PsychHub™

2nd Edition
November 2021

GUIDE FOR SHARING LIVED EXPERIENCE

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WHY SHARE LIVED EXPERIENCE?

WHAT IS LIVED EXPERIENCE?

"We are experts by experience—people who have lived with mental health conditions, people who've been suicidal, people who are trauma survivors. That is just as valuable as the kind of academic credentials that people earn. And it's incredibly important that we work together as partners."

- Leah Harris, MA, Suicide Attempt Survivor and Trainer with the National Center for Trauma-Informed Care

Lived experience is a term for the expertise and insight into a condition or issue possessed by someone who has at some point experienced that condition or issue themselves. People with lived experiences of mental health or substance use issues are often referred to as peers, and people that have attempted or lost someone to suicide are often referred to as survivors (Suicide Attempt Survivors Task Force, 2014).

WHY DOES IT MATTER?

"The stigma that surrounds mental illness remains perverse and it creates an additional burden to those who face a brain health challenge. Stigma can cause people to feel ashamed and it can prevent those who suffer from seeking the help they need. An effective way to reduce mental illness stigma is to share our own brain health stories with those we know and the general public as a whole."

- One Mind

Research suggests that elevating the voices of people with lived experience has numerous benefits:

- Sharing lived experiences is one of the best ways to promote empowerment and combat stigma.
- Helping others is a powerful way for people to help themselves and assists in community-building.
- Sharing of personal experiences is a crucial relationship building element of peer-based programs and services (Marino et al., 2016).
- When people are able to share their experiences with peers in a workplace setting, it may help improve people's wellbeing and foster diversity and inclusion (King et al., 2020).
- Support from peers who have also experienced a mental health disorder can significantly reduce readmission rates for acute psychiatric hospitalization (Johnson et al., 2018).
- Nursing students that take mental health courses taught by instructors with lived experience may be less likely to have negative attitudes toward people with mental illness and more likely to pursue careers in mental health nursing (Happell et al., 2014).

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SHARING LIVED EXPERIENCE EFFECTIVELY

REDUCING STIGMA

Sharing lived experience is more likely to reduce stigma when stories include the following (Corrigan et al., 2013):

- **The challenges of the issue or condition.** What aspects of the illness, issue, or condition were most difficult for you to cope with? What was it like to experience?
- **Aspects of recovery.** Recovery is a journey. For most people, it comes with ups and downs, and a number of factors (such as lifestyle changes, therapy, medication, support from family and friends, workplace support, and/or peer support) help them find a way to live fulfilling lives. Which factors were most helpful for you?
- **The effect of stigma.** Mental illness, substance use, and suicide are often stigmatized. Have you encountered instances at home, work, school, or anywhere else in your daily life where you felt judged or without support regarding your issue or condition?
- **A call to action for the audience.** Consider who your message is for, and then communicate how you feel your audience could make a difference in your life and the lives of others who have experienced the same issue or condition.

INSPIRING HOPE AND COMMUNITY

"When you find other people going through it, it's like realizing you belong on Earth once more."

- Graham Panther, Mental Health Advocate and Consultant

Having hope for the future and a sense of belonging are important protective factors that improve resiliency. Here are some tips on practical ways to promote these crucial ideas in your message:

- **Offer realistic strategies for fostering hope.** Avoid toxic positivity or all-or-nothing messages that can invalidate people's experiences. Balance the affirmation of people's difficult experiences with a clear message that there is always hope that things can improve.
- **Communicate that change is possible with time, intention, and action.** Remember the Chinese proverb, "A journey of a thousand miles begins with a single step." Breaking bigger goals into smaller ones can help foster a sense of mastery and demonstrate change is really possible.
- **Encourage efforts to connect with others.** Think about ways people can start to build their networks and get involved in their communities, such as volunteering, attending peer groups, and joining hobby or special interest groups.

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OTHER KEYS TO EFFECTIVENESS

- **Normalize receiving and providing support and assistance.** Avoid messages that people must achieve their goals or success all on their own. We are inherently social creatures who need community and support from others for our health, survival, and success.
- **Focus on your personal experience.** Avoid speaking too generally or assuming your own experience applies to everyone. Use "I" statements whenever possible. Your personal experience is what you know best.
- **Don't give direct advice.** Even therapists avoid telling others what to do, because they aren't the ones that will experience the consequences of those actions and choices. Remember everyone and every circumstance is unique and something that works for many will not work for all.
- **Avoid using prescriptive or certain language.** For example, "This will help." or "The solution to this problem is "___." "Instead of using absolutes like "will", "always", "never," use more neutral terms like "can" or "may." Remember to speak from your own experience: "This helped me, so it may be helpful for you too."
- **Keep social issues in mind.** Remember you are communicating to a general audience with diverse backgrounds and differing access to resources. For example, avoid recommending taking a vacation as a coping mechanism, since that is something not everyone can afford. Additionally, when pointing people to resources, keep in mind that not everyone has access to affordable mental healthcare and do your best to include information on free or sliding scale options.

SHARING LIVED EXPERIENCE SAFELY

CONSIDER YOUR OWN WELLBEING

- **Take care of yourself.** Talk about ways you care for yourself to lead by example, such as socializing, exercise, healthy diet, meditation, etc. Also by putting these things into practice, you reap all the benefits you want your audience to receive. Helping ourselves enables us to best support and uplift others.
- **Embrace boundaries and balance.** Don't feel pressured to share and ensure you feel comfortable with all the details you are sharing. Balance being honest and real in a way that's healthy and not over-sharing and uncomfortable for you.
- **Be ready.** Consider your personal recovery journey, and consider the timing and your personal readiness to share (American Foundation for Suicide Prevention, n.d.).
- **Have a plan to deal with negativity, practically and emotionally.** If you're using social media as a tool to share your story, know how to block or report users who leave comments with spam or harmful content. Remind yourself of your purpose and all the good you are doing by sharing your story. One idea is to write a letter to yourself of things to remember if someone criticizes you for sharing, and make sure you have it readily available, perhaps even by posting it to a wall, or to talk to someone you trust to process the incident and how it may have impacted you.

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CONSIDER THE WELLBEING OF OTHERS

- **Avoid stigmatizing and contagion-spreading language** (American Foundation for Suicide Prevention, n.d.). Please reference the Psych Hub Communication Guide for recommendations on language best-practices for mental health, substance use, suicide, and representation of diverse identities.

- **Provide disclaimers.** Use verbal and/or text disclaimers to communicate that the content you are providing is no substitute for professional care or medical treatment. Include a statement that people should check with a licensed provider before making adjustments to their lifestyle or treatment plan that could pose a risk to themselves or others.

- **Point to help.** Include information on accessing crisis or mental health services somewhere within or attached to your content. It's good practice to include the information for a suicide hotline when discussing mental health or substance use, and it should ALWAYS be included when discussing suicide (American Foundation for Suicide Prevention, n.d.). For the United States, that is the National Suicide Prevention Lifeline (call 1-800-273-8255), and the Crisis Text Line (text TALK to 741741). For a list of hotlines for different audiences and issues, visit psychhub.com/hotline.

- **Use content warnings.** People who have experienced difficult or traumatic events should be able to make an informed decision about whether or not to view sensitive content. Disparaging talk about "trigger warnings" has emerged in recent years in part due to misunderstanding the difference between content notices (or trigger warnings) and completely shielding people from challenging subject matter. We affirm that there is a time and a place for people to engage with content that is potentially challenging. However, providing content notices aligns with input from survivors (Abadi, 2014), demonstrates care and empathy, prevents people from being unexpectedly triggered or experiencing preventable emotional distress (Benness, 2017), and allows people to prepare through self-care and coping strategies before reading or viewing the content (LSA Inclusive Teaching Initiative, n.d.). The University of Michigan offers a non-exhaustive list of topics for which content notices are recommended: (LSA Inclusive Teaching Initiative)
  - Sexual assault and abuse
  - Self-harm and suicide
  - Eating disorders and body hatred
  - Substance use
  - Violence and weapons
  - Death or dying
  - Discrimination (e.g,. racism, ableism, sexism, classism, transphobia, homophobia, fat phobia)

- **Respect the privacy of others.** Only share your own story, and avoid naming others in your life, even close family, who have mental health or substance use issues. Don't discuss other people or their experiences without their express permission.

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ACKNOWLEDGEMENTS AND REFERENCES

Psych Hub Lived Experience Guide was authored by Emily St. Amant, LPC-MHSP and Abigail Asper, LMSW and reviewed by Sakinah Omar, LCSW.

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