

Preparing to Share Your Personal Journey

V2 Sept 2024

Empowerment. Self-Reflection.

This resource has been structured to include multiple parameters of engagement that involve sharing your personal lived/living experience (patient) and/or family (caregiver) experience. There is an emphasis on developing and planning what to share, and how to safely share in ways that are effective, meaningful, and trauma informed. A trauma-informed approach helps create a safe space, recognizing that patients, families, caregivers and other stakeholders may have a history of trauma.

It is a skill and a craft. **But most of all it is your life.**

How to Use This Resource

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If you have questions about this resource, please contact
centreinfo@supporthouse.ca | www.supporthouse.ca

About the Centre

Recognized provincially for its award-winning services, Support House Centre for Innovation in Peer Support (the Centre) has evolved into a "Benchmark of Excellence" in peer support and experience-based engagement and co-design. The Centre is dedicated to implementing innovative best practices for meaningful and equitable engagement and partnerships with individuals who have lived/living experience, as well as their family/caregivers, across Ontario.

Our History

Originally established as a Consumer Survivor Initiative in 1999 under the name TEACH (Teach, Empower, Advocate for Community Health), the need for support and training for agencies providing authentic peer support was identified. As a result, in 2015, the Centre received new base funding from the legacy Mississauga Halton LHIN to offer regional and provincial system support for Health Service Providers (HSPs). This support includes hospital psychiatric inpatient units, addiction residential treatment, supportive housing programs, central access, employment support programs, justice, community mental health and addiction providers, and self-help education and support groups. This scope has since expanded to encompass regional, provincial, national, and international collaborations.

Supporting People Engaging in Services

Our service offerings include wellness-based, peer-led self-help and social connection programs for community members. These programs are designed, developed, implemented, and evaluated by individuals with lived/living experience. We work together to foster community and connection by creating safe spaces where people navigating mental health and substance use/addiction challenges, can heal and grow.

Supporting Provincial Systems & Partners

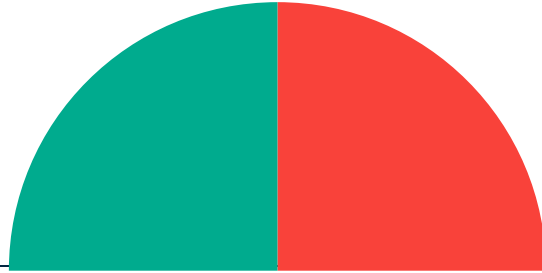
The Centre's Provincial, Systems & Partner stream is continually evolving to support organizations that provide peer support services and to foster meaningful, equitable engagement, co-design, and partnership with individuals who have lived/living experience, as well as family/caregivers for roles on advisory tables, working groups, committees, and government boards. We create learning opportunities through co-design, education and training, consultations, capacity building, collaborations and partnerships, and the development of resources and toolkits, drawing on our expertise in engagement stewardship.

Additional learning resources are available in our Virtual Learning Centre and Resource Hub, where you can explore information about our provincial communities of practice, toolkits, models, and other resources. The Centre is committed to enhancing the capacity of individuals with lived/living experience, family/caregivers, peer support workers, supervisors, health service providers, and regional and provincial healthcare systems. We aspire to co-design and co-create an inclusive and equitable healthcare response, regardless of complexity.

About Support House

Support House is guided by our core values, which shape 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, starting 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 values-based oath of conduct.

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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 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 stigmatization, bias, discrimination and judgement.

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 trauma-informed 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.



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.

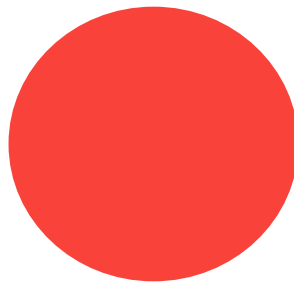
Your life experiences, from childhood to the present, show that anyone can struggle & develop health issues. You know best when your "situation" started, how they got worse and what helped you move toward wellness.

Talking about these experiences helps others by educating them.

It is also valuable information for health care system transformation. Your experiences 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 sharing your personal journey.



Benefits from Sharing Your Personal Journey

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 people and health care system for sharing your experience.

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.



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

-John Stuart Mill

Sharing your experiences 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.

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 and/or doing a focus group or consultation.

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>Self-Advocacy</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>System Advocacy</p> <p>Opportunity to assist in the development of strategic priorities, legislation, new programming with health service providers and the health care sector.</p>
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Pages 6, 7, & 8 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. Betty-Lou Kristy Director at Support House Centre for Innovation in Peer Support was involved in co-creating that body of work from inception to completion.

SELF-REFLECTION

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 publicly or in relation to their advisement efforts and you want to do the same thing.

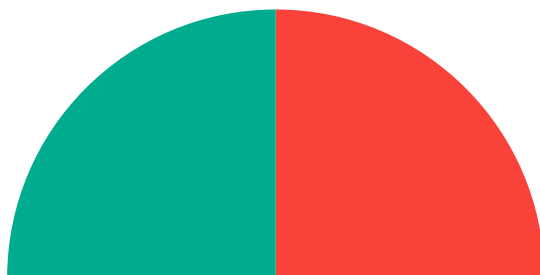
You stay connected. Even though you’ve been on a good path for a while, you keep in touch with those who support you.

SIGNS THAT MAY INDICATE 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.



DO YOU HAVE SUPPORT?

If you make presentations about your experiences or serve in a role as a lived, living or family/caregiver experience advisor (patient and/or family) and/or sharing in a consultation or focus group etc., 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 talk about your experiences. (For example, how comfortable do you feel talking about the underlying issues that led up to and impacted your journey. 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 journey.
- can help you decide how much of your lived experience journey to disclose.
- can help you recognize your triggers and how to manage them.
- will offer encouragement.

However, if you are doing well and are comfortable where you are in your own wellness and are motivated to 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.

EXPERIENCING TRIGGERS AS YOU PREPARE



The process of 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.

Preparing before you share 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/life journey, 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 ready to share your experiences with others.

DIFFERENT WAYS TO ENAGE AND SHARE

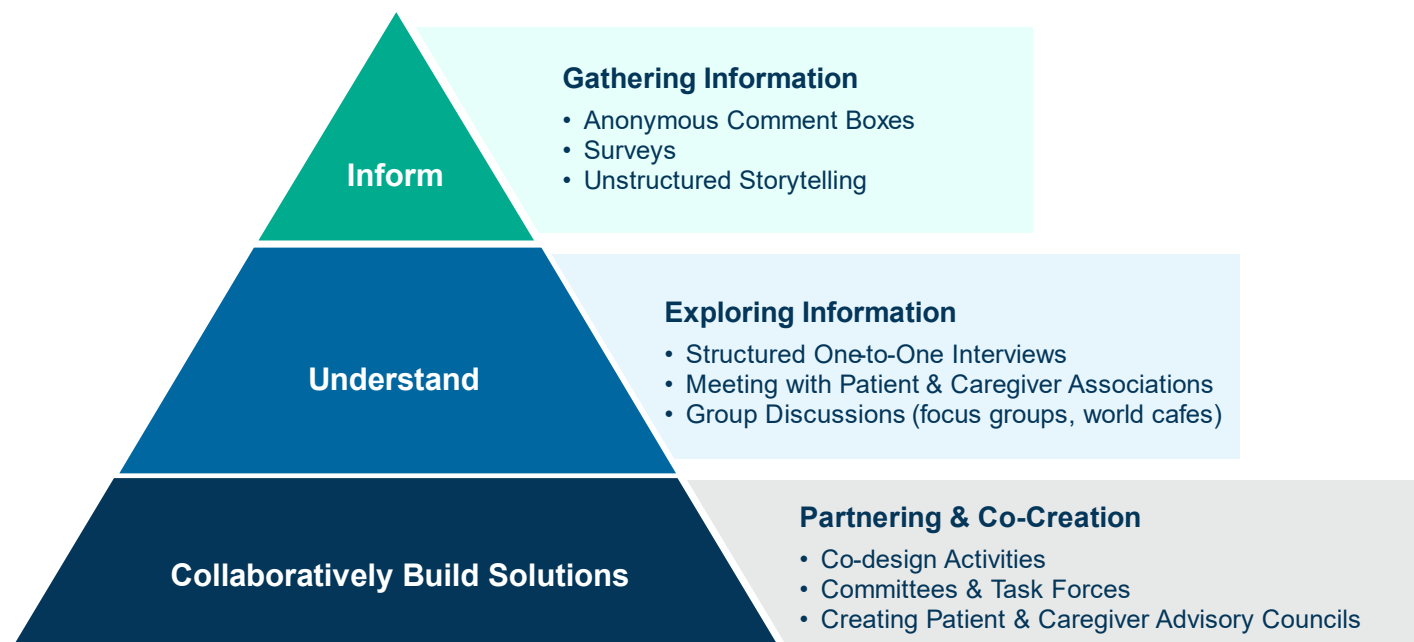
It is important to note that there is a variety of ways to engage and share from your lived/living experience. The involvement of people with lived/living experience and/or family/ caregiver experience has grown over the years.

It is no longer about only sharing your lived experience for “story telling” or public speaking at an event, part of a panel, or inclusion of your life journey for videos, reports or client journeys. The opportunities have grown into different roles that involve engagement, co-design and partnership for healthcare transformation. These roles can be across the domains of personal care and health decisions, program and service design or policy, strategy and governance.

Each role is uniquely different and therefore requires ALL of your skill sets and many layers of your lived experience such as education, training, employment or volunteer experiences. Roles such as sitting on systems tables for healthcare such as advisory tables, committees, councils or task forces. Or it can involve you doing one-to-one interviews, citizen assemblies, town halls etc. You might even be on a Board of Directors or share to shape policy, governance, research or funding decisions.

Each opportunity requires a different approach to how and when you share from your personal journey. No matter how much or how little you may be sharing from your personal journey it still requires a degree of emotional vulnerability and reflection.

Degrees of Engagement



Meaningful engagement: respectful, dignified and equitable inclusion of individuals with lived experience in a range of processes and activities within an enabling environment where power is transferred to people; valuing lived experience as a form of expertise and applying it to improve health outcomes.

Meaningful Selective Disclosure



Meaningful selective disclosure is when we share from our personal lived/living experiences in support of the engagement we are involved in. When we selectively disclose parts of our life with other people, we need to consider the impacts of our sharing as it relates to ourselves and the persons receiving the information. Meaningful selective disclosure requires us to reflect on points of connection between our experience and the experience of others.

Sharing our experiences in a way that is meaningful can convey that people are not alone in their experiences and struggles, inspire hope, provide validation, and aid in the exploration of choices, options, and key considerations; including sharing the ways that we take care of ourselves.

We share meaningfully when we approach sharing our experience in a trauma informed way. This way of sharing from our journey addresses the pain or struggle of an experience but focuses on the impact of our experiences, the learnings we've had, the actions we took and supports we found helpful. Trauma informed sharing is brief, as the interaction is not about us, but rather to be of support to others or the engagement we are involved in.

W.A.I.T. - Why Am I Talking? This acronym is taken from: (TED - The Empowerment Dynamic, 2017).

What will I share?

- Does my share connect with an aspect of the other person's journey?
- How much detail will I share?

What's my purpose in sharing?

- To share for exploration? To validate? To inspire?
- Is it in service of the listener(s) and not just about me?

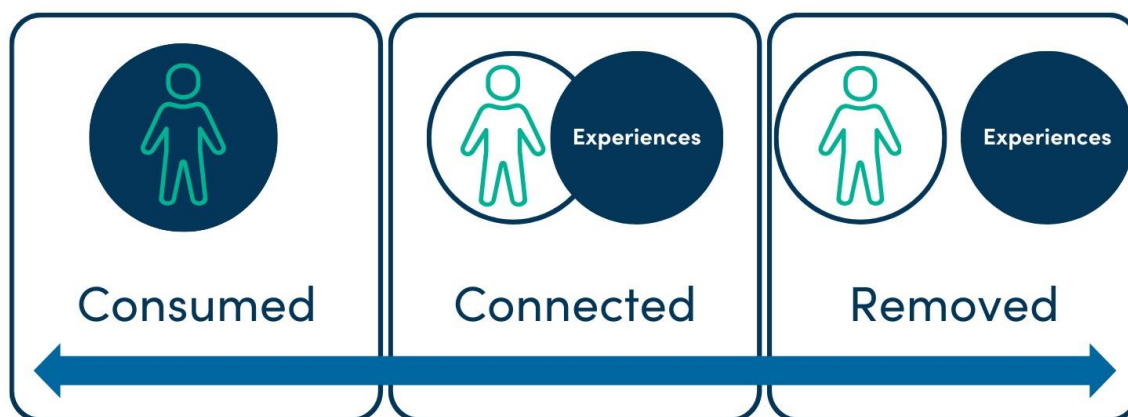
What's the risk to others?

- Will this enhance or hinder the conversation?
- Will I cause harm? – shame, blame, create comparison, re-traumatize

What's the risk to myself?

- Am I ready to share?
- Will this have a negative impact on me?

The Relationship to Lived Experience Spectrum



The Relationship to Lived Experience Spectrum was created as a visual aid to help people explore the relationship they have to their lived and living experiences. Awareness of the relationship someone has with their experiences is not meant to bring up shame or comparison. It is not about judgement or implying that there is a “right or wrong” type of relationship. Having a better understanding of this relationship is integral as it will help guide self reflection and decisions about what to share and how to do that meaningfully.

The spectrum shows three different relationships that someone might have with their experiences. These include being consumed by, connected to, and removed from them.

If someone is **consumed by their experiences**, they may overshare painful details, emphasizing the pain and struggle. These feelings are valid and may be a part of the experience, but if they are what receives the most focus when a story is shared this may cause harm (e.g., vicarious trauma).

If someone is **removed from their experiences**, this might be a barrier to being able to share meaningfully in a way that acknowledges the challenges someone faced and how they navigated that challenge. They may share from the surface level or minimally.

If someone is **connected to their experiences** then sharing can be balanced, trauma informed, relevant and meaningfully. The sharing can highlight both the challenges experienced and how they were navigated which can validate other people’s experiences, and foster hope. Additionally, it can highlight gaps in services and create opportunities to explore solutions, share supportive actions and resources.

Selectively disclosing parts of our journey that focus on the impact of our experiences and the learnings we’ve had are meant to be brief as the interaction is not about us. It is about working together towards co-designing healthcare transformation.



Getting to Know Your Journey

(This handout has been adapted from: (Mental Health Commission of Canada).

Key Reflection Questions

Pick a few of the following questions that you would feel comfortable sharing in a peer support relationship and record your answers below.

What are some successes you have had in your life?	What was your life like before your struggles?*	What activities do you enjoy?	What factors do you think contributed to your experiences?
What effects did/does your lived experience have on your life?*	What is/was it like living with _____?	What contributed to your decision to seek support?	How did your family and friends respond? What responses were helpful/unhelpful?
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 would you have done differently if you could do it over again?	What means the most to you in your journey?	What have you learned?	What is your life like now?
What signs did you have that something was becoming a problem?	What/who was helpful in supporting your journey?	What positive experiences happened in your recovery journey?	What are your coping strategies? How do you manage now?

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

Exploring Trauma Informed Messages

By exploring the events and feelings we have experienced, we may find areas that connect with other people's experiences. We can then explore the impact, learnings and actions to help create ~~resilience stories~~ trauma informed messages-to share with others. This is also a chance to identify experiences you do not want to share with others.

Part 1: Circle the boxes below that connect with your experiences.

Loneliness and/or isolation	Sadness	Anger
Substance use and/or Addiction	Disability	Psychosis
Caregiving for others	Self-Harm	Grief and feelings of loss
Violence	Chronic illness	Hoarding
Confusion	Sex work	Trauma
Mental Illness	Extreme Mood Changes	Stress
Poverty	Bullying	Happiness
Harm Reduction	Self – help	Shame and guilt
Fear and Phobias	Avoidance	Experiences with Medication
Employment Challenges	Gender Identity and Sexual Orientation related challenges	Connection with the justice system and/or incarceration
Discrimination and/or Oppression (racism, sexism, etc.)	Homelessness and challenges with housing	Stigma, Prejudice, Being “Labelled”
Challenges with relationships (friends, partner, family etc.)	Suicidality (thoughts and actions)	Engagement with Supportive Professionals/Groups
Engagement with Community Supports and Hospital	Being self-critical and negative self-talk	Other: _____
Experiences in my life I do not want to share about...		

Part 2: Choose some of the experiences you circled. And answer the following questions about those experiences. This will give you some trauma informed messages to include when you share with others.

What went well?

Where were the gaps?

What was the impact?

What were your learnings?

What actions did you take and what supports did you have?



Sharing From Your Experiences

Craft your messaging. Take a situation you struggled with and reframe it – where were the opportunities, what did you learn, what was helpful, what was not, what did you gain?

Thought Record

Situation/ Activating Event	Feelings Emotions- (rate 0-100%) Body sensations	Unhelpful Thoughts/Images	Facts that <u>support</u> the unhelpful thought	Facts that provide evidence <u>against</u> the unhelpful thought	Alternative, more realistic and balanced perspective	Outcome re-rate emotion
<p>What happened? Where? When? Who with? How?</p>	<p>What emotion did I feel at the time? What else? How intense was it? What did I notice in my body? Where did I feel it?</p>	<p>What went through my mind? What did those thoughts/images/ memories mean to me or say about me or the situation? What am I responding to? What 'button' is this pressing for me? What would be the worst thing about that, or that could happen?</p>	<p>What are the facts? What facts do I have that the unhelpful thoughts are totally true?</p>	<p>What facts do I have that the unhelpful thoughts are NOT totally true? Is it possible that this is opinion rather than fact? What have others said about this?</p>	<p>STOP! Take a breath... What would someone else say about this situation? What's the bigger picture? Is there another way of seeing it? What would I say to someone else experiencing this? Is my reaction in proportion to the actual event?</p>	<p>What am I feeling now? (0-100%) What could I do differently? What will be most helpful for me or the situation? What will the consequences be?</p>

This page was adapted from 7 column Thought Record Sheet ©Carol Vivyan www.getselfhelp.co.uk www.get.gg



Wellness Plan Template

This template was created based on information from the following source. For more context, we encourage you to review the work of the original author:

Stoewen D. L. (2017). *Dimensions of wellness: Change your habits, change your life. The Canadian veterinary journal = La revue veterinairecanadienne, 58(8), 861–862.*

What is this resource?

This is a template that can be used to record self-care strategies related to several dimensions of our wellness.

How can this tool be used?

This tool can help you identify what you already do to support different dimensions of your wellness and areas to which you may wish to give more attention. This can be an opportunity to brainstorm, explore resources, and try something new!

There are many different dimensions of wellness in existence. We have included 7 dimensions: physical, spiritual, emotional, intellectual, vocational, social, and environmental. The descriptions of each have been included on the final page of this resource. As you record self-care strategies in each section, it might also be helpful to identify why you find that particular strategy helpful or the desired impact (e.g., ‘walking’ may become ‘walking outside to reconnect with my environment’).

We also hope that you make this template unique to you. In the eighth section, feel free to add any dimension that reflects an area of your wellness that you wish to highlight.

Please Note: Dimension descriptions are on page 23 after template



Physical

Spiritual

Emotional

Intellectual

Vocational

Social

Environmental

Add your own!

Dimension Descriptions

Physical

- Caring for your body to stay healthy now and in the future

Intellectual

- Growing intellectually, maintaining curiosity about all there is to learn, valuing lifelong learning, and responding positively to intellectual challenges
- Expanding knowledge and skills while discovering the potential for sharing your gifts with others

Emotional Dimension

- Understanding and respecting your feelings, values and attitudes
- Appreciating the feelings of others
- Managing your emotions in a constructive way
- Feeling positive and enthusiastic about your life

Social Dimension

- Maintaining healthy relationships, enjoying being with others, developing friendships and intimate relations, caring about others, and letting others care about you
- Contributing to your community

Spiritual Dimension

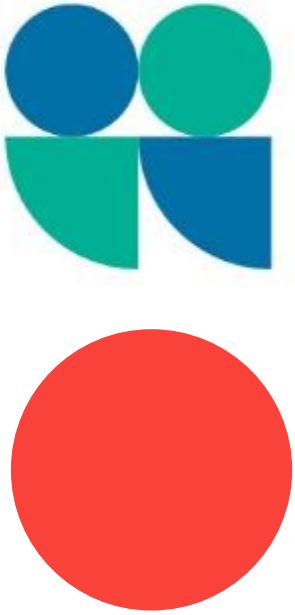
- Finding purpose, value, and meaning in your life with or without organized religion
- Participating in activities that are consistent with your beliefs and values

Vocational Dimension

- Preparing for and participating in work that provides personal satisfaction and life enrichment that is consistent with your values, goals and lifestyle
- Contributing your unique gifts, skills, and talents to work that is personally meaningful and rewarding

Environmental Dimension

- Understanding how your social, natural, and built environments affect your health and wellbeing
- Being aware of the unstable state of the earth and the effects of your daily habits on the physical environment
- Demonstrating commitment to a healthy planet



Health touches every aspect of our lives. Today, health is no longer simply defined as an absence of illness. We now know that wellness extends beyond health care to include the social determinants of health that shape a person's overall well-being and quality of life; and social services more broadly. It is more important than ever that we work to humanize care by providing people the space to share their lived/living experience and health journeys to be the driving force behind health care transformation.

Health touches the lives of people very personally

Support/
House



Centre for
Innovation in
Peer Support

1-833-845-WELL (9355) Ext 390
supporthouse.ca | centreinfo@supporthouse.ca

