SANE

SELF-ADVOCACY

Quick Facts

- Self-advocacy is about speaking up for your needs, rights, and preferences within mental health care system.
- You can self-advocate or another person can advocate on your behalf.
- Understanding your needs and strengthening your communication skills are important aspects of self-advocacy, to ensure your choices are respected and appropriate support is provided.

• WHAT IS SELF-ADVOCACY?

Self-advocacy involves asking for what you need and speaking up for yourself and your interests. You can do it on your own or with the support of an advocate or other person. Self-advocacy has three key elements: understanding your needs, knowing the kind of support that might help, and communicating these needs to others

• UNDERSTANDING YOUR NEEDS

It is difficult to self-advocate for what you are feeling when you yourself are having a hard time identifying what your needs are. However, recognising that you have needs as a first step is an important start. Once you recognise your needs, you can then begin to develop an understanding of acceptance that having needs is normal, leading you to build confidence, recognise your rights and to ask for what you need.

• RECOGNISING FEELINGS AND EMOTIONS

Recognising your feelings and emotions can be vital for impactful self-advocacy because emotions influence and inform what you say and do. This is the case for the person with complex mental health issues as well as their carers. As a carer it can be challenging to acknowledge your own feelings when the focus is often on the person you are assisting, sometimes even leading to the suppression of your own emotions. There are tools available to help you recognise and understand your emotions and practice this skill. For example, psychologist Robert Plutchik devised an emotion wheel based on eight primary emotions (see Figure 1). This wheel identifies your emotions but also the degree of the emotion you could feel at a given time. For example, within the emotion of joy, you could feel ecstasy or serenity. This can help you understand the range and complexity of your



emotions which can inform the way you respond, react, and behave to certain situations.

• WHAT DOES SELF-ADVOCACY LOOK LIKE?

Knowing your rights: there are resources available to help you understand more about what your rights are. For example, this<u>video</u> by the Independent Mental Health Advocacy (IMHA) organisation outlines a <u>six-step self-advocacy model</u>. One of the most valuable resources for understanding your rights as a mental health consumer is <u>Mental</u> <u>health statement of rights and responsibilities</u>.

Building emotional resilience: emotional resilience refers to your ability to adapt, change or 'jump back' from a challenging and distressing mental and emotional experience. Building emotional resilience could involve:

- practicing accepting yourself
- learning how to establish and maintain boundaries
- noticing emotions before they become overwhelming
- $\circ\,$ learning how to have open communication about your capacity to care for yourself and others
- $\circ\,$ connecting with others for solidarity and validation
- recognising how emotions feel in your body
- \circ learning how to say 'no' or ask for help when things get too hard
- $^{\circ}\,$ developing strategies that allow yourself to effectively $\underline{\text{communicate}}$ what you are feeling.
- developing different ways to express yourself

Understanding what triggers your reaction to situations: being triggered results in the activation of the sympathetic nervous system to prime our body to protect us, and how we react informs our trauma response. Developing a sense of self-awareness about our trauma response may be helpful in maintaining composure when advocating for yourself and while being challenged in difficult situations. This can equip us with the knowledge and self-awareness to recognise when a situation may be distressing and help empower us to practice regulating our responses to stress.

To learn more about the responses and symptoms associated with each, see <u>The</u> <u>Polyvagal chart of Trauma Responses</u>.

Having a good knowledge of the health and social services system: navigating the complex mental health system across Australia can be quite challenging in terms of understanding which group to refer to in what scenario. A good way to start off would be understanding the several treatment and support options available so you can advocate for the one you believe is the best option for you. See <u>SANE's Treatment for Mental</u> <u>Illness Factsheet</u> and <u>Guide to Mental Health Clinicians</u>.

Each state or territory has a dedicated website explaining the ways to seek support and treatment for people with complex mental health issues and their carers. Some of the websites are listed below for further information.

- Victoria State Government | Mental Health
- Mental Health Commission for New South Wales
- Primary Health Tasmania | Mental Health
- Mental Health Coalition | South Australia
- Mental Health Commission | Government of Western Australia
- <u>Mental health and wellbeing | Health and wellbeing | Queensland Government</u> (www.qld.gov.au)
- Find support services | Queensland Mental Health Commission (qmhc.qld.gov.au)
- NT: Mental health | NT.GOV.AU
- <u>NT: Mental health and suicide prevention support in the NT</u> (mentalhealthnt.com.au)
- ACT: Mental health ACT Government Self-Advocacy (Consumers) Mental Health

Self Advocacy is possible by becoming a member of one of the Statewide Mental Health Consumer Peak Bodies which are Lived Led:

- VIC: Victorian Mental Illness Awareness Council (VMIAC) VMIAC Home Page
- NSW: Being Home BEING Mental Health Consumers Ltd.
- <u>ACT: ACT Mental Health Consumer Network Home ACT Mental Health Consumer</u> <u>Network (actmhcn.org.au)</u>
- WA: Consumers of Mental Health WA (CoMHWA)
- SA: LELAN | SA Lived Experience Leadership & Advocacy Network
- TAS: Mental Health Lived Experience Tasmania MHLET: Mental Health Lived Experience Tasmania – experience, knowledge, change
- <u>NT: Top End Mental Health Consumers Organisation (TEMHCO) Home Top End</u> <u>Mental Health Consumers Organisation (temhco.com.au)</u>

Self-Advocacy is also possible for Carers, Family and Friends through the following Carer Peak Bodies that are (Carer) Lived Experience Led:

- <u>NATIONAL: Mental Health Carers Australia Mental Health Carers Australia | Mental Health Organisation</u>
- <u>NSW: Mental Health Carers NSW Mental Health Carers NSW Empowering Carers</u> <u>for Mental Health Since 1974</u>
- <u>VIC: TANDEM Home (tandemcarers.org.au)</u>
- <u>TAS: Mental Health Family and Friends Tasmania Mental Health Families & Friends</u> <u>Tasmania (mhfamiliesfriendstas.org.au)</u>
- <u>QLD: ARAFMI QLD Arafmi You are not alone</u>
- WA: HelpingMinds is a Provider of Mental Health Education & Support in WA
- <u>NT: Mental Illness Fellowship of Australia (NT) Home (mifant.org.au) Figure 1:</u>

• LEARNING HOW TO BEST COMMUNICATE

It can be important to understand your communication style when advocating for yourself or the person you are supporting. A good resource to help you understand your communication style is the <u>Princeton | Communication styles</u>. Practicing tools and techniques like assertiveness and preparedness can help grow your capacity for effective communication. Another good resource to learn effective communication techniques is the <u>Carer Gateway – Skills Module #2: Effective Communicating Techniques</u>

• HELP FOR FAMILIES AND FRIENDS

Below are some links to useful information for families and friends to support with selfadvocacy.

Self-advocacy and your rights:

- The UN's Universal Declaration of Human Rights
- Mental health statement of rights and responsibilities
- Speak Up Be Heard- Self Advocacy Toolkit
- [Podcast] The Square Peg 98. (S8-E6) The fight for equality in education and work: an inspiring...
- Self-advocacy for the NDIS Workbook
- <u>Self-Advocacy Toolkit Mental Health Family & Friends Tasmania (For Carers, Family and Friends)</u>
- How to Think More Assertively Module
- Mental Health Advocacy e-learning

Self-development, recovery and personal growth tools:

- Improving Assertiveness Self-Help Resources
- <u>A bill of rights for confidence, self-esteem and assertiveness</u>
- Developing Balanced Core Beliefs
- Living Into Our Values Brené Brown
- The Transformation of Silence into Language and Action by Audre Lorde
- [Podcast]: Paradigm Shift with Ayandastood- Episode 10 Finding Your Voice
- Polyvagal Theory: A Science of Safety by Stephen W. Porges
- Why Healing Trauma Starts with Creating Safety

• **RESOURCES AND SUPPORT**

Resources for empowering us to keep speaking up:

- Self-Care for Advocates 101
- Staying Resilient Workbook by Amnesty International
- How Call Out Culture Is A Catalyst For Intersectionality At Work
- Doing Activism My Way by Carly Findlay
- The Revolution Starts With Me! Promoting Self Care & Preventing Activist Burnout by Nicole Clark & A...
- Effective Activist Zine An Evidence-Based Guide to Progressive Social Change
- How to Use Activism as Self-Care
- How to be an Activist Without Burning Out
- [Podcast] Unlocking Us with Brené Brown- Brené with Laverne Cox on Transgender Representation, Advoc...
- Solidarity with Palestine: Free Resources and Further Reading | Verso Books
- Why self-care and collective wellbeing are critical to winning change

• FREQUENTLY ASKED QUESTIONS

Based on the discussion with a SANE Peer Support Worker about advocacy, agency, authenticity and the power of using your voice: Speak Up: The Power in Using Your Voice

1. How do you build confidence in speaking up, especially about what your needs are?

Practice accepting that having needs is ok! Practice thinking of yourself as a human being that needs certain things to survive and thrive which is help you move towards being able to embrace what you need. Know what your rights are – anything from knowing consumer rights when accessing care and treatment to thinking about what your human rights are in terms of safety and security in relationships. This can challenge how you think about your needs. Start to give yourself some grace – building confidence is hard and it can take a lot of work. Put values into action to help yourself feel more confident. How you act is quite subjective but some of the examples listed by the peer support workers were – caring about community, valuing honesty, practicing allyship and so on and so forth.

2. How does speaking up relate to safety and self-expression?

A quote by Audre Lorde shared by the PSW that really resonated with them was: "Of course, I am afraid, because the transformation of silence into language and action is an act of self-revelation, and that always seems fraught with danger." Speaking up goes hand in hand with the experience of being perceived. There is a tension between safety, speaking up and people pleasing. While speaking up can be about expressing your needs and values, it can be hard for anyone who might have people pleasing tendencies. Speaking up can be confrontational and terrifying for some. You can start small by building trust in yourself, try to restore connection with your sense of agency by learning how to say no and cultivate a deeper understanding of yourself and your neurophysiological functioning.

Additional resources:

- Podcast: Episode 10 Finding Your Voice- Paradigm Shift with Ayandastood
- The Importance of Safety, Belonging, Self-Regard by Margaux Feldman

3. How can we put into action what our values are?

Start by asking, what is truly important to you? What do you like? The relationship that you have with yourselves can become a driving force for action in situations related to speaking up about safety and self-expression.

A resource to understand what your strengths and values are to answer those questions:

• VIA Institute on Character - Strengths survey

Be mindful of where you are at before you put anything into action. If you are feeling at limited capacity, come back to actions of:

- Communication "the best way to get what you want is to tell people what you want"
- $^{\circ}\,$ Choice reconnect to your sense of agency of being able to make decisions, and choosing how you want to show up
- $^{\circ}\,$ Connection to yourselves, to your bodies, environment, personal relationships, and community
- $\circ\,$ Compassion it is the utmost act of care, and it shifts the focus away from you to others
- Creativity move, imagine, express, create. Lean into the methods that become the vessels of what you value.

A resource to read more about this topic:

• Living Into Our Values - Brené Brown

4. How can you feel more prepared for difficult conversations?

Difficult conversations can look different for everyone. For someone it might be feeling prepared to disagree with a mental health diagnosis or for some it might to talk to their housemate about week-old dishes. A difficult conversation can be political, can be about life and death or can be about what to have for dinner.

Some ways to feel prepared include being mindful of your approach – make a plan, be prepared, take responsibility for how you engage, acknowledge accountability in the circumstances. Have the capacity to engage with your words whenever you can. Be aware of your window of tolerance, which is, engaging in hard conversations only if you have the capacity to do so. Engage with a wise mind and be careful to not make assumptions.

Be present, minimise distractions so you can actively listen, speak with honesty and integrity so you can trust the other person's word too. Know that you cannot control how the other person responds. It takes vulnerability to be present and willing to accept accountability. It takes emotion regulation skills to be able to respond and not react. Recognise the difference between constructive criticism and attacking.

Acknowledge the power and privilege in speaking up in challenging conversation and navigating conflicts. Be aware of the power imbalance that could possibly impact engagement (patient – doctor/mental health professional). Develop a sense of self-awareness about how you respond to stressful situations to recentering and maintaining composure when being challenged <u>Nervous System Responses (for visual learners)</u>.

Resources to help with difficult conversations:

- DEAR MAN- Interpersonal Effectiveness Tool
- We Have to Talk: A Step-By-Step Checklist for Difficult Conversations Be willing to understand that you may not always walk away with the expected outcome.

Be willing to compromise and collaborate and knowing that sometimes walking away is the best current outcome for the situation.

5. How might you be able to care for yourself while advocating for yourself or as a carer? What does self-care look like in practice when advocating?

- Give yourself permission to feel your feelings allow for your emotions to exist as they are destined to – do not repress, avoid, compartmentalise, distract them. Advocacy can be uncomfortable so practice tolerating discomfort. Speaking up can be loud, intense, unfamiliar, and stressful so build resilience towards discomfort.
- Respect your boundaries ask hard questions such as: how tired are you? Where is your capacity at today? Advocacy can be distressing at times, and we all have our limits. Be conscious of how your engagement in advocacy impacts your mental health – what are the risks that come up with being an advocate.
- Mindfulness can help keep in check what you can control in a situation and can also help sustain an advocacy practice. Recognise that sometimes advocacy takes time and patience, and you might be in it for the long haul.
- Practice nervous system regulation techniques to manage stress and cultivate safety. Start here: <u>A Beginner's Guide To Polyvagal Theory by Deb Dana</u> and for a fantastic resources of tools check this out - <u>The Nervous System Regulation Mega-Toolkit | 115 Exercises, Techniques and Practices</u>
- Embrace solidarity lived experiences are so significant when practicing selfadvocacy. Learn the importance of sharing perspectives and connect to other advocacy groups to feel a part of a community.
- Ask for help you do not need to know everything. Sometimes it can be validating to have another person hold onto hope for you when you might have run out of strengths to hold onto it for yourself.