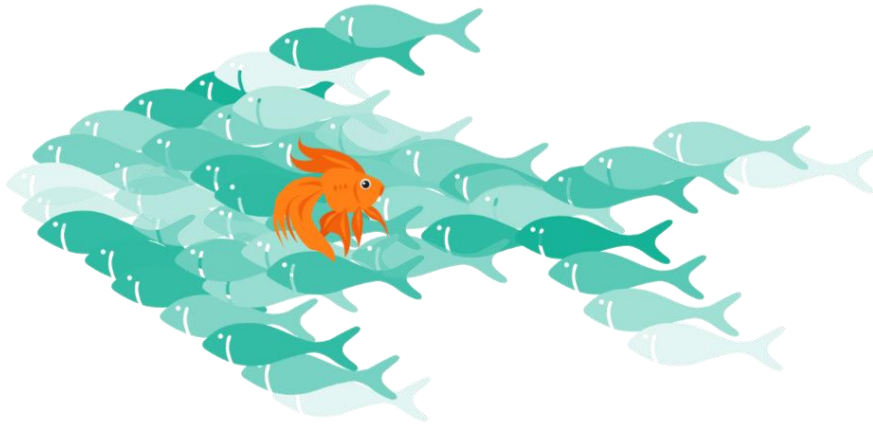
### Recovery

Recovery is, a term that is recognized but not a term universally used to by each person to describe their personal experience. Many people see recovery as a way of holistically negotiating one's life to live the life they want. However, it has been discovered through interaction with people with lived & living experience (patients), that recovery can often be mistakenly interpreted as being a destination or being something you must get back to instead of just evolving as a person. It can also be used to restrict parameters or define what someone's journey should look like. The word recovery is used in this guide because it is a "philosophy" that is helping to guide healthcare policy and care provision away from medical/clinical to an expanded view of what people holistically need. Recovery is a journey that can have fluctuations. Recovery is self-defined wellness, health and good quality of life. (Life worth living). This self-defined wellness may still include the use of substances, or experiences of mental illness.

### Stigma

Although the word stigma is used in this guide because it is a recognizable concept, there is a growing recognition that stigma is a word that has distracted people from what it really means. Stigma means prejudice, stereotypes and discrimination. The anti-stigma campaigns do not seem to be moving society's barometer in any meaningful sustained way to create a paradigm shift of two necessary actions; 1. Genuine care for others, 2. Not judging others. We need to re-direct. **Simply and yet boldly, talk about what it "is"**. Informing and sharing so society better understands people's perspectives on their experiences. This is the number one way to reduce "stigma," by gathering a true understanding of the lived experience of someone. Prejudice and discrimination contribute to the destruction of life; create barriers to care and are culpable in many deaths. They are inherently dangerous to any vulnerable demographic because they are misperceptions that breed harassment, abuse, violence and dismiss the human rights and choices of those affected. Stigma and the stereotypes, prejudice and discrimination that creates an innate ability to de-humanize people.

## Guiding Principles in the Development of this Resource



“Every person will be recognized, appreciated and respected for the unique person they are on their unique journey”

### Inclusivity

All recovery (wellness) paths are respected. Every person is unique and therefore will have discovered what works for them. Those choices can appear to be in conflict between different treatment/recovery options & philosophies. This resource nurtures acceptance and recognizes that people can and will work together to embrace a common goal of not judging each other which includes each other’s choices, understandings and experiences.

### Trauma Informed

It is imperative to create safe space for all. Too many graphic details of traumatic experiences can re- create trauma responses in yourself and others. There is a safe way to express what has happened in your lives without minimizing what is important for you to share. Ensuring that all people are not retriggered is integral in the development of this resource and follow up training.

## Reflection and Reflexivity

**Reflection** can enable people to learn from experience about themselves, their work, and the way they relate to home and work, significant others and wider society and culture.

With a **Reflexive** lens we utilize our ‘reflections’ to begin a process of change, action or enhancement to either understanding ourselves or others. It gives strategies to bring things out into the open, and frame appropriate and searching questions never asked before.

It can provide relatively safe and confidential ways to explore and express experiences otherwise difficult to communicate. It challenges assumptions, ideological illusions, damaging social and cultural biases, inequalities, and questions personal behaviours which perhaps silence the voices of others or otherwise marginalize them.- (Reflexive Practice: Writing and Professional Development, Gillie Bolton, 2010)

At the same time we also believe in people’s ability to be aware of what affects them and to do what they need to do for themselves when they have been emotional impacted by content. It is not possible to always know what will affect someone. However, we can avoid common triggers such as graphic details and poor language choices.

Questioning the  
relationship between  
ourselves and others: how  
we see the world, our  
assumptions/what we  
take for granted and the  
impact, our responsibility  
for ‘constructing’  
life/self/social” – Cunliffe 2009

“Never forget that you are one of a kind. Never forget that if there weren’t any need for you in all your uniqueness to be on this earth, you wouldn’t be here in the first place. And never forget, no matter how overwhelming life’s challenges and problems seem to be, that one person can make a difference in the world. In fact, it is always because of one person that all the changes that matter in the world come about. So be that one person.”

—Richard Buckminster Fuller

## Sharing Your Life Journey (Story)

No one can tell your life journey so tell it yourself. No one can write your life journey so write it yourself.



“Trying to capture the complexity of our life journeys (stories) and the impact of systemic failures, lack of early interventions, stigma, family cycles and breakdown, loss of hope-dignity and the punitive nature of failed outcomes is hard to describe when one’s intention is to provide evidence and not judgement.

The one unique way that people with lived experience and family members can bring life to evidence and indeed empower its impact – is to capture the emotion, the pain, the fight to survive, the love that wasn’t enough, while also showcasing the resiliency, strength and the ability of the human spirit to get up over and over and over again.

When one is sharing their life journey (story) for public disclosure, it is important to share in a way that expresses what happened but also the feeling, so that the intended audience can actually recognize how something must have felt. The complex part? Expressing feeling in a way that’s professional and thorough enough to break through all the politics, differing philosophies, bias, sensitivities, and territorial issues.

Somehow, the ‘voice’ has to quickly try and leverage the common ground in any given situation. The ‘voice’ has to be neutral but not waning. The ‘voice’ has to be inclusive, yet have the ability to differentiate. The ‘voice’ has to break through stigma but not be viewed as a threat. The ‘voice’ has to communicate things that people do not want to hear and do it in a way that makes people grateful they heard it”.

- Evidence Exchange Network, Excerpt 2012: Bringing it Home Blog Series, Betty-Lou Kristy

## Why Speak & Advocate Publically About Your Experiences?

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**“Because you can champion social and healthcare change that fosters person-directed care to ensure every person will be recognized, appreciated and respected for the unique person they are on their unique journey; and to ensure that care provision is adaptable to the fluctuations in peoples’ wellness and needs. The roots of equality & inclusivity are found through engaging the people who know ‘what it’s like’, and how that can promote values driven/person directed service delivery, inform quality improvement, co-create service provision, inform policy change, encourage cultural humility and transform organizations and systems”**

Centre for Innovation in Peer Support, Support House

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People who have lived through an experience know it better than anyone else, can speak more passionately about it and can be in a better position to change others’ attitudes about it. Your life experiences, from childhood to the present, show that anyone can struggle & develop health issues. You know best when your “situation” started, how they got worse and what helped you move toward wellness. Talking about these experiences helps others by educating them, helping them avoid developing problems of their own or, for those experiencing difficulties, increasing their ability to reduce the harms and/or desire to seek support. Helps others by providing other options or solutions, and choices to their situation that may lead to a better quality of life. It is also valuable information for the health care system we all access for support. Your experiences, trials and tribulations can help shape a health care system that is free from stigma and discrimination and may help others from falling through the same cracks and gaps in the health care system that you did.

If you want to share your experiences with others or working in an advisory role position and are ready to do so, you will find that your willingness to give brings you many positives in return. Below is a list of some of the benefits you can expect to receive from making presentations.

**Healing:** When you reach a point in your self-defined wellness that you feel you have accomplished the things you want and feel good about where you are at and feel able to share your experiences in a way that can be helpful to others can help in your recovery.

**Education:** You are educating others while learning at the same time.

**Empowerment:** You continue to confirm that your life is heading where you want it to, that you are in control and that others want to learn from your experiences. Knowing that you continue to change in positive ways is empowering, and so is knowing that your story will benefit others.

**Personal growth:** Every time you share your experiences you will come away with new insights about yourself.

**Dignity:** Knowing that you are helping others brings a sense of dignity within yourself. Knowing that others may view you as representing a group of people (for example, youth, and Indigenous people) can bring a sense of dignity to the group.

**Respect:** You feel genuine appreciation from the audience and health care system for sharing your experience and you respect the audience and health care system partners' engagement regardless of their understanding.

**Self-esteem:** Sharing can bring balance to your life. You may feel you have created negative experiences for yourself and others in the past. Knowing that you can help others brings value to these experiences and helps you see value in yourself.

**Reduced shame:** The more you speak about some of the more difficult aspects of your life, the more you will be able to accept them and learn from them. This can be an opportunity to re-evaluate the experiences you've had and to reconsider your negative impressions about yourself.

**Opportunities:** Through speaking and advising you are informing others, you develop a network of contacts and develop skills that you can use in other areas of your life.

**Affirmation:** Audiences and health system partners give you positive feedback. For example, they may tell you how hearing you talk about your experiences has helped them. It also opens the doors for systemic change in the health care system. This encouragement helps you feel gratitude, appreciation, and that your efforts are making a difference.



Sharing your experiences as a public speaker and advisor contributes to building essential skills needed for lifelong learning, securing and sustaining self-defined wellness, elevating conversations, and showcasing reality and resilience. It also allows you the opportunity to turn your experiences into tangible change as you can provide insight into aspects of the health care system that no one else can. When trained and mentored to provide this personal expertise (experiential knowledge) many doors can open. Often dignity is restored, perspective is found, and a pathway is provided to help others negotiate what is needed and what needs to change.

### A platform for Advocacy

Advocacy is an individual’s ability and right to speak up for the things they feel are important to them and for their loved ones. This “speaking up” could be in the form of a formal speaking engagement in front of an audience or it could be in the boardroom of a health care partner as a lived experience and/or family/caregiver advisory committee member. Regardless of which platform you choose to pursue there are 2 keys areas of advocacy that you should take into consideration as you move forward as a health care advocate.

<p><b>Self-Advocacy</b></p> <p>Knowing what your rights and responsibilities are and being comfortable enough to speak up for yourself when these rights are being violated</p>	<p><b>System Advocacy</b></p> <p>Opportunity to assist in the development of strategic priorities, legislation, new programing with health service providers and the health care sector.</p>
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## Addressing Stigma

Although the word stigma is used in this guide because it is a recognizable concept, there is a growing acknowledgement that stigma is actually discrimination, prejudice, stereotyping and bias. “Stigma” contributes to the destruction of life; create barriers to care and is culpable in many deaths.



Stigma refers to negative attitudes (prejudice) and negative behaviours (discrimination) toward people based on a characteristic that others see as negative.

You have probably experienced prejudice and discrimination as you struggled, and on your journey to wellness (recovery). You may have experienced negative reactions from individuals and in health care, housing, social services or other settings. And you may have experienced additional prejudice and discrimination because of your age, gender, sexual orientation, religion or some other personal characteristic.

This may have been really heightened for you if you struggled with substance use/addiction, mental health, HIV/Aids etc. Depending on your wellness pathway (example Methadone), you have likely experienced prejudice and discrimination about that too. You may also have internalized other people’s attitudes and think negatively about yourself.

It's important to address stigma when you're making a presentation or serving on an advisory committee, because prejudice and discrimination toward people are major reasons why people do not seek treatment – and they are barriers for people who do seek help. There are also stereotypes about who develops problems; stories like yours show that *anyone* can.

You should address this topic directly and also sprinkle insights and suggestions throughout your presentation and in your advisement role.



“Both my late son and I struggled with substance use and mental health issues. Pete died Dec 23 2001, at age 25, from an accidental opioid overdose. That is how he ‘technically’ died but in fact he died from a loss of hope and the pervasive feeling that the world did not care about him. That he was an addict. That it was his fault. No matter what I did, I could not love my son back to wellness or restore his dignity. In large part because I did not have any self-worth myself- that had been stripped from me too- an indelible stain left over from when I too was considered a useless addict. We, at separate times in our journeys, were blamed, shamed and dismissed as drug using misfits who “choose that lifestyle”.

Pete and I were both irrevocably harmed by so many layers of stigma at so many intersections of our collective journeys. Both my late son and I struggled with severe & complex mental health issues and the self-medicating of those unresolved issues. But somehow the most prevalent label that we received from the professional world and society was ALCOHOLIC & DRUG ADDICT and that label caused us to be condemned”

- Betty-Lou Kristy



“Until I was aware of the impact of stigma on my mental health, and learned to advocate for myself, I was unable to heal. It is vital that I now take that wisdom and share with the community so change can happen” - Cheryl

Parts of this section have been adapted (with permission) from “Strengthening Your Voice” (SYV)- A public speaking guide for people with lived experience of problems with prescription opioids; which was created by the Centre for Addiction and Mental Health’s (CAMH) Knowledge and Innovation Support Unit. CAMH followed an impeccable process and thorough engagement with lived experience, families and other expertise in the development over many years. The PFAC Chair, Betty-Lou Kristy was involved in co-creating that body of work from inception to completion.

## Speaking Publically

### Are you ready to share your story?

You may be thinking about sharing your experiences with others, but don’t know if it’s the right thing for you or the right time. This section will help you decide. You may also wish to discuss the idea of sharing your experience with your counsellor or other support person.

### SIGNS THAT YOU ARE READY

**You are in recovery (self-defined wellness).** You have moved beyond the impact of the illness in your life and are focused on developing new purpose, meaning and a plan to stay well.

**You are passionate.** You want to share your message so others can avoid the things that caused you problems.

**You can articulate your story.** You feel ready to talk about your experiences.

**You are reflective.** You habitually ask yourself how you’re feeling. You are in a good place emotionally and question your own biases and assumptions.

**You take the initiative.** You are ready to approach your support worker, an event planner, or a health care system partner and indicate you want to speak or volunteer for an advisement role within a health care organization.

**You are confident about yourself.** You feel comfortable preparing and sharing your story. You know that it’s natural to be a bit nervous.

**You want to heal.** And you want to move on.

**You are resilient.** You are able to “bounce back” from difficulties or challenges

**You are motivated.** You have heard others speak publically or in relation to their advisement efforts and you want to do the same thing.

**You stay connected.** Even though you’ve been on a good path for a while, you keep in touch with those who support you.

## SIGNS THAT YOU ARE NOT READY

**You have a lot of anger.** You feel angry about what you've gone through, about the system or about yourself. Maybe you blame others for what happened to you.

**You feel extreme or negative emotions.** Your wellness may be disturbed by the topic you plan to share.

**You are easily triggered** into cravings or emotional reactions.

**You have not been in “recovery (self-defined wellness)” for long.** You do not feel grounded or have a sense of stability.

## DO YOU HAVE SUPPORT?

If you make presentations about your experiences or you serve in a role as a lived, living or family/caregiver experience advisor (patient and/or family) you will find it best to have one or more people supporting you along the way. This may include professional or personal support person, who:

- will help you look at your life holistically to determine how safe you feel to stand up and talk about your experiences at a health care systems table or publically ( For example, how comfortable do you feel talking about the underlying issues that led up to your problems? Do you feel you can talk about your experiences without getting too emotional or feeling out of control)?
- will guide and advise you as you develop your lived experience story and your values as an mental health & addictions advocate
- can help you decide how much of your story to disclose publically and what's parts of your story fit into a role as an lived experience and/or family/caregiver advisor and advocate
- can help you recognize your triggers and how to manage them
- will offer encouragement
- are likely to know if speaking opportunities arise or where to find opportunities to participate in being a change agent within the health care system.

However, if you are doing well, have a stable life, are comfortable where you are in your own wellness, and are motivated to speak publicly or share about your experiences for the purpose of system transformation, you might choose to seek out these engagements and opportunities on your own.

Having family and friends to support you and to run ideas past may be all that you need.

## Developing your lived experience story for public discourse

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As you develop your story, you will want to keep in mind a number of things, such as who the audience is, what the topic is and how much time you are given to speak.

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### WHAT YOU BRING TO THE AUDIENCE

It is important that the people who ask you to speak let you know who the audience will be. You will want to adjust your presentation based on the type of audience you are speaking to. You can give the same message in different ways: you might emphasize different things, or vary the softness or directness of your message, or use different words. **Give a message of hope to every audience.**

You will likely speak to a variety of audiences. They could include youth, parents, health care workers, people currently struggling with a health issue, and many others. Following are examples of how specific types of audience members may benefit from hearing about your experiences:

#### General public

When you speak to a general audience, you are speaking to people from different backgrounds and experiences. Each person has come to hear your story for a different reason. Each can learn and later apply the knowledge you present. Some people in a general audience will be there because a family member or friend is struggling with an issue or may have lost someone. They may be emotionally fragile and may lack the tools or connections to seek help for their family member or themselves. Your successes and message of hope may help them move forward.

## Health care workers

Healthcare workers, such as physicians and social workers, are in the field of helping people. They will have heard stories like yours before. It's OK to tell them about the emotions you've felt. Share with this audience any failures or gaps you have experienced in the system. Let them know how they can help you and others by changing things that have been unnecessarily difficult. Suggest potential solutions if you can. However, always keep in mind that all workers can have their own personal or family experience too, so always relate on a human level, regardless of profession. Everyone wears different hats.

Health care workers may have difficulty tracking the outcomes of their many clients. Listening to your particular story and your positive outcome gives them job satisfaction and empowers them to make changes where necessary. They may give hope to their clients by sharing your story.

## Youth

Youth audiences respond best when you talk from the heart and in language they can understand. They are especially interested in hearing about your lived experiences. Talk about hope and what people have done to help you.

## Parents/Caregivers

Parents will be listening with their children in mind. It's best to stick to the facts and leave out some of the rougher moments. Avoid saying things that may scare parents. Be honest in what you say, but be careful. As with other audiences, talk about hope and what people have done that helped you.

## People who are currently struggling

Your story can be empowering to people who are currently struggling with the same issue that you are sharing. You will be talking in the past tense to people who are looking for positive messages to help them or a family member move into recovery. Your comments may help them avoid some of the "mistakes" you feel you have made. Your comments may help them navigate the health care and other systems more effectively. You may be a role model for how they want to be, and your story may give them hope. They will know they are not alone.

You can be more yourself with this type of audience. However, just as you are careful not to talk about things that may trigger you, consider too what things might trigger people in the audience and leave out certain details as you tell your story.

## WHAT IS THE TOPIC?

When a support worker or organization asks you to speak at an event, make sure they are clear about the topic they want you to speak about. This could include letting you know the overall topics as well as some key messages they hope you will focus on. **It is up to you to decide which parts you want to share.**

## WHAT TO INCLUDE

What to include and how much to include in your presentation will depend on the topic and on whether you are the only speaker or part of a panel. You want to be able to provide a “resilience story” a story of your wellness journey (see information sheet 4 for more info.) Audiences will connect with your human story. Share with them some details about the beginning and middle parts of your life and where you are today. Depending on the amount of time you have and how relevant you think it is, you might include information about:

- your childhood
- your family
- your education
- your career
- your relationships
- why and when you began to develop problems
- what your life was like when you were unwell/struggling
- what helped you
- interactions with support workers
- complications and barriers to your care
- how you feel the system helped and how it could have helped you better
- what helped you improve your situation or recover
- what you might have done differently if you could do it over again
- any interactions with the justice system
- how your life is now
- comments that you hope will inspire and give hope to others.

## **SPEAKING SOLO OR ON A PANEL**

You will speak solo or as part of a panel, and will usually be told how long you have to speak. Someone will introduce you.

### **Speaking Solo**

If you're the only speaker, you will likely be given a certain amount of time to speak and answer questions. Know that audiences often have a hard time concentrating for a long time so you might want to keep your presentation limited to 30 minutes and then answer questions. (Q&A can help people get a deeper understanding of your messages, it can also help you to incorporate information into future sessions and can be a fun and interactive way of sharing your experiences and knowledge). There is advice later in the manual for types of questions you need to be prepared for. It is YOUR choice whether you answer a question or not.

### **Speaking on a Panel**

If you're part of a panel, each panelist will likely be given about 15 minutes to speak, with everyone having an opportunity to answer questions at the end. There are more dynamics at play in a panel situation. For example, you may feel uncomfortable if you perceive others on the panel (such as physicians or police) are in positions of power. Or someone speaking ahead of you might say something that triggers you. If that happens, you'll need to draw on your self-care practice to manage your response. On the positive side, panel members can provide support to you before, during and after the presentation.

## **USING MIXED MEDIA**

People learn in different ways. Using a variety of approaches in your presentation increases your ability to make a connection with everyone in the audience. If you are new to speaking in public, you may find it enough to focus on what you're going to say and getting that across to the audience. But with time and experience, you may feel comfortable adding other media to enhance your presentation, such as PowerPoint, films and interactive exercises.

Using mixed media can take pressure off you as a speaker as you let the media speak for you. It can also help you feel that your presentation is more polished.

Whether you use mixed media or not, each time you present it gets easier.

## EXPERIENCING TRIGGERS AS YOU DEVELOP YOUR STORY

The process of writing out and preparing your presentation will bring back memories and may bring out triggers. A trigger is something that causes a craving or an emotional reaction. For example, watching a friend take pain medication may trigger a craving in you for the medication. Or being in a place similar to one where you experienced abuse may trigger an emotional reaction such as fear.

Writing out your story before you present it gives you the chance to work through your triggers and emotions ahead of time. Otherwise, you risk having them surface while you're speaking. If you know what will trigger you, you can leave those things out of your presentation. (If you *are* triggered during your presentation, take a moment, have a sip of water, ground yourself and then continue.)

When you are ready to share your story, you will be aware of your triggers and will have a plan for how to take care of them. When you are developing your story, use that plan as needed. As you get more comfortable with sharing your life journey and managing your triggers, you can change some of what you talk about in your presentation.

Having triggers and emotions arise, and working through them, can be a healing opportunity. However, if you find that they are overwhelming and have negative consequences for you, this could be a sign that you are not emotionally ready to share your experiences with others.

## YOUR PRESENTATION STYLE

There are various ways to present your story. Some people, especially if they are new to public speaking, feel most comfortable writing out their story and reading it to the audience. Others are comfortable writing down bullet points to remind them of the topics they want to address. And others, especially once they've done public speaking for a while, are comfortable speaking without any notes.

Choose the style that works best for you. You will likely find that your presentation style changes over time or depending on the audience.

## What makes a good public speaker?

Several things will contribute to your success as a public speaker – and they will come more naturally to you as you make more presentations. You are selling yourself as much as you are selling your message.



**Show self-confidence** – even if you’re feeling unsure of yourself.

**Be prepared.** Know what you are going to say and the messages you want to get across to the audience.

**Be aware of the language you use** when speaking with different audiences. If you’re speaking with youth, for example, speak in language that they can relate to. If you’re speaking with health care workers, use language that will get their attention. Whatever you say, be natural – and avoid using slang or jargon if you’re unfamiliar with it.

**Know how to relate** to different types of audiences.

**Be engaging.** Act like you want to be there. Having an open and honest demeanor, smiling and making eye contact help you connect with the audience.

**Build trust with the audience.** Speak from a place of truth and integrity. Show that what you say is who you are and how you live your life.

**Connect with the audience.** Bring the audience into your story. For example, start with what your early life was like. Then talk about what changed and how it felt (this could involve several stages or events). Mention how you developed problems. Then discuss why and how you changed. End with comments about how your life is getting better.

**Be positive.** Talk about the strengths you've gained from your experiences. If you criticize the system, do so in a way that leaves the audience with suggestions for change and feelings of hope.

**Show that you have a sense of humour.**

**Demonstrate that you have compassion** for yourself and others. This will help others learn from your experiences.

**Appear clean, tidy and presentable.** You want people to focus on your message and not on how you look.

### Developing presentation skills

How you give your presentation is as important as what you say. You want to make a connection with the audience so they listen to your story, feel your emotion and learn. Here are some suggestions to engage your audience.

**Practice your story.** This builds memory for your story and helps you deliver it. Know the order of what you want to say – and say it with some emotion. You can practice on your own or in front of people you know and trust.

**Be a bit nervous.** This keeps you alert.

**Hide signs of nervousness that you think might be observed by the audience.**

For example:

If your hands shake, don't hold anything in them.

If your legs shake, wear looser pants or skirt.

If you perspire, wear looser, darker clothes.

**If you feel anxious, take a deep breath and continue.** You can be honest with the audience and tell them you're taking a deep breath because you're nervous or emotional. Do not apologize: you have a right to the way you're feeling in that moment. You can also move around and gesture with your hands to help you expend some of your nervous energy and calm you down. You could also do this before you get up to speak.

**Bring some notes.** Even if you don't use them, notes are a safety net: they're there for you to refer to if needed.

**Show enthusiasm.**

**Be natural with your movements.** Embrace your own movement and style. For example, if you tend to talk with your hands, continue to do so. If you don't talk with your hands, don't start. Avoid standing with your arms crossed in front of your chest or your hands behind your back.

**Make eye contact.** Eye contact engages the audience. Find a friendly face in the audience: you will find empathy in people's eyes and that will keep you grounded. Look at different areas of the room, not at just one or two people.

If you're feeling nervous, you could avoid eye contact until you're feeling more comfortable. In some cultures, such as Aboriginal cultures, making eye contact is considered disrespectful; in that case, you could look just above people's heads. Talking to organizers about cultural practices can be important.

**Think about how you're going to use your voice.** Project your voice into the room: some people have voices that naturally carry while others have to work at it.

**Pause to collect your thoughts if you need to.** It is OK to take a short break, have a sip of water and compose yourself.

**Dress for success.** Appear clean, neat and presentable. Think about who the audience is and what you want to get across to them. Be yourself, but dress in ways that keep the audience focused on your story and not on your appearance.

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**To get your message across clearly, speak slower than you normally would. You might naturally speed up because you're nervous. Remember to slow down and breathe. If you have notes, you could write the words "space" or "breathe" at appropriate points to remind you.**

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## Managing audience questions and reactions

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**Each presentation should include an audience question-and-answer session. If you are new to public speaking, you may find these sessions challenging or even triggering. With time, you may come to enjoy and even prefer the question-and-answer part of the program.**

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### **When you are asked a question, keep in mind the following tips.**

**Take your time.** It's OK to collect your thoughts before responding. You might pause, take a deep breath, repeat the question or say, "That's a good question" to gain some time before answering.

**Keep your answers short.** You won't necessarily know the intent of someone's question. So you don't want to give a five-minute answer and then be told that what you said is not what the questioner wanted to know. Instead, respond with three or four sentences and then leave space for the questioner to clarify his or her question if necessary. It's better to have three short exchanges between you and the questioner than to give a longer response that did not answer the intended question.

**If you are asked a question you don't know the answer to, say so.** It is OK not to know. Never "fake it till you make it" because that will take away from your authenticity and the trust you are building. You are there because you are an expert on your own experience. You could also defer the question to someone else on a panel whom you think has the expertise to answer the question. Or, if a support worker is with you, that person might answer the question.

**If you are asked a question you don't want to answer, say so as politely as possible.** (E.g. "I do not share that part of my journey but thank you for wanting to know"). If you know before you speak that there are questions you don't want to answer, tell the moderators so they can direct the questions to someone else. If a question makes you feel flustered or attacked, ask for the moderators' assistance. If someone asks you a question you do not know the answer to, you can refer to another person on the panel or simply say "I do not know the answer to that question, or I do not know enough about that topic to share my opinion"

## Taking care of yourself

Strengthening your inner resources will enhance your success. You can increase your well-being by introducing several of the following strategies into your life. These strategies will help keep you centered and grounded, with a more positive state of mind.

**Find balance in whatever you do.** For example, add exercise to your schedule every other day – rather than not exercising at all or feeling you have to exercise every day.

**Develop stress management techniques that work for you.** We all have stress in our lives. What matters is how we respond to it. Choose positive coping skills rather than negative ones.

**Be assertive.** Ask for what you want and need, and say no to things that you think may decrease your well-being.

**Have a support network.** This could include a support worker, family and friends. Spend time with people you like and trust.

**Establish healthy, daily personal wellness routines.**

**Practice relaxation techniques.** These techniques help you to maintain calm and balance and to respond to situations rather than overreacting to them.

**\*See checklists and resources in the appendix section of this guide**

\*Patient & Family Advisory Councils (PFACs)

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## Lived Experience and/or Family/Caregiver Advocacy

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**As you plan to move forward into a lived experience advocate role, you will want to begin to build your knowledge base around the health care system in which your efforts are aimed at influencing. Building a knowledge base about your role as an advisor and the expectation of that role will enable you to be successful as a health care system partner and co-collaborator.**

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### What is a Lived Experience and/or Family/Caregiver Advisory Committee?

A Lived Experience (Patient) and/or Family (Caregiver) Advisory Committee is an intentional committee that has been created by a health care organizations or government body to reflect the input, experience and skills sets of individuals receiving's services within the health care sector. \* They are more commonly referred to as Patient & Family Advisory Councils (PFACs) where that language fits.

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As a person with lived experience and/or family/caregiver, you get the opportunity to be in a partnership with Health Care system and you are instrumental in effecting change to improve overall health outcomes for all individuals accessing health services within your community.

You do not have to be a professional health care worker or a politician to assume an advisory role position as a change agent in health care reform. Your lived experience as a person receiving services or a family/caregiver is your most valuable asset, you have earned it and can provide insights into the health care system in a way that someone working as a health care profession or in a political role may not.

The next few pages will give you a framework for understanding your role as a lived experience and/or family/caregiver advisor, and provide some key areas of advisory committee functions you might want to understand and consider as you take your unique experiences and stories to the table as a lived experience and/or family/caregiver health care advisor and systems partner.

# What are the Different Levels of Advisory Engagement?

## Ontario's Patient Engagement Framework

### THE STRATEGIC GOAL

A strong culture of patient, caregiver and public engagement to support high quality health care

### THE GUIDING PRINCIPLES

Partnership

Learning

Empowerment

Transparency

Responsiveness

Respect

### ACROSS THESE DOMAINS

Personal care and health decisions

Program and service design

Policy, strategy and governance

### ACROSS A SPECTRUM OF ENGAGEMENT APPROACHES

Share



Provide easy-to-understand health information

Consult



Get feedback on a health issue (e.g., policy or decision)

Deliberate



Discuss an issue and explore solutions

Collaborate



Partner to address an issue and apply solutions

### ENABLED BY:

A culture of continuous quality improvement

Access to easy-to-understand health information

Commitment to health equity and cultural competence

Rigorous research and evaluation

Image retrieved from <https://www.hqontario.ca/Portals/0/documents/pe/ontario-patient-engagementframeworken.pdf>

In 2016 Health Quality Ontario, which is now a part of Ontario Health released the “Ontario Patient Engagement Framework” to provide assistance and direction to the health care system in Ontario for engagement relationships between health care providers and individuals and caregivers receiving supports from the health care system. Participating on an advisory committee regardless of where you are should reflect the themes and values identified in this framework. (Health Quality Ontario, 2017)

Engagement work should have a strategic goal and be grounded in the 6 guiding principles of engagement. It should also encompass the “Patients Declaration of Values” and should identify what domains the work and advisory committee will engage in. As an advisor, you should have a clear understanding around which spectrum of engagement approach is being utilized.

For more information and to review the “Ontario Patient Engagement Framework” please visit:

<https://www.hqontario.ca/Portals/0/documents/pe/ontario-patient-engagement-framework-en.pdf>

The level of engagement in which you participate and the amount of influence you have on the health care system will depend largely on the overall commitment of the organization or government body’s expectations for the advisory work you will be engaged in. A strong commitment to creating pathways of communication and shared power from the organization or government body is critical if the work you are about to engage in will have any lasting impact of the health care transformation project you are advising on.

## Lived Experience and/or Family/Caregiver Advisory Role & Expectations

These are a few key areas to consider when you assume the role of a lived experience and/or family advisor.

### You can expect to;

- Collaborate in shaping programs, services and initiatives using your unique experiences as someone who openly identifies as a person with lived experience.
- Be counted on and sought after to represent and provide the perspective for the experiences and needs of other service users and family caregivers as a result of active engagement as an advisory committee.
- Participate as a Partner in collaboration and co-creation for improvements to existing programs and new services with Ontario Health Teams, health care professionals, policymakers and community health care service providers.
- Empower other individuals with lived experience to engage in sharing their voice at local, regional and province platforms and be a change agent in challenging the damaging stigmas around mental health and addictions within your community.

### You can also expect to;

- Be treated with dignity and respect by health care professionals and your fellow advisory committee members.
- In Ontario, to have the necessary supports in place that you require to perform your roles to the best of your ability as per compliance with Accessibility for Ontarians with Disabilities Act, 2005 (AODA). (Government of Ontario, 2021)
- To be provided fair compensation for your time and involvement with any and all advisory committee duties as requested by the health care organization or system you are working in.
- Have written policies and procedure for committee functions, pathways for communication with leadership and clear role definitions from the onset of committee engagement in committee meetings.
- A right to ask questions, seek clarification and fully comprehend what the expectations are in your role as an advisor and the functions of the advisory committee.

## Core Lived Experience and/or Family/Caregiver Advisor Competencies;

- Cultural effectiveness
- Teamwork; collaboration
- Empathy
- Commitment
- Resiliency; adaptability
- Integrity
- Critical thinking
- Problem-solving
- Sound judgement
- Ability to present information in a clear manner
- Communications-written/verbal/facilitation
- Embraces inclusion and tolerance to ambiguity

## 6 Habits of Highly Effective Advisors

Below are some tips and things to consider when serving in an advisement role on a lived experience advisory committee. These insights have been borrowed from a Health Quality Ontario (2018) presentation and was co-created by HQO Patient & Caregiver Advisors and members of HQO Patient & Caregiver Resource Development Advisory Group co-chaired by Betty-Lou Kristy. Betty-Lou Kristy was also one of the co-facilitators of this training. As you have expectations, there is also expectations that will be placed on you as a lived experience leader in an advisement role.

Listed below are the 6 habits of highly effective advisors. These habits and tips will enable you to enter into your role and be successful as a lived experience advocate.

### 1. Take a professional approach to your advisory work

- Practice good meeting etiquette
- Respect confidentiality
- Be inclusive & sensitive to others
- Be adaptable to change
- Arrive prepared

### 2. Keep calm and conduct yourself in an appropriate manner

- Practice respectful assertiveness
- Be willing to compromise
- Support differences of opinion
- Be mindful of your emotions
- Remember collective collaboration

### **3. Aim to communicate in a strategic way**

- Prepare before a meeting
- Think before you speak
- Do not monopolized the meeting
- Practice actively listening
- Take your own notes during meeting

### **4. Move beyond your own story**

- We all have different experiences and that is okay
- Connect to perspectives that are not your own
- The decisions you make will have future impacts
- Be inclusive, empathetic and non-judgmental
- Remember that we are not experts

### **5. Get into the Organizations head**

- Understand the organization's goals & priorities
- Don't be afraid to ask questions
- Educate yourself on the health care system
- Be aware of the diversity of the population served
- Understand your roll within the organization

### **6. Build lasting relationships with others**

- Remember everyone is here for a shared purpose
- Build allies not enemies
- Support each other, we are all learning together
- Expand your connections

(Health Quality Ontario, & Health Quality Ontario PFAC, 2019, p. 14-20)



## APPENDIX 1

# INFORMATION SHEETS

This section includes tips and information for speakers. Most are formatted to fit onto a single page so that you can print them out and refer to them as needed.

- 1. Potential gains and risks of sharing your story for advisement & public disclosure\***
- 2. Public Speaking Tips\***
- 3. The Power of Language**
- 4. Sharing Your Journey – Responsible Public Sharing & Speaking**

\*These information sheets have been used/adapted (with permission) from “Strengthening Your Voice” (SYV)- A public speaking guide for people with lived experience of problems with prescription opioids; which was created by the Centre for Addiction and Mental Health’s (CAMH) Knowledge and Innovation Support Unit.

## INFORMATION SHEET 1: POTENTIAL GAINS AND RISKS OF SHARING YOUR STORY FOR ADVISEMENT & PUBLIC DISCLOSURE

### GAINS

- You feel empowered.
- You experience personal growth.
- You feel respected.
- Your self-esteem goes up.
- You share your accomplishments.
- You help others.
- You give a human face to a story that could happen to anyone.
- You raise awareness of stigma (prejudice and discrimination) and its negative side effects. You may also reduce some of the negative attitudes and behaviours in your audience and within the health care system.
- You see your story in a new light. You gain a better understanding of where you were and how your recovery is progressing.
- You learn new skills that can also be used in other areas of your life.
- You show others (for example, health care professionals, people with experiences similar to your own) that there is hope and that people can find wellness.
- You reaffirm the positive things people can do to support themselves/or others.
- Through sharing your experiences and journey you teach others about the power of human connection, resilience and empathy.
- You influence positive change within different health care systems

### RISKS

- You may feel your story could be rejected or minimized.
- You may feel shame and fear being judged. You wonder: “What will the audience, advisors and health care professions think of me?”
- You may see someone from your past sitting at an advisement table or in the audience.
- You risk triggering yourself, re-experiencing the trauma or having a relapse if you’re not emotionally ready to talk about your experiences.
- Your emotions – as a result of negative or positive feedback – may overwhelm you.
- You may feel anxious or vulnerable before, during or after sharing.
- You may not be able to get the support you need when you need it.
- You could experience legal consequences if you talk about illegal things you have done.
- You could experience social or employment consequences when you expose details of your life. Think things through before making any disclosure. Impulsive disclosures can have long-lasting negative outcomes.

## INFORMATION SHEET 2: PUBLIC SPEAKING TIPS\*

**Understand your goals.** Consider what messages you would like to get across to the health care system you are working with and/or the audience you are speaking to. Consider why you are sharing your experiences and what you would like to get out of it.

**Know who the audience is.** You could be speaking to a variety of people, such as the general public, mental health and addiction workers, parents, youth and peers. Knowing who they are, what their attitudes might be and what messages are important for them to hear will help you tailor your talk and advocacy efforts.

**Know what you are going to say.** Preparing your story ahead of time – whether scripted or unscripted – will help you to feel more comfortable with the presentation, stay on topic and avoid potential triggers.

### Tell a story.

- Audiences and health care system partners generally like to hear what your life was like before you developed “problems”. This normalizes your story and helps the audience relate to you. It also provides a backdrop for the rest of your story and experiences.
- Next tell the audience how your “struggles” developed and how it affected your life.
- Conclude with your path to stability and wellness, and how your life is today.
- If you read your story, write it the way you would speak. This keeps your presentation feeling natural.

**Reduce your nervousness.** Most people feel nervous when they speak in front of a group. Ways to reduce nervousness include being organized about what you want to say, practicing what you are going to say, taking deep breaths and making eye contact with the audience and other committee members.

**Take a deep breath.** One good inhalation before speaking can keep your head clear, keep your voice strong and keep you grounded.

### Consider your presentation style.

- Speak clearly and at a moderate pace.
- Show your enthusiasm. Participants respond best when they feel that you are engaged with the topic and committed to the message.
- Make eye contact with the audience and health care professionals to build rapport and keep them involved in what you’re saying.
- Show some emotion if appropriate.
- It’s OK to have tears in your eyes if that’s where the moment takes you.
- It’s OK to show anger if you can calmly say, “This is what makes me angry” and explain why.
- A goal of your presentation or advisement role is to remove the stigma that may be attached to your experiences. Do not express shame or apologize for any aspect of your life.

**End with emphasis.** Endings are important: how you end your presentation contributes to its success. You could use your closing comments, for example, to refocus on the intent of the event or to talk about how you’re feeling as you conclude your presentation.

**Watch your appearance.** What you wear can be as important as what you say. You want your story and your message to be the focus – not the way you look.

### INFORMATION SHEET 3: THE POWER OF LANGUAGE

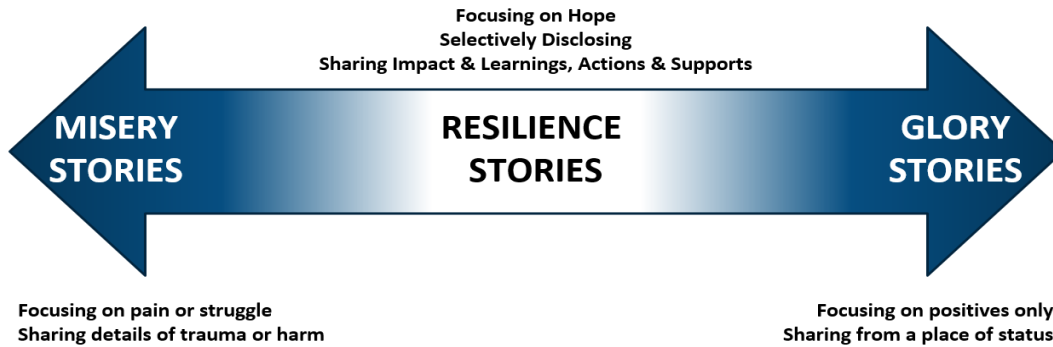
Language is a powerful tool. One word can have many different meanings to different people. It can also perpetuate shame and stigma. Below is a list of words to reconsider and alternatives you can include in your talks. Sharing the reasons behind our language choices can reduce stigma, shame and acknowledge strengths. It can help people reconsider their own language choices or how they look at themselves. If you choose to use one of the terms in the left column, it can be helpful to share with the audience and health care partners what this means to you and if possible, acknowledge any potential harms (stigma, shame etc.) this may have for others.

Avoid/Reconsider	Explanation	Alternatives:
Suffering from...	May dismiss the benefits, or the process of one's journeys Perpetuates stigma and undermines messages of hope and wellness	"Living with..." "Currently experiencing..." I have experienced
Labels (Addict, schizophrenic, bum etc.)	Putting a person first humanizes Perpetuates and normalizes negative stereotypes	I live with _____ I have experienced ____
Jargon, Slang or Abbreviations	People may not understand or misinterpret Exception: If the audience understands these it may be useful to include jargon or slang	Use other words, say the full meaning
Relapse, Slip up, Setback, Falling back...	"Relapse" perpetuates an idea of "All or nothing" instead of a journey and learning Focuses on a loss /problem versus an opportunity or process of wellness	I started ___ again I experienced ___ again
Clean	Implies "dirty" or less worthy	stopped using _____, abstinence, abstaining from, no long doing
Recovery	Recovery has different meaning to different individuals It is important to actually understand what "recovery" means to you Recovery in medical sense inherently implies absence of symptoms, especially substances – all or nothing outcome Shifting this language is a way of recognizing the importance of the process - not just an outcome	Wellness Wellbeing Personal journey
Committed suicide Successful suicide Completed suicide Failed attempt at suicide Unsuccessful suicide	Acknowledges and legitimizes suicide in the same way other causes of death are discussed, without shame, blame or moralization "Suicide is no longer a crime, and so we need to stop saying that people commit suicide..." ~ Susan Beaton, <i>Suicide Prevention Specialist</i> Avoids quantifying (successful, unsuccessful) suicide and suicide attempts	Die(d) by suicide End(ed) their/my life Took their/my life Attempt(ed) to end their/my life

## INFORMATION SHEET 4: SHARING YOUR JOURNEY - RESPONSIBLE PUBLIC SHARING & SPEAKING

Below are some considerations and tips on how to ensure your talk has the greatest impact, while maintaining professionalism and comfort.

### THE SHARING SPECTRUM



"The Sharing Spectrum" was created by Ethan Hopkins and Alyssa Gremmen at the Centre for Innovation in Peer Support (2021)

**Misery Stories** primarily focus on sharing struggles, anger and frustrations. They can seem helpful but usually perpetuate stigma, misunderstanding and do not provide calls to action. They can create us versus them mentality that undermines collective solution and change.

**Resilience Stories** do not stop at sharing struggles. A resilience story shares these struggles for a purpose; ex. to dispel myths, build understanding. These stories focus on the impact of our experiences, the learnings we've had, the actions we took and supports we found helpful or would have been helpful. These messages involve our audience in changing systems and disabling stigma, discrimination and prejudice. Resilience story sharing also opens the door to meaningful advisement for health care system engagement and transformation.

**Glory Stories** only focus on positives. They focus on a sense of status being achieved, from a place of ego and not of service to others. Glory stories often miss the opportunity to share the learnings of resilience stories. Sharing glory stories creates shame, comparison, and they can be dismissive and prescriptive (ex. "do what I did to get better")

Avoid: **Too many details. It may cause your message to be lost. Practice finding ways to get your points across clearly while still achieving the response you want from your audience and health care professionals.**

Do: **Share the "headlines" and key messages not the details.**

Example: if you wanted to talk about your lunch yesterday:

**I enjoyed a delicious burger yesterday. It was juicy, thick and came on a fancy bun. I think I will be going back in the future.**

Instead of...

**I went to a restaurant yesterday, ordered the ultimate burger. It comes with fries but I don't like fries so I got a salad. The burger was delicious! The burger was about 1 inch thick, I could tell it didn't have any fillers in it, there were 3 different types of meat. It had brie cheese melted on top, caramelized onions, mushrooms and some amazing sauce too. The bun was toasted and fresh, it had poppy seeds on it. I think I will go back, I already told my friend about it. I am just so busy in the next few weeks. I really do enjoy a good burger though.**

## Managing Triggering or “Heavy Topics”

(Self-harm, suicide, violence, traumatic events, abuse, drug use, bullying, sexual assault etc.)

Talking about the “tough stuff” may be relevant and can be important to your overall message. Talking about these requires awareness. These experiences have the potential to upset you and members of your audience, other advisory members, family/caregivers and health care professionals. Although we cannot always account for triggers people experiences there are responsible and safe ways to approach these experiences in your talks.

**Avoid: sharing details about: self harm actions, suicide plans, violent actions, traumatic event details, drug use rituals, abuse details**

**Do: Acknowledge and identify tough experiences and their impact on your journey. Without sharing the how’s and details. Headlines not the details.**

Examples:  
**I am a survivor of abuse**  
**I used to self harm**  
**I experienced assault**  
 Etc.

There is no research evidence that indicates talking to people about suicide, in the context of care, respect, and prevention, increases their risk of suicidal ideation or suicidal behaviours. Research does indicate that talking openly and responsibly about suicide lets a potentially suicidal person know they do not have to be alone, that there are people who want to listen and who want to help.

(The Crisis Intervention and Suicide Prevention Centre of BC (Crisis Centre), <https://crisiscentre.bc.ca/frequently-asked-questions-about-suicide/>)

## Talking about Services and People

Like medication, people’s experiences with services are unique and personal, often affected by many different factors. It is important to share your experiences with services and people. Remaining neutral and respecting confidentiality shows integrity, respect and wellness, further enhancing your message and impact. Not using identifying information about services or people ensures your story does not deter someone from seeking help, or feeling upset if their experiences were different from yours.

**Avoid: Identifying information such as names, details about programs unique to that organization (if possible), addresses or street locations**

**Do: Share about your experiences, good or bad. Use language that does not identify a person or organization.**

Examples: **my psychiatrist, a nurse, a family member, someone I know, an organization, a hospital, a treatment centre, a shelter**

**“I have learned how important it is to find the right support people, this can be anyone. I found a support person in my mother. Another family member was not as supportive. “**

**If you identify a service or person: if possible, acknowledge that this may not always be the case for others and you recognize that experiences may be personal.**

## Talking about Medications

Medications may be part of your journey. It is important to maintain a neutral stance as people's relationships and experiences with medication and dosages are unique and personal, often affected by many different factors. Deterring people from medication can be harmful, only promoting medication may miss other wellness options.

**Avoid: names and brands, dosages**

**Do: Speak about how medication impacted you, acknowledge that it is unique for all. Share about what would have helped you with managing medications and any effects.**

**You can share a classification instead of the name/brand.**

Examples: **I was prescribed a medication for \_\_\_\_ it seemed to work well. Medications are unique to everyone so I am glad I found one that worked. It helped me\_\_\_\_\_.**

**I was prescribed a medication for\_\_\_\_. I experienced some pretty negative side effects so we changed my medication. We finally found a combination of medication that worked for me. It really is a process to find the right medication for each person I am glad I talked to my doctor and that they were willing to listen.**

Examples: **pain medication, anti-depressants, anti-psychotics, opioid medication, stimulant medication.**

If someone asks you for the medication name/dosage:  
**Politely explain why you don't share.**

Example: **"Thank you for being interested. I do not share that information because I recognize that experiences with medication are very unique to each person. Researching and talking with doctors and pharmacists is the best way to get information on medications."**

## Personal Contact Information

The health care system partners and audience members may use you as a support. This can be draining and actually cause harm to you and the person reaching out.

**Avoid: sharing personal contact information unless it is for advisement or speaking opportunities.**

**Do: direct them to services. Let them know that you are not a trained support person but that you are glad your story connected with them. Offer to share some resources or connect them with the event organizer/supporters in the space**

Example: **I am glad that my story resonated with you. I do not give my personal information out. Would you like me to connect you to\_\_\_\_?**

**If the setting allows you can offer to answer their questions at the time.**

## APPENDIX 2

# DEVELOPING AND PLANNING YOUR TALK WELLNESS CHECKLISTS

These resources and checklists can be useful to help you learn more about yourself as a speaker and lived experience and/or family/caregiver advocate and allow you to tailor your talks and advocacy efforts for different audiences, settings and formats.

- 1. Resource 1: Know your Presentation Style\***
- 2. Resource 2: Reflecting on your Journey**
- 3. Resource 3: Developing your Sound Bites\*\***
- 4. Resource 4: Checklist - Planning your talk\***
- 5. Resource 5: Preparing for Questions\***
- 6. Resource 6: Checklist - Emotional Wellness\***
- 7. Resource 7: Speaker Wellness Plan**

\*These information sheets have been used/adapted (with permission) from “Strengthening Your Voice” (SYV)- A public speaking guide for people with lived experience of problems with prescription opioids; which was created by the Centre for Addiction and Mental Health’s (CAMH) Knowledge and Innovation Support Unit. (see References page)

\*\*This information sheet has been adapted from the Mental Health Commission of Canada’s Headstrong: Sharing your Personal Story: Speaker Toolkit. (see References page)

### RESOURCE 1: KNOW YOUR PRESENTATION STYLE

There are several ways of presenting when you are a speaker at an event. Know the style that you are most comfortable with and that feels empowering for you. Over time, as you become more comfortable and confident, you may find that you move from one style to another. Or you may vary your style based on the audience or on your comfort level with the topic. Do whatever works best for you and for the occasion.

<b>SCRIPTED</b> Writing it out and reading it to the audience		<b>SEMI-SCRIPTED</b> Referring to bullet points and a closing statement written out		<b>UNSCRIPTED</b> Speaking without any notes	
<b>Pros</b>	<b>Cons</b>	<b>Pros</b>	<b>Cons</b>	<b>Pros</b>	<b>Cons</b>
<p><b>Provides</b> you with guidelines or a road map</p> <p><b>Keeps</b> you on topic and organized</p> <p><b>Keeps</b> you to the timeline</p> <p><b>Allows</b> you to experience emotional process and triggers ahead of time</p> <p><b>Helps</b> you keep nerves and emotions in check as you follow the script</p> <p><b>Acts</b> as a safety net</p>	<p><b>Detracts</b> from the natural or authentic feel of your story</p> <p><b>Risks</b> being boring for the audience if you show no facial expressions and make no eye contact</p>	<p><b>Provides</b> you with guidelines</p> <p><b>Keeps</b> you on topic and organized</p> <p><b>Keeps</b> you to the timeline</p> <p><b>Allows</b> you to experience emotions and triggers ahead of time</p> <p><b>Helps</b> you keep nerves and emotions in check as you follow your notes or cards</p> <p><b>Acts</b> as a safety net</p> <p><b>Helps</b> you appear more natural, genuine, engaging and spontaneous</p> <p><b>Empowers</b> you with the ability to alter your story to suit the event, audience</p>	<p><b>Risks</b> your speaking longer than you wanted to</p>	<p><b>Helps</b> you appear more natural, genuine, engaging and spontaneous</p> <p><b>Empowers</b> you with the ability to alter your story to suit the audience and circumstances</p>	<p><b>Requires</b> someone who is a good speaker and can manage all scenarios</p> <p><b>Risks</b> speaking longer than you wanted to</p> <p><b>Risks</b> getting off topic and appearing sloppy and unprofessional</p> <p><b>Doesn't allow</b> you any protection in case your emotions get the better of you</p> <p><b>Increases</b> the likelihood that you will be affected by a negative reaction from the audience</p> <p><b>Can increase</b> your anxiety, feelings &amp; vulnerability before, during &amp; after speaking</p>

Adapted from: (CAMH, 2013)

## RESOURCE 2: REFLECTING ON YOUR JOURNEY

This may help you organize some of your journey and the messages you want to share.

I do not want to share about ...	
Event/Theme/Feeling	Is there a key message/learning you want to share?

Event/Theme/Feeling	Is there a key message/learning you want to share?

## RESOURCE 3: DEVELOPING YOUR TALK AND/OR MESSAGING

Below are some key messages and questions that will help you develop your talks and give you context in an advisement role. Choose the number and order of questions that make sense for your audience, time limits, setting and format of your talk. Your Sound Bites are your responses to key questions based on your experiences and your key messages (why you are sharing this?)

### Key Messages:

There is hope	People are not defined by past histories or experiences	People are resilient: People with experiences like yours can and do have happy, successful lives	Everyone can take steps to reduce stigma
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### Key Questions:

What lived experiences/key topics are you speaking about?	What was your life like before your struggles?*	Why are you sharing your experiences today?	What factors do you think contributed to your experiences?	What signs did you have that something was becoming a problem?
What effects did your lived experience have on your life?*	What was it like living with _____?	What made you decide to get support?	How did your family and friends respond? What responses were helpful/unhelpful?	What/who was helpful in supporting your journey?
What were your experiences with the health system? What was helpful/unhelpful?	What were your experiences with community services? What was helpful/unhelpful?	What were your experiences with the justice system? What was helpful/unhelpful?	What were the challenges or barriers in your journey?	What positive experiences happened in your recovery journey?
What might you have done differently if you could do it over again?	What can other people do to support people who are currently struggling?	What can people do to eliminate stigma?	What is your life like now?	What are your coping strategies? How do you manage now?
Tell us about your life before, during and after your lived experience*	What activities do you enjoy?	What have you learned?	What meant the most to you in your journey?	What do you want other people who are currently struggling to know?

\*work, education, relationships, activities, spirituality, childhood, attitudes and beliefs about life

Adapted from: Mental Health Commission of Canada: Headstrong

## RESOURCE 4: CHECKLIST – PLANNING YOUR TALKS

### TOPIC

- What would the event organizer like you to focus on?
- What key Sound Bites do you want to share about your story?
- What topics are other speakers focusing on? How can you complement their presentations or provide alternative viewpoints?
- What key messages may be important to your audience

### AUDIENCE

- Who is in the audience?
- What does the audience know about this topic?
- What will help keep the audience’s attention?
- What type of language does the audience use (for example, medical terms, slang)?
- Are you willing to answer questions posed by the audience?
- Are the people available to support audience members if needed? Who are they?

### LOGISTICS

- Will you be speaking on your own or as part of a panel?
- Who else is speaking? Who is speaking before and after you? What are other people sharing about?
- How much time are you given to speak?
- Will you be using presentation tools, such as PowerPoint or a film?

### COMFORT

- What are you comfortable sharing? What are you not comfortable sharing?
- What will help you stay on topic?
- Are you able to manage triggers as you develop your story?
- Are you prepared emotionally?
- Are there some topics you do not want to answer questions about?
- What skills do you have that you can draw on to help you?
- What new skills would you like to learn as you develop and deliver your story?

### REMEMBER: AUDIENCE TIPS

#### People Currently Struggling, Youth, Parents/Caregivers and General Public

Keep language simple and talk from the heart.

Be honest and try not to scare anyone.

Positive messages, learnings and navigation tips.

Not alone, recovery is possible.

Avoid triggers for yourself and others.

What can people do in their own journeys?

What can other people do to support people in their journeys?

What is important to know?

#### Service Providers

Emotions and experiences

Challenges and gaps in the system

What is important to know?

What was helpful?

Adapted from: (CAMH, 2013)

## RESOURCE 5: PREPARING FOR QUESTIONS

Following are some typical questions that speakers and advisors are asked. To prepare for the question-and-answer portions of presentations, review the questions and think about how you could answer them.

- What helped you start and keep on your journey of wellness (recovery)?
- Is there anything people could have said that would have allowed you to make changes sooner?
- Was there any one thing that someone said or did to help you decide to change?
- Was there any one thing that someone said or did to support you at a point of change?
- Is there one thing that people can do to help someone in recovery?
- What is your biggest regret?
- What do you do now to cope?
- Did your friends know?
- Is there anything you can tell me, as a parent, about how I can help my children?
- My family member takes drugs, lies to me and will not listen to me. What can I do to make him or her do what I say?
- Do you have any suggestions for how child protection services can operate as humanely as possible?
- What is your opinion of the health care specialists you have encountered?
- Have you ever been arrested?
- Have you ever been in jail?
- Did you find that the legal, justice, parole and police workers you encountered were helpful?
- Where did you sleep when you were homeless?
- How do you control your rage about how the system failed you? How are you able not to be mad all the time?
- Sharing your experiences with people you don't know takes away your anonymity. Why would you do that?
- Do you have a faith, higher power or God in your life?
- How important is eating well, exercising and going to bed on time?

**If you have disclosed about substance use/addiction you could be asked:**

- When did you start taking drugs, including using alcohol?
- Why you became addicted but other people do not?
- What made you want to stop taking drugs?

**Consider:**

How would you answer these questions if they are asked?

Which questions are you not comfortable answering?

How will you share that you are not comfortable?

Can you think of other questions you may be asked as a speaker or in an advisement role?

Adapted from: (CAMH, 2013)

## RESOURCE 6: CHECKLIST – EMOTIONAL WELLNESS

- Do you feel confident about sharing your story with others?
- Are you motivated to share your story with others?
- Do you feel safe enough within yourself to stand up and tell your about story?
- Are you appropriately nervous speaking in public?
- Do you have someone (for example, a friend, a support worker) you can talk to and who can support you about sharing your story publicly?
- Are you feeling good about where you are in your recovery?
- Are you aware of your triggers? Do you have a plan for how to take care of them?
- Do you feel confident in an advisement role?
- Do you have a mentor that you can confide in?
- Do you follow a program of self-care (for example, meditating, eating well, walking, listening to music, yoga)?
- Are you willing to ask for help?
- Are you able to maintain a balance in your life?
- Do you have a desire to help others?
- Does talking about your story publicly feel like a positive experience for you?
- Do you feel prepared to speak and share your experiences? Are you prepared emotionally? Are you prepared in terms of what you're going to say?

**It is important to take care of and monitor your well-being before, during and after a speaking event and/or advisory meeting. Ask yourself the following questions to determine how you're doing.**

**If you're feeling angry, extremely emotional or easily triggered, these could be signs that you need more time before sharing your story publicly.**

Adapted from: (CAMH, 2013)



## RESOURCE 7: SPEAKER WELLNESS PLAN

**Supportive People**

**Supportive Activities**

**Before my talk I will support myself by...**

**During my talk I will support myself by...**

**After my talk I will support myself by...**

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