

SPEAK UP.

BE HEARD

Self-Advocacy Toolkit

A Workbook to prepare yourself to
speak up for what you need.

CoMHWA



Consumers of Mental Health WA (Inc)



Government of **Western Australia**
Department of **Communities**

This project is an NDIS Information, Linkages and Capacity Building (ILC) initiative. For more ILC events and resources please visit: <http://www.disability.wa.gov.au/wa-ndis/wa-ndis/information-linkages-and-capacity-building/resources>

A Consumers of Mental Health WA Workshop

This workshop is to help gain your confidence when talking to services or to your supports like your case manager, support worker, GP and psychiatrist.

SPEAKING UP FOR YOURSELF

Speaking up in such a way that you will be heard can be tricky, many obstacles can get in the way. Some of the obstacles that can get in more way include:

- Feeling distressed and overwhelmed*
- Finding it hard to put into words what you want to say*
- Not knowing what you do want to say*
- Fear you will be misunderstood*
- Past experience where speaking up did not go well*
- Fears of being aggressive or passive when you do speak up*
- The perceived consequence of speaking up carries too much risk*

This toolkit will help you to:

Pre-prepare Write the important points down, talk to others. Be prepared for big emotions- aware of your likely reaction to these emotions and have a plan.

- know what you want to say to help you find your voice
- figure out what and how to say it

Realistic Outcome- Know what outcomes you will be happy with, know what you are prepared to let go of, ask questions to find out options.

- know how to ask the right questions to help you be understood

Responding if it does not go the way you expected- Know your rights and your responsibilities- Be prepared to own your part in it. Be prepared to hold others to account- ask others- what are you prepared to do ...who else in your organisation can advise me on my options?

- gain awareness around decision making and choices.

Essentials for Self Advocacy



Self Awareness

Being aware of your expectations, your aim and purpose, and your emotional reactions.

Knowing what your rights and responsibilities are and aware of what is realistic .

Information



Approach

When the aim is resolution the outcome is likely to be different to when the aim is confrontation. Your outlook and purpose can influence the outcome.

Use confident, calm and simple **LANGUAGE**, and **LISTEN** to understand another's perspective. Be curious to **LEARN** and expand information, knowledge and skills.

Do



SELF-ADVOCACY

“Self-advocacy is the ability to speak-up for yourself and the things that are important to you. Self-advocacy means you are able to ask for what you need and want and tell people about your thoughts and feelings. Self-advocacy means you know your rights and responsibilities, you speak-up for your rights, and you are able to make choices and decisions that affect your life. The goal of self-advocacy is for YOU to decide what you want then develop and carry out a plan to help you get it. It does not mean you can’t get help if you need or want it, it just means that you are making the choices and you have to be responsible for the choices you make.”¹

Self-advocacy is speaking up for yourself.

Speaking up for our needs commonly follows a simple cycle. When speaking up for our needs it is common to have to move back and forth through these stages of self-advocacy



THE SELF-ADVOCACY CIRCLE



Step 1: DEFINE the need

Problem- What is the problem?

Issue- What is the impact on your life or wellbeing?

Wants- What needs to change? What do you want?

Step 2: PREPARE to speak up

- Seek good information
- Enlist help
- Rehearse the conversation
- Consider your responses and reactions

Step 3: Take ACTION

- Speak up and communicate your need
- Listen to understand
- Assess the options
- Make an informed choice

Step 4: LEARN

- Are there other steps to meet your need?
- What could you do better next time?
- What did you do well?
- What did you learn about yourself?

¹ <https://mhcc.org.au/media/76067/certivmhpw-pfsa-resource-book.pdf>
Consumers of Mental Health WA www.comhwa.org.au

DEFINE YOUR NEED

One way to think about what your needs is that needs are made up of the problem or problems that are being experienced, the impact these problems are having and what you want to change.

Have a go at completing the sentences to try and define your need.

My problem is _____

It makes me feel _____

The effect on my wellbeing is _____

What has helped me before is _____

The things that haven't helped are _____

I would like it if _____

Can you make a **CLEAR, CONCISE, COHERENT** statement of your need?

For example,

- **PROBLEM:**
 - Moved to a new house recently
 - Physically can't unpack
 - Have no one available to help
- **IMPACT**
 - Overwhelmed and depressed
 - Mentally spiralling
 - Getting other help but not with this
- **WANT**
 - Immediate help with cleaning and unpacking
 - More hours of support to assist with this
- **CLEAR, CONCISE, STATEMENT of need**
 - I have moved to a new house recently, I am finding unpacking overwhelming, physically impossible and it is causing me to spiral mentally. I would like to get some extra hours of support to begin untangling the mess at home.

Try writing your own statement of need now: _____

Knowing yourself as a starting point

Knowing yourself is helpful when seeking help and making the right choice for you. Fill out the following to take an asset inventory snapshot.

<p>My Strengths</p> <p>I am good at.. I find it easy to.. I have been able to..</p>	<p>My Challenges</p> <p>I find it hard to.. It is difficult for me to.. I sometimes react...</p>
<p>My Community</p> <p>I like going to.. My local services are.. My community groups are...</p>	<p>My Supporters</p> <p>My personal supporters are.. My health supporters are.. My support services are...</p>

SPEAKING UP CAN BE DIFFICULT

Conversations are usually difficult because of-

- Distress and disappointment
- Heightened emotional reactions
- Difficulties to be challenged
- Repetitive patterns
- Feelings of helplessness
- Fear of reaction
- Triggers own personal experiences

Overcoming the obstacles and barriers to expressing your needs and wants helps when decision making and exploring your choices. What are your difficulties.

I find speaking up difficult because...

I struggle to speak up to... because...

The things that have helped before are...

I can prepare for these challenges by...

Who can I ask for help?

Know your rights and responsibilities

You have the right to be treated equally, respectfully and fairly without discrimination

You have a right to privacy and confidentiality

You have a right to make a complaint

You have a right to expect people to do what they say they'll do

You have a right to receive good quality services

You have a right to be informed

You have a right to make decisions about your support.

WHAT IS GOOD INFORMATION?

Whether the information you find is good or not depends on a number of factors, such as the source and purpose of the information. Friends, peers, family can all be sources of information as can the internet, library and other written forms of information.

Gathering good information to help you make your choices is key to exploring options. There are all sorts of ways of finding information out, talking to people and hearing their experiences, information on the web, books and pamphlets, information sheets and social media. Below is a checklist to help work out if the information you have is helpful and in what way it is useful.

Some of the ways we can check information are to ask;

Is the information RELEVANT?

- Is the information needed, does it relate to me and my situation?

Is the information RELIABLE?

- Is the information from a reliable source?

Is the information CONSIDERED?

- Has the information been reviewed by a number of different sources/people, are these reputable?

Is the information based on EVIDENCE?

- Are there facts, figures, examples from a number of places/people that support the information?

Is the information ACCURATE?

- Are the details true?

Does the information contain BIAS?

- The people providing the information have their own point of view or special interest?

Is the information TIMELY?

- How does the timing of the information impact whether I trust the usefulness of the information?

PUT IT INTO ACTION

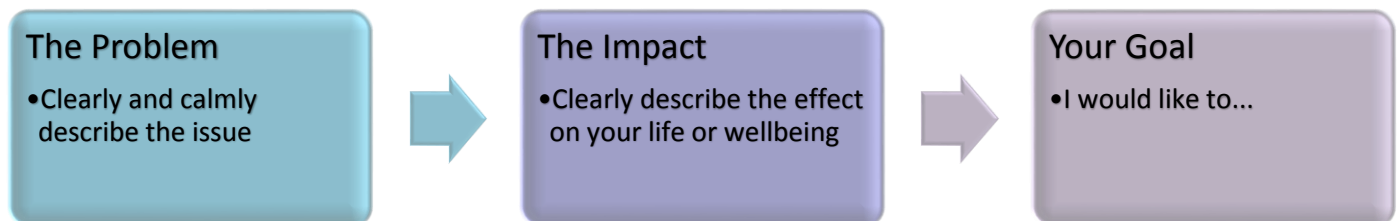
LANGUAGE

1. **Speak with a view to create understanding-** Eg: Instead of saying “You talk too fast,” say something like “I find it hard to listen when things are fast, are you able to slow down a little”
2. **Talk from your knowledge and experience-** you are the expert on how you experienced a situation or problem. If you speak from how you experienced a situation or problem you are providing the listener with new information. This information is of value to improving understanding. Using “I” statements helps, for example “I find it difficult to”
3. **Plain, non-inflammatory words** Seek to understand and invite understanding rather than defensiveness and confrontation. Using phrases like” Can you please explain that further, I would like to understand” Or “I am wanting to say this so that you have a picture of what I am experiencing” etc...

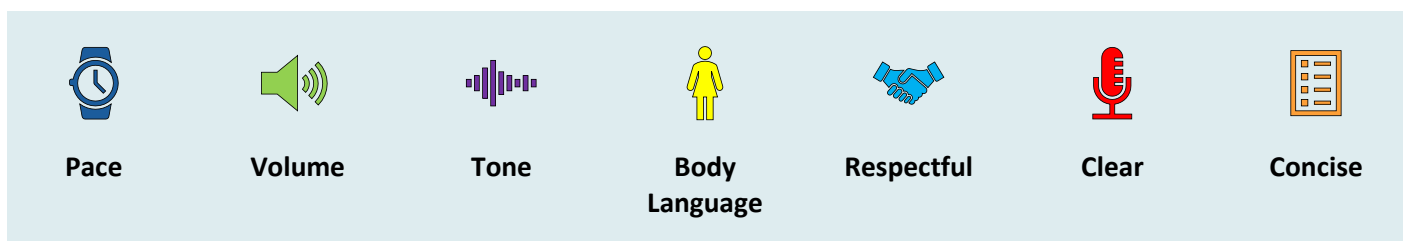


REHEARSE THE CONVERSATION

Practicing what you are going to say helps you to be prepared. If you are prepared you can start the difficult conversation with a clear, calm, concise statement. It helps to write it down.



TIPS FOR SPEAKING UP



Pace- Often when feeling uncomfortable about doing something people speak fast, slow down and breath between sentences. If you need to take more time, you can slow the conversation down or put a stop to it if necessary e.g. “I have a lot to think about when would be a good time to continue this conversation”.

Volume- Regulate how loudly you are speaking, breathing can help to manage this.

Tone- Tone can add to the meaning of the words by communicating emotions and expectations. Be aware of your tone of voice a firm but friendly tone is often suitable for a number of different situations.

Body Language- non-threatening body language is best that still shows that you are listening, paying attention and engaged in the conversation.

Respectful- Respecting the rights and responsibilities of the people involved.

Clear and Concise- Clarity is often best achieved when you use key words, find out what the key words are for your situation, stick with one point at a time rather than rambling many points at once, limit storytelling and instead provide short explanations. Ask yourself am I trying to explain with the intention of convincing the person to understand me or am I stating a fact and asking for my realistic needs to be met.

To prepare yourself spend a few minutes writing down your responses to the following questions.

Things that help me with my language are...	<hr/> <hr/> <hr/> <hr/>
I am good at...	<hr/> <hr/> <hr/> <hr/>
It is difficult for me to...	<hr/> <hr/> <hr/> <hr/>
Words to use...	<hr/> <hr/> <hr/> <hr/>
Words to try to avoid...	<hr/> <hr/> <hr/> <hr/>
Things that have helped me before are...	<hr/> <hr/> <hr/> <hr/>
Self-talk I can use to keep my voice clear, confident and calm...	<hr/> <hr/> <hr/> <hr/>
The ways I can prepare to speak up are...	<hr/> <hr/> <hr/> <hr/>
Things that have helped me before are... I am good at...	<hr/> <hr/> <hr/> <hr/> <hr/> <hr/>

LISTEN

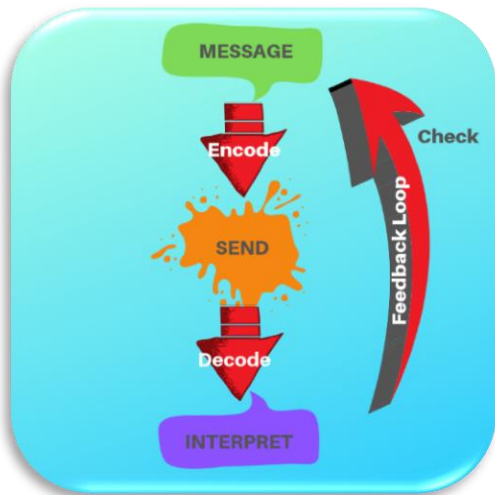
After we have spoken up for our needs, we need to listen. We need to hear the response to achieve the goal. It is important that we listen with purpose. We may be listening to learn, for answers to questions, to get information or to understand something or to inform our questions to ask.

Hear what the other person is saying, not just the words but the message they are trying to give.

Tune in to their non-verbal cues.

Check that they understood you and you have understood them. Common listening tips are

- Maintain eye contact
- Be present
- Pay attention
- Keep an open mind
- Listen to hear not to respond (don't get defensive)
- Try to create a mental picture of what the person is saying (try to see things from their point of view)
- Try to avoid interrupting (if needed do so politely)
- Be curious- "I would like to understand.... can you please explain..."



Being able to communicate well means using clear and simple language to communicate the message. Simple language is used as it is less open to interpretation. Once you have put your words into a message and it is sent with a firm but friendly tone of voice, the message is then received. The person tries to make sense of the message based on their current knowledge and understanding. At this point it is important to check for the person has understood the message in the way you intended.


WHAT HELPS ME LISTEN? _____


WHAT CAN I SAY IF I THINK THE OTHER PERSON HAS DECODED MY MESSAGE INCORRECTLY? _____


HOW CAN I CHECK I HAVE UNDERSTOOD WHAT THE OTHER PERSON HAS SAID? _____


ASKING THE RIGHT QUESTIONS


Asking questions is a useful tool when advocating for your needs to be met. Some tips to help ask the right question include- finding the right time, planning your questions, and know the purpose for the question


 No such thing as a stupid question

 Write them down

 Direct it to the right person

 Questions can generate more questions

 Have a starting point

 Be brave

Self-reflection questions to inform your questions. Ask one question at a time.

1. **What** do I want to know?
2. **Why** am I asking this?
3. **Who** am I asking?
4. **When** is an appropriate time to ask this?
5. **Where** should I ask them?

Prepare your questions-

What do I want to know?

Why am I asking this?

Who am I asking? When is it an appropriate time to ask?

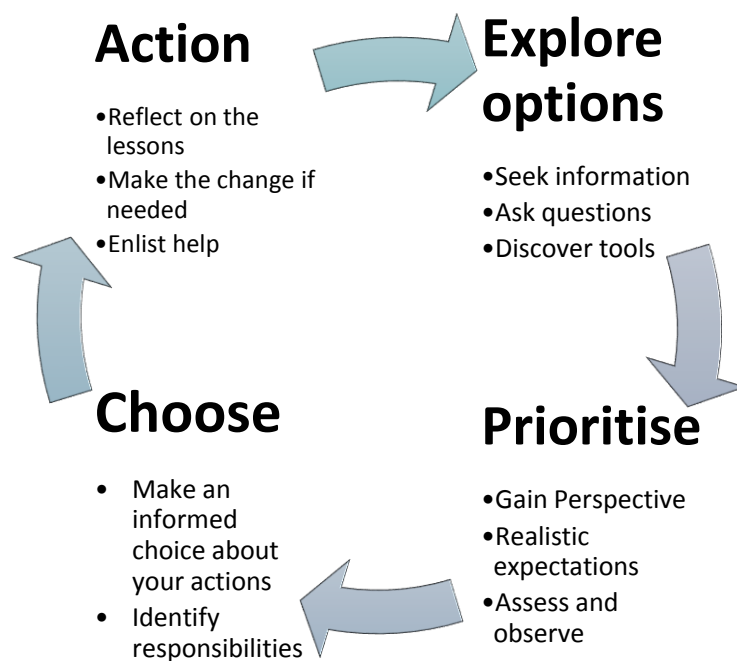
How can I frame the question well?

What is my plan if I do not get the answer I want?

How do I follow-up?

LEARN

Self-advocacy is a skill that can be learnt. The cycle below explains the learning process involved in advocacy and decision making.



MAKING A CHOICE

Principles of Decision Making

- 1 Everyone has the right to make decision about the things that affect them
- 2 The persons ability to make decisions must be assumed
- 3 Every effort should be made to support people to make their decisions
- 4 Capacity and capability is specific to each individual decision
- 5 People have the right to learn from experience
- 6 People have the right to change their minds
- 7 People have the right to make decisions others might not agree with

Making a choice can be tricky. When we are able to explore our options and prioritise we are able to make a choice. When making a choice I can;

- Take my time
- Ask questions
- Seek information
- Use helpful decision-making tools, for example-
 - o Option grids
 - o Pro's and Con's list
- Reflect on my lived experience
- Talk to my supporters
- Seek expert advice
- Make use of supported decision making or shared decision making

What has helped me make a choice before?

Supported Decision Making



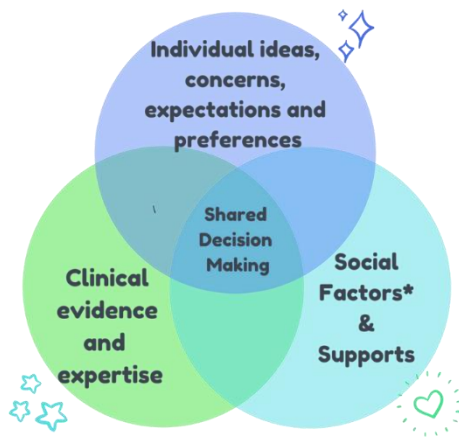
In times where it is difficult to see things clearly supported decision making is a process whereby another person can assist you to make your own decisions.

Supported decision making empowers recovery by providing you the opportunity to develop and pursue your own goals, make choices about your life and exercise some control over the things that are important to you. You determine the support you receive.

Supported decision making is based on encouraging a person's autonomy, the person remains at the centre of the decision-making process at all time.

Shared Decision Making

Being active in treatment and recovery decisions and making decisions together is based on having an open and honest relationship with your healthcare professional. It is a respectful exchange of information between two experts.



“Shared decision making (SDM) has been defined as: ‘an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences’”²

Shared decision making is the process of using your personal expertise, preference and values and the doctors clinical experience to decide on health care decisions. To make a shared decision you need to use yourself advocacy skills to represent your needs, wants and preferences.

TAKE CARE OF YOU

- **Realistic Outcome-** Know what outcomes you will be happy with, know what you are prepared to let go of, ask questions to find out options.
- **Responding if it does not go the way you expected-** Know your rights and your responsibilities- Be prepared to own your part in it. Be prepared to hold others to account- ask others- what are you prepared to do ...who else in your organisation can advise me on my options?
- **Be prepared for big emotions-** aware of your likely reaction to these emotions and have a plan.



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² https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3445676/pdf/11606_2012_Article_2077.pdf