



## TIPS AND TRICKS FOR LIVED-EXPERIENCE ADVOCACY

### **PURPOSE:**

These tips and tricks have been prepared by lived-experience advocates as a guide for those who may wish to share their story with the public domain and/or media.

### **Protect yourself first**

Be aware that every presentation will require your energy, stamina and personal investment. It can be draining and overwhelming. *For example: I rarely speak without given the chance to prepare and know who is in the room. I even more rarely speak without being financially compensated.*

### **Remember, no one owns your story but you**

Do not allow others to sensationalise or victimise you or your story. Many will want you to speak only on what they want to hear about. Your story is your own and you can say no. *For example – I no longer speak in detail about specific events that concern my biological family.*

### **Ask for a theme or a topic to focus on**

Our stories are long and complex. Focusing on one aspect of it or telling a linear story that has a relation point is a lot easier and will flow better. *For example: the journey of DBT programs or the harm minimisation strategy I used to stop self-harming after 20 years.*

### **Write your presentation down and practice it**

Write it over and over and share it with people who know you well and even someone who doesn't (like an organiser). This allows you to get perspective.

### **Include trigger warnings**

Remember that what might not seem like a traumatic event or traumatic language to you could be to someone else. ALWAYS let people know before you mention trauma, domestic and family violence, sexual assault, self harm and suicidality. Always invite the audience to feel safe to leave the room at any time. Always inform the audience if names or images of Aboriginal and Torres Strait Islander people will be shared.

### **Know your audience**

Ask the organiser who you are speaking to and write your presentation accordingly. *For example – when speaking to a room of consumers, it may be triggering and probably unhelpful to go into detail about trauma or the public mental health system procedures, unless you are asked to.*

### **Think carefully about the repercussions your story will have**

Many lived-experience advocates face the impact of the world knowing personal details about them. This can affect your future career, relationships and anonymity. Make sure what you are sharing you feel ok with the world knowing. For example - a Radio National interview went international. Be aware that photos may lead to people in your neighbourhood identifying you.

### **Acknowledge power and control dynamics**

In many places, those with Prof. or Dr in front of their names command respect; most lived-experience advocates have to earn it. Never allow a person in power to speak for or about you and be

mindful of this inequity. For example – having a support person or mentor is great for this. You can check-in with them. If you do not have someone with you ask the organiser who you could talk to.

### **Make it FUN**

What we talk about is heavy so relax and make a few jokes. I always have pictures of Skylar (my pug) in my presentation as they make it more human and help others connect.

### **If you identify a problem, come with a solution**

This is a big one. Don't go in guns blazing and leave on a negative note. Always offer solutions and create opportunities to work together to fix what is broken. *For example – offer to work closely with an organisation to overcome their reticence and support consumer engagement.*

### **Distract the audience to help you feel less “watched”**

I like to have a presentation behind me that is playing at all times. Even if it's just pictures of my dog or artwork. People will focus on that and won't stare you down!

### **Get invited back**

Be kind, patient, professional and rational Be tough, advocate for your rights and others, but do it with dignity, integrity and respect. Have a systematic and systemic long-term approach and put in the hard work. No-one responds positively to blame and shame.

### **Acknowledge and face internal stigma and discrimination within the sector**

For many diagnoses, this is still a massive issue. The sector is only recently opening up and hearing the voices of lived experience. *BPD is still incredibly stigmatised, discriminated against and has one of the smallest pools of advocates.*

Be aware - for someone with lived experience it is often extremely challenging to hear professionals speak in their 'professional jargon' about us. This requires a culture change which, with time and perseverance is happening. *'Your story' is important to you. Not everyone will agree with you and unfortunately bullying within the sector, and from peers and advocates still occurs.*

### **Prepare for others to disclose**

People will listen to you then feel they have found someone they can confide in, so may come up and speak with you. Many will do this in ways that are not safe or healthy for themselves or you. Get support and training on how to manage this. *For example – I'm fortunate as I learnt those skills during my training as a social worker!*

### **Have an exit strategy**

People will want your attention and time after you speak at events. It can be a harrowing and exhausting experience. Have a way to take a break from this. *For example – bring a support person who is there to make sure you eat, drink, have quiet time and get a chance to debrief. If you cannot bring a support person, let the organisers know that you will need space and time after you present and make sure they facilitate that!*