

Adapted from  
the artwork of  
Jasmine Sarin

# Your Guide to Being a Consumer or Carer Representative

Ways to Partner with Mental Health Drug and Alcohol



FOR A DIGITAL COPY OF THIS  
GUIDE, PLEASE SCAN THE  
QR CODE WITH YOUR DEVICE



**Health**  
Western NSW  
Local Health District

This document was developed in  
partnership with consumers and carers

Western NSW Local Health District acknowledges the traditional custodians of the lands across our region. We acknowledge that we live and work on Aboriginal lands. We pay our respects to Elders past and present and to all Aboriginal people.



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## Interpreter Services

We provide a free interpreter service to people who do not speak English or who are deaf. Please ask our staff if you need an interpreter.

**Need an Interpreter?**



Ask one of our staff for help.



## Welcome from the Director

This guide is for consumers and carers who would like to partner with WNSWLHD Mental Health Drug and Alcohol Services.

In a partnership approach, the people who provide services and the people who use services come together as equals to help make mental health services the best they can be. This may be called consumer or carer representation.

The guide is designed to:

- Provide information on partnership roles
- Provide information on support and self care
- Provide an overview of advocacy and consumer representation

Thankyou for your time and commitment to partner with Mental Health Drug and Alcohol and to be part of the work being done to enhance health outcomes for all.

We recognise that your lived experience brings a different view of accessing or receiving services. Hearing your experience helps us to deliver safe and high quality services. It's about working together to improve services, improve our culture and improve people's lives. You will make a difference to the people and families who use health services. Thank you for your contribution.

**Jason Crisp**

If you are an Aboriginal or Torres Strait Islander or a person from a culturally or linguistically diverse background, your unique and personal perspective is important to help inform the cultural safety and cultural appropriateness of MHDA. You can make a difference to the future health outcomes of your community.

## Welcome from Consumer and Carer Partners

As a consumer partner for over 10 years, I commend this opportunity to you as a real and significant way to support your peers. The process of reform and service development requires your experience based input to assist MHDA in implementing requirements for the delivery of recovery oriented services and trauma informed mental health care. As you progress along this path, I hope you find, as I have, that in serving your community you discover a deep satisfaction which contributes greatly to your own wellbeing. Thank you for your commitment to this essential aspect of healthcare in this community.

### **Mark Noble**

I would like to welcome you as a contributing partner in helping MHDA to better meet its goals of 'effective partnerships with consumers and carers, good consumer experience and high quality health care'. MHDA is a large, complex service. The ways that services are delivered to consumers and carers is governed by laws and policies that can seem impersonal. However, engagement with MHDA services is deeply personal, and the experience of participating in these services can be complex. Your experiences and perspectives are unique and valuable. . Becoming a partner with MHDA (in ways that best suit you), is a way of ensuring that your voice is heard. Your insights and ideas will help the service better meet your needs, and the needs of others.

### **Helen Pokorny**





## Speaking Up: Advocacy and Partnerships

Everyone in mental health has a different experience and perspective and that's why we need to hear from you. To help build a service that meets the needs of many different people, it is important to hear from many different people.

Your role is to complete the picture.

Effective advocacy promotes, protects and supports a person's, or group's, full and equal human rights. Advocacy is at the core of being an effective consumer or carer representative.

### Self Advocacy

Self advocacy is when you speak up on your own behalf or for your own interests. You can advocate for another person on their behalf, for example a carer or support person advocating for the person they are caring for. In self advocacy you may speak specifically about a circumstance that has affected you or your loved one.

### Systemic Advocacy

Systemic advocacy works to solve an issue that affects a large group of people. The sorts of issues this advocacy addresses are often a problem with the system such as information or access to a health service.

### Why is Advocacy Important?

Advocacy is important as it is a way of telling Mental Health when things are working well, when they aren't working well, what is missing and ideas for making things better.

As an advocate you can give the health service information they may need to provide effective care and contribute to care planning.

It may be helpful to have a look at relevant legislation. There are often user friendly guides developed by peak consumer bodies.

The Mental Health Coordinating Council has a good selection of resources for consumers, carers and clinicians.

<https://www.mhcc.org.au/our-work/resources/>

You will be able to use your advocacy skills in partnerships with the Health District including focus groups, committees and invitations to share your experience and perspectives.

|                          |  |
|--------------------------|--|
| <b>Equal Partnership</b> | Consumers, families and staff work together from the beginning with equal voice and shared ownership and control.              |
| <b>Openness</b>          | Work together on shared goals, trust the process and learn together.   |
| <b>Respect</b>           | Acknowledge and value the views, experiences and diversity of consumers, families and staff.                                   |
| <b>Empathy</b>           | Practice empathy and maintain an environment which feels safe and brings confidence to everyone.                               |
| <b>Design together</b>   | Consumers, families and staff work together to design, implement and evaluate improvements, activities, products and services. |

Adapted from the Agency for Clinical Innovation (ACI)



## What are Partnerships with Consumers and Carers?

Partnerships are a way of working in collaboration with people who use WNSWLHD Mental Health Drug and Alcohol Services. Partnerships in MHDA can occur at 4 different levels.

### INDIVIDUAL LEVEL

Consumers make decisions and participate in planning their own care through informed consent processes such as care planning.

Carers are able to contribute to care planning and are assisted to get support for themselves.

### SERVICE LEVEL

Consumers and carers contribute to planning, implementing and evaluating changes in the services by being involved in committees and reference groups or surveys.

### DISTRICT LEVEL

Participate in policy and planning through committees and networks that report to Mental Health Drug and Alcohol executive.

### STATE AND NATIONAL LEVEL

Planning and development of health services through peak state and national health agencies.

## Examples of Partnerships



Miguel attended a meeting with clinicians and managers to discuss ways of improving communication and teamwork in hospitals.



Josh talked about his health care experience at the Patient Experience Forum. He had many suggestions about ways to improve the system.



Sophie, Naadi and Brian reviewed a patient information flyer about a particular medication to ensure that it could be understood by consumers and carers.



Hannah delivered training and education to mental health drug and alcohol clinicians to help them recognise the impact of caring on her day to day life.



Will was on an interview panel for a drug and alcohol clinician. Will provided an independent and person centred care perspective during recruitment.



Ali, Mary, Rosa and Tam met with 2 staff members to talk about discharge. The staff asked everyone to share their experience of when they left hospital and asked for suggestions to make the process better. The whole group joined in discussions and workshopped different ideas.

*I became a consumer representative to have the chance to influence and maybe change some aspects of MHDA for the better.*

**Mrs B, Consumer, Dubbo**

## Why Have Partnerships?

Partnership and participation is at the core of a person centred mental health drug and alcohol system. Collaborating in the design services or processes will result in benefits for all parties. Some of the benefits include:

- Person-centred approaches to care can lead to improvements in patient and staff satisfaction
- Person-centred approaches to care can lead to improvements in safety, quality and cost effectiveness
- Service delivery is fully informed by the experience and needs of people who use mental health services and their families or carers
- Service delivery models are developed from diverse and experienced perspectives
- Hearing a lived experience perspective can drive cultural change

*Staff want to hear your experiences of the service and how the service can be improved. Staff will listen and talk with you and you will be encouraged to contribute to all discussions. It is an opportunity for you to put forward your views in a clear and respectful manner.*

*Sometimes change does not come quickly and maybe staff will not agree with your perception of how changes should take place. Please keep in mind that what you discuss today may not be seen in practice for some time.*

**Mark**

*I have enjoyed being involved and can assure you that the perspectives and ideas of all consumers and carers are treated with interest, respect and consideration.*

**Helen**



## How can I Provide My Perspective?

### Learn How You Can Contribute

- Ask questions about your role and understand what you can and cannot do, and the level of influence that you can have.

*I am here to learn, I feel heard and understand mental health so much more. **R, Dubbo***

### Be informed

- Find out about the issue being discussed to support your role.
- Do your own research, read more about your area of interest, talk to other consumers, to your family and your friends.
- Highlight gaps in services or care.

*I want to improve the service for others.  
**Mrs B, Consumer***

### Speak Up

- Speak of your experience.
- Speak up for consumer and carer rights.
- You are not expected to have all the answers or solutions but are there to ask critical questions.

### Build Your Network

- Be connected to other consumers and carers with lived experience.
- Get to know other committee members.
- Partnering is relationship based work and the more you connect with others the more effective your involvement will be.

*This is a valuable opportunity to learn how Mental Health Drug and Alcohol works and how they support the community. It also helps me in my other roles.*

**Bruce Prince, Bathurst**

## What are Your Healthcare Rights?

The Australian Charter of Health Care Rights promotes the active involvement of anyone who uses health services in decision making about their individual treatment and care, and in health services and health care planning decisions.

These rights are useful for supporting your views or putting forward a consumer or carer perspective.

### My healthcare rights

This is the second edition of the **Australian Charter of Healthcare Rights**.

These rights apply to all people in all places where health care is provided in Australia.

The Charter describes what you, or someone you care for, can expect when receiving health care.



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AUSTRALIAN COMMISSION  
ON SAFETY AND QUALITY IN HEALTH CARE

For more information  
ask a member of staff or visit

#### I have a right to:

##### Access

- Healthcare services and treatment that meets my needs

##### Safety

- Receive safe and high quality health care that meets national standards
- Be cared for in an environment that is safe and makes me feel safe

##### Respect

- Be treated as an individual, and with dignity and respect
- Have my culture, identity, beliefs and choices recognised and respected

##### Partnership

- Ask questions and be involved in open and honest communication
- Make decisions with my healthcare provider, to the extent that I choose and am able to
- Include the people that I want in planning and decision-making

##### Information

- Clear information about my condition, the possible benefits and risks of different tests and treatments, so I can give my informed consent
- Receive information about services, waiting times and costs
- Be given assistance, when I need it, to help me to understand and use health information
- Access my health information
- Be told if something has gone wrong during my health care, how it happened, how it may affect me and what is being done to make care safe

##### Privacy

- Have my personal privacy respected
- Have information about me and my health kept secure and confidential

##### Give feedback

- Provide feedback or make a complaint without it affecting the way that I am treated
- Have my concerns addressed in a transparent and timely way
- Share my experience and participate to improve the quality of care and health services

<https://www.health.nsw.gov.au/patientconcerns/Pages/your-health-rights-responsibilities.aspx>

## Privacy and Confidentiality

You have a responsibility to comply with confidentiality through the NSW Health Code of Conduct. You will be asked to sign the Code of Conduct.

The code of conduct outlines that you:

- Cannot share information outside meetings
- Cannot share personal information from other consumers or carers
- Should be considerate of other consumers, carers and staff
- Cannot share items from a meeting before they are released publicly
- Should use language that is respectful
- Cannot comment to the media on information from meetings
- Cannot comment on social media including facebook on information from the meetings
- Will be held accountable for maintaining confidentiality and protecting privacy
- May be removed from the committee for breaching these conditions
- May have formal action taken against you for breaching these conditions

If you have any comments or questions about the Code of Conduct, please speak to the District Consumer and Carer Coordinator.



## All About Committees

Committee work is based around discussion of ideas and consideration of options within a meeting structure.

Many committees are made up of health professionals or managers, who bring experience and knowledge to the table but may not have the experience of receiving health care or supporting someone with a lived experience.

Some points to remember are:

- Only share information about yourself or the person you care for that you are comfortable to share.
- Sharing a broader experience of the service and how this has had an effect on you can be more useful than a detailed account of a personal journey.
- You do not have to provide representation on behalf of everyone who uses the service. Consumers on committees are not expected to put forward the views of all people with lived experience.
- Please be on time for the meeting. If the meeting is by videoconference or telephone, it is a good idea to dial in a few minutes early to test your settings. Let the chair know if you are running late or will be absent.

## What are the Roles of the Meeting Chair and Secretary?

The chair runs the meeting by following the agenda and keeping the meeting on time. The secretary keeps a record of the meeting minutes. The roles of chair and secretary can be filled by consumers, carers or staff.

There are a number of tasks for the chair and secretary to do to help coordinate and run the meetings and these may be shared between both people.

- Provide meeting participants with the terms of reference and other relevant documents prior to the meeting.

- Be a point of contact to answer questions and provide any extra information needed for meeting participants.
- Be a point of contact for executive or guest speakers to speak to the meeting group.
- Be a point of contact for guest speakers to request to attend the meeting.
- Coordinate payment for meeting attendance if required.

The Consumers Health Forum has a comprehensive guide to meetings and consumer representation at meetings  
<https://chf.org.au/book/export/html/1062>

## What Can I Do if it is Not Working?

If you feel that your opinion is not being heard or you feel unsupported in your role, you should reach out to the chairperson or the District Consumer and Carer Coordinator. You may be able to work together to fix the problem. If you decide to leave your partnership role, please consider providing feedback to the chair or District Consumer and Carer Coordinator to help improve partnership opportunities.

## Acronyms / Jargon

Sometimes clinicians will use acronyms or jargon. It is important for good health care that everyone understands and can act on the information that is provided to them. Please ask clinicians to repeat anything that is not explained clearly or to repeat the sentence without using acronyms. This can be in individual health care or in meetings or forums.

## The Power of Your Story

You may be asked to share part of your experience to help clinicians understand how people experience the service.

Personal story sharing can be an important part of being a consumer or carer representative and can be powerful educational tool.

A useful resource is Speaking our Minds: A Guide to How We Use Our Stories produced by Our Consumer Place at [www.ourconsumerplace.com.au/files/SpeakingOurMinds.pdf](http://www.ourconsumerplace.com.au/files/SpeakingOurMinds.pdf)

### Telling your story:

- If you are speaking to an audience, you may like to type up your talk with double spacing and/or some big margins, so you have room to add new thoughts or changes on the day.
- It is recommended not to name staff members. It is the experience that should be highlighted for improvement not the people involved.
- Consumers and carers need to be mindful that once they have shared part of their personal story they cannot unshare it.
- Your experience is valuable as it presents another option that maybe wasn't considered before. As part of telling your story you could consider suggesting a change or improvement in process.

*I wanted to aid my recovery by coming to terms with what happened and try to turn it around to something positive.*

**Mrs B, Consumer, Dubbo**



## Before You Start

- Find out who your audience is and what it is you want the audience to learn?
- Ask the facilitator if there is a topic they would like you to speak about.
- Decide what message you want to send.
- Decide what is off limits. Some things may be too personal or too emotional to discuss. It is a good idea to work out beforehand where your boundaries are.
- If you are going to speak about someone else, please ask for their permission or change some details of the story.
- Carers should be mindful and respectful of the person they care for when sharing an experience of caring. To respect their privacy, you could use a made up name or change minor parts of the story.

*I feel people might appreciate hearing about my journey and my experience.*

**Deb, Consumer**

## Afterwards

- Telling your story may be an emotional experience for you and you may like to have a support person with you to debrief afterwards. This could be a staff member or a friend.
- Staff might be interested in asking questions or finding out more information. Consider having contact details available if you are agreeable to being contacted.

## What Training is Available for Consumer and Carer Partners?

Mental Health Drug and Alcohol provide training and education opportunities, including advocacy, co-design training, forums and networking events.

Opportunities for training, networking and support from a mentor will be distributed through the email list or please contact the Consumer and Carer Coordinator if you have suggestions for training needed.

All new consumer and carer partners will be supported to learn and participate in the advocacy roles in Mental Health Drug and Alcohol. There are a number of ways this may happen, please contact Jen Coote for further information on 0409 334 191

*I've learnt new transferable skills such as project planning and negotiation, I've met interesting and like minded people and I've had the opportunity to collaborate on interesting and engaging projects.*

**Mrs B, Consumer, Dubbo**



## Other Committees

There are many committees and opportunities for consumer and carer representation in the Health District. There may be opportunities to bring experiences of Mental Health Drug and Alcohol Services to general health service meetings or committees. Western NSW Primary Health Network (PHN) and Western NSW Local Health District (LHD) both facilitate consumer and carer partnerships and more information can be found on their websites.

<https://www.wnswphn.org.au/advisory-councils>

<https://wnswlhd.health.nsw.gov.au/get-in-touch/giving-back/join-your-local-health-council>





## How Does the District Consumer and Carer Coordinator Support Partnerships?

All staff have a responsibility to consider opportunities to partner with consumers and carers. The role of the District Consumer and Carer Coordinator is to guide these partnerships by:

- Identifying committees that require consumer or carer representation and facilitate the partnership.
- Coordinating orientation and providing ongoing support to consumer and carer partners.
- Coordinating training opportunities for consumer and carer partners.
- Providing training to staff about how to partner with consumers and carers.
- Coordinating training and education opportunities for teams for best practice partnering.

*Please contact Jen Coote on 0409 334 191 or [jennifer.coote@health.nsw.gov.au](mailto:jennifer.coote@health.nsw.gov.au) for more information*

## Your Wellbeing

Choosing to be a consumer or carer partner can be challenging. It is important to take time to reflect how you are feeling in your mind and body in relation to your role.

### Keeping a Balance

If you find that things are not working for you then perhaps it is time to take a break or pull back your involvement. It is your time and expertise, and if you are not able to participate then that is okay, there will be more opportunities. It is about creating a balance in your life that works best for you.

### Self Care

Look after yourself; take time to rest, rejuvenate, eat well and be physically active. Consider people in your network and family who can support you as well as the health organisation you are involved with. Reach out and ask for help if you need it.

### Physical and Mental Health

There will be times where your physical or mental health might affect your ability to be present at a meeting. Please let us know if you need additional support. Ask if you can phone or video conference in, or provide feedback before the meeting by reading papers. You can still be involved without being present at all times.

### Emotional Health

In your role as a consumer representative you will deal with many different personalities, some of whom you may disagree with. Your role is to bring a fresh perspective. This may be emotionally and mentally draining. Think about ways you can manage this. What can you do that allows your mind to de-stress? How do you support your mental and emotional wellbeing? Everyone has their own way to look after themselves.

## What is Health Literacy?

Health literacy is a term that means a person should be given clear health information, in a way they can understand, to successfully manage their own health care. You can support Health Literacy by making sure we provide information that is clear and easy to understand.

The infographic is titled "What is health literacy?" and is set against a light blue background. It features six cartoon illustrations of a woman in an orange dress, each representing a different aspect of health literacy. The top row shows: 1) "your health" with a sad woman; 2) "health & health care information" with a woman looking at a phone and a book labeled "Info"; 3) "your health decisions" with a woman looking at a balance scale labeled "A" and "B". The bottom row shows: 4) "making decisions together" with a woman talking to a doctor; 5) "taking health action" with a woman holding a bow and arrow; 6) "feeling good about your health" with a smiling woman. At the bottom left, it says "AUSTRALIAN COMMISSION ON SAFETY AND QUALITY IN HEALTH CARE" and at the bottom right, "www.safetyandquality.gov.au".

Health Literacy is:

- your health
- health & health care information
- your health decisions
- making decisions together
- taking health action
- feeling good about your health

AUSTRALIAN COMMISSION ON SAFETY AND QUALITY IN HEALTH CARE

[www.safetyandquality.gov.au](http://www.safetyandquality.gov.au)



## A Note About Language

Language has an impact on people and the use of inclusive and contemporary language minimises stigma and changes culture over time.

After consultation, the terms used in this guide are:

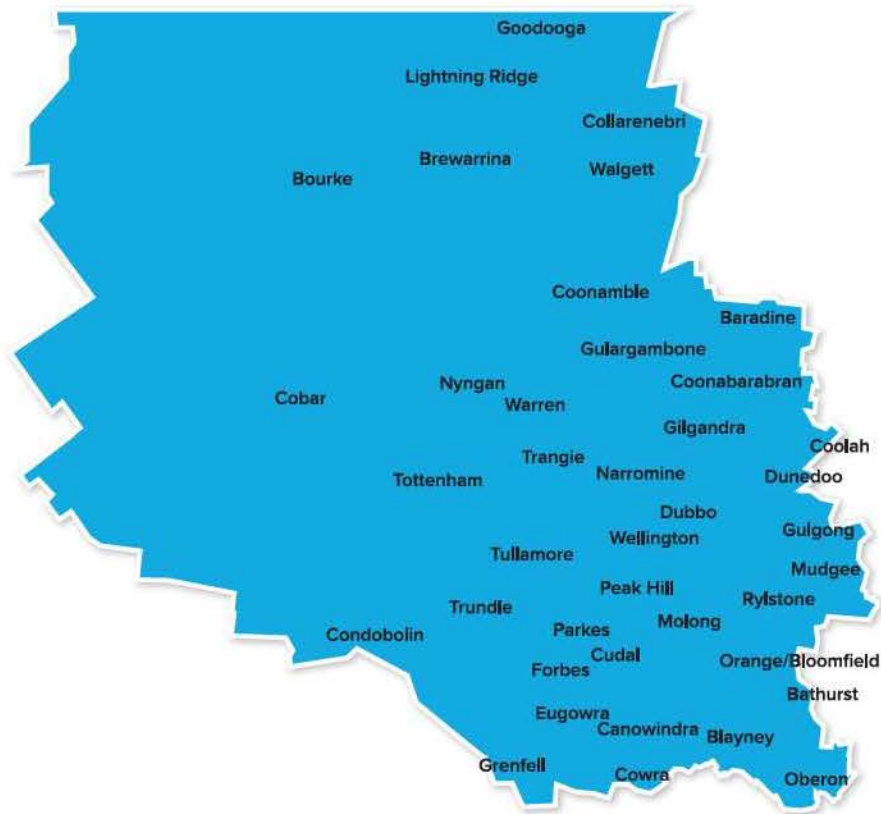
1. 'person/people with lived experience' refers to a person who:
  - has had an experience of mental illness and has recovered
  - are currently experiencing mental illness and are on their recovery journey
  - has had a drug or alcohol experience and have recovered
  - are experiencing a drug or alcohol problem and are on their recovery journey
  - has a current or previous experience of caring.
2. 'patient' refers to a person who is currently in hospital
3. 'consumers and carers' may be used when referencing a group of people



## Western NSW Local Health District

Western NSW Local Health District (WNSWLHD) covers 31% of NSW. It is one of the largest LHDs in NSW with a population of 276,000 people and 13% of our residents identify as Aboriginal. The communities we serve are diverse – people live in large regional centres, rural and remote towns and villages. Mental Health Drug and Alcohol Services are made up of community and inpatient services located across the District.

Every year, our services provide mental health treatment and care for 9,000 people and substance use treatment and support for another 2,500 people.



## **Overview of WNSWLHD Mental Health Drug and Alcohol (MHDA) Services**

### **Mental Health Inpatient Services**

Bathurst: Sub-acute unit (Panorama) Dubbo: Acute unit (Gundaymarra) and sub-acute unit (Barraminya)

Orange: Bloomfield Hospital has acute, sub-acute and re-habilitation units.

### **Community Mental Health Teams**

Community Mental Health Teams provide a range of supports to suit the persons' needs. They are located in Bathurst, Cowra, Orange, Mudgee, Wellington, Dubbo, Parkes, Lightning Ridge and Bourke and provide outreach services to smaller towns.

### **Drug and Alcohol Services**

Drug and Alcohol Services are available in all community teams as well as an 8 bed involuntary drug and alcohol treatment program at Bloomfield.

### **NSW Mental Health Line 1800 011 511**

24 hour, 7 day a week telephone triage, assessment and referral service staffed by mental health clinicians. Also provides video link assessments to rural communities.

### **Western NSW LHD Drug and Alcohol Helpline 1300 887000**

An intake referral service to drug and alcohol services.



## Acknowledgments

WNSWLHD Mental Health Drug and Alcohol Services are committed to providing information about resources and service delivery.

Thank you to everyone who helped inform the contents of this guide, especially the people who shared their experiences and knowledge.

### Information Guide for Consumers

A comprehensive resource for people who access Mental Health or Drug or Alcohol Services.

### Information Guide for Carers

A comprehensive guide to Family and Carer Supports



For more information or to provide feedback please contact:

**Jennifer Coote**

**District Consumer and Carer Coordinator**

**6881 4000 or [Jennifer.coote@health.nsw.gov.au](mailto:Jennifer.coote@health.nsw.gov.au)**

