



## Tip Sheet: Sharing Your Lived Experience Story

People with lived experience (PWLE) are often asked to share their stories and personal experiences. These stories serve as powerful tools for bringing about change in research and in the health care system. As a L.E.A.R.N. member, there may be an expectation that you will share your personal experiences with your research team members. It is of fundamental importance that PWLE are enabled to choose when, and about what types of information, they share with the group.

Remember...

- Sharing your story is VOLUNTARY
- Your story will remain CONFIDENTIAL
- YOU are the EXPERT

The way you present your story can have a long-term effect on the way people view you and others in similar circumstances. Consider the following questions prior to agreeing to share your story:

- What am I willing to share?
- What do I feel is too private to share?
- What will my story teach those who are listening?
- Have I had negative experiences that are still bothering me and will be difficult to share in a constructive manner?

Plan what you will share and how you will share it. Your story is a precious resource, use it thoughtfully and wisely.

### Why Share Lived Experience?

- Research suggests that elevating the voices of PWLE 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.
  - When people share their experiences with peers in a workplace setting, it may help improve people's wellbeing and foster diversity and inclusion.
  - Support from peers who have also experienced a health concern can significantly reduce readmission rates for hospitalization.

## Sharing Lived Experience Effectively

### Reducing Stigma

- Sharing lived experience is more likely to reduce stigma when stories include...:
  - 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. Health 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. 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. 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 & Community

- 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.

### Other Keys to Effectiveness

- 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 language. For example, "This will help." or "The solution to this problem is \_\_\_\_." Instead of using absolutes like "will", "always", "never," use 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. 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.
- Be ready. Consider your personal journey, the timing, and your personal readiness to share.
- Have a plan to deal with negativity, practically and emotionally. 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, or to talk to someone you trust to process the incident.

### Consider the Wellbeing of Others

- Avoid stigmatizing language.
- Provide disclaimers. Use disclaimers to communicate that the content you are providing is no substitute for professional care or medical treatment. Note that people should check with a licensed provider before adjusting their lifestyle or treatment plan that could pose a risk to themselves or others.
- Use content warnings. Providing content warnings can demonstrate that you care, prevent someone from being unexpectedly triggered or experiencing preventable emotional distress, and allow people to prepare through self-care and coping strategies before reading or viewing the content.
- Respect the privacy of others. Only share your own story, and avoid naming others in your life, even close family, who have health issues. Don't discuss other people or their experiences without their express permission.