

Aboriginal Patient Advocacy Training Program





I acknowledge that we are meeting on Whadjuk Country and pay my respect to Elders past present and emerging.

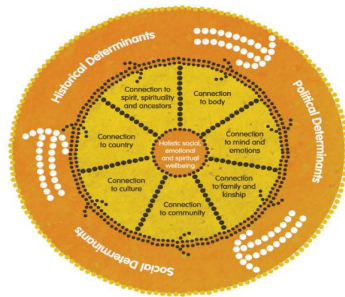
I recognise and respect Aboriginal peoples cultural heritage, beliefs and relationship with the lands which continues, unbroken.

I acknowledge that Australia always was, and always will be, Aboriginal land.



ACTIVITY

What are some things that might influence health?



© Gee, Dudgeon, Schultz, Hart and Kelly, 2013
Artist: Tristan Schultz, RelativeCreative.



Aboriginal Health

Good health isn't just the absence of disease and isn't just about physical and mental health. It includes social, cultural, ecological and spiritual wellbeing for the whole community

These factors play a large part in determining someone's health and are all interconnected with one another, but the ongoing marginalisation, separation and disconnection has led to poorer physical and mental health outcomes in the Aboriginal and / or Torres Strait Islander Community.



Aboriginal Health

Closing the Gap is a commitment by all Australian Governments to improve the lives of Aboriginal and / or Torres Strait Islander peoples.

It aims to reduce the disadvantage and inequity in many areas, with health being one of them, and recognises that closing the gap in housing, education and employment will contribute to this.

The Indigenous Australians' Health Program provides specialised Indigenous care which is needed to ensure Aboriginal and / or Torres Strait Islander get the care they need to improve health and life expectancy, and close this large gap in health.



For more information see the Closing the Gap Report

Culture

What is it?

It is the shared patterns of behaviours, beliefs, knowledge.



High Context / Low Context Cultures

High Context Cultures tend to be more collective, traditional societies

Low Context Cultures tend to be more individualistic, direct communication





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Looking through a different cultural lens



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FOUNDED 1995

National
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How would you describe your culture?

Is your culture the dominant culture in Australia?

Now thinking of what you know about Aboriginal culture, how is that different to the dominant culture and how might that impact on health services?

Culturally Secure Services

Putting the patients needs and at the centre of a health service can ensure a culturally safe health setting.

The environment should be safe, free of racism and inequity. It should be affordable & high quality, and needs to understand your culture and be responsive to it.

For Aboriginal and / or Torres Strait Islander people, this means the service needs to recognise the history of colonisation and racism, and the impact those things have on First Nations people





A healthy relationship between all these factors is important for holistic Aboriginal wellbeing. For Aboriginal people, for us to be well, our families and communities, our country, needs to be well. It is very difficult to feel truly healthy when we see our family and community suffering ill health, disadvantage and racism.

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Barriers for Aboriginal and / or Torres Strait Islanders receiving good health care



Implicit Bias

Implicit bias is the unconscious belief or attitude we hold toward any social group.

It is what leads to stereotyping.

Everyone does it, it doesn't mean that you are likely to discriminate against people, just that the brain likes generalisations.

It is possible and healthy to challenge these biases and thoughts.



Racism in Health Care

Institutional racism refers to the way that racist beliefs are built into our system. It can be things like:

- Sustained practices that discriminate through laws and policies
- Inequities in funding, treatment, Medicare & PBS
- Inadequate attempts at removing cultural barriers or making cultural considerations
- Different performance criteria for Aboriginal services

OR racism in health care can just be people being racist

- People being assessed according to certain stereotypes
- People being treated in a way that disadvantages them



What can I do

- Believe us when we say something/someone was racist
- Preference our voices. Ask where we are when we should be around the table
- Be ok with not always being part of the conversation
- Be ok with not always understanding the outcome of our conversations, trust us
- Be there when its hard and when its fun!
- When you hear something racist or inappropriate, say something. The standard you walk past is the one you accept
- Understand Aboriginal people are not all the same. We have different views, opinions, experiences



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.



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 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
- Request access to 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

AUSTRALIAN COMMISSION ON SAFETY AND QUALITY IN HEALTH CARE

For more information, ask a member of staff or visit safetyandquality.gov.au/your-rights

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YOUR VOICE IN HEALTH
 **National Justice Project**
 **AHCWA**
Aboriginal Health Council of Western Australia

Our health rights are broadly based on two things

THE RIGHT TO SAFE COMPETENT CARE

THE RIGHT TO GIVE INFORMED CONSENT

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What are some things these health rights might include?



Medical Records

There are lots of reasons why you might want to access your medical records – you might want to understand what happened or you might need to show it to another health professional.

- Medical records are notes, medical imaging like X-Rays, and test results
- Every doctor or Health service will take notes
- But they each have their own separate medical record
- These records belong to the service, not us
- We can apply for our medical records
- If the record is at a Public Health service like a Hospital, we can apply for them under the Freedom of Information act.
- If we want the record that our GP has, we must apply under the Privacy Act.



My Health Record

My Health Record is an online record which you can access through MyGov. It may have information from your GP, medication history, hospital discharge summaries and test results

In an emergency, healthcare providers can see your medications, allergies and immunisations which will lead to safer care.

You can also access your COVID-19 proof of vaccination certificate.



Consent

- Consent is a persons agreement for a health professional to go ahead with treatment
- Consent is an important legal requirement
- Consent can only be valid when the person knows about their condition, treatment options, risks and benefits
- An interpreter or translator must be provided if there is need
- You do not have to agree to treatment on the spot
- The person make have capacity to make an informed decision



Under WA policy, there is a very clear six step process

Work out which health professional is responsible for seeking

Assess the patients capacity to make a decision

Provide enough information so the patient can make an informed decision.

Verify the patient has understood the information and all their questions have been.

Ask the patient for their decision

Record the consent.

Capacity

Capacity is a term used for people who are 'mentally competent' and have capacity to make a big decision

All adults are believed to have capacity unless there are reasonable grounds to believe otherwise



A person has capacity if they:

- Understand the information given to them
- Are able to remember the information
- Are able to weigh the decision
- Are able to communicate their decision

Hierarchy of Decision Makers

When seeking a treatment decision for a person who lacks capacity, either due to a disability or accident, health professionals must follow a set of orders of decision makers.

When obtaining treatment, the health professional must go to the first person in the hierarchy who has legal capacity and willing to make the decision.

If they are not available, the health professional can go to the next person in the hierarchy.



An Advance Health Directive enables you to make decisions now about the treatment you would want - or not want - to receive if you ever became sick or injured and were incapable of communicating your wishes. In such circumstances, your AHD would effectively become your voice.

An enduring power of guardianship is a legal document which enables you (the appointor) to appoint a person of your choice to make personal, lifestyle and treatment decisions on your behalf if you lose the ability to make these decisions for yourself because of an illness or injury. This person (the appointee) becomes your enduring guardian.

Open Disclosure

Open disclosure is the open discussion between the clinical workforce and patients, family and carers about an adverse event that may have resulted in harm to a patient while receiving health care.

- It is a patient right anchored in professional ethics
- Should include an expression of regret and an apology, an explanation of what went wrong and the details
- More than one meeting may be needed

It is not an admission of negligence or wrong doing



Open disclosures are intended to:

- Assist patients who have experienced harm
- Guide clinicians, the clinical workforce and health service organisations in supporting patients that have experienced harm
- Ensure that health service organisations learn from adverse events.

Mental Health

The Mental Health Act 2014 sets out the rights of people with mental illness in WA

There are different rights for:

- Voluntary patients
- Involuntary patients
- Aboriginal patients

The Australian Charter of Healthcare rights also applies to mental health patients



See Mental Health Principles handout

Aboriginal Mental Health Patient Rights

The 2014 Mental Health Act specifies how Aboriginal people experience assessment, examination and treatment.

- It requires psychiatrists to collaborate with Aboriginal mental health workers and other significant people from their community such as elders and traditional healers to assess the patient
- A mental health service must provide treatment that is consistent to their cultural and spiritual beliefs
- They must have regard to the families, and to the extent that is it practicable and appropriate the views of significant members of their communities



Voluntary Patient Rights

They have a right to:

- Refuse any treatment they don't want and leave if they want to
- Be fully informed about their rights and any treatment offered
- A physical examination
- An interview with a psychiatrist
- Contact people by phone, email etc and have visitors (conditions may apply at some hospitals)



See Voluntary Rights Handout

Involuntary Patient Rights

Involuntary Patients have the right to:

- Be fully informed about their rights and any treatment offered
- A physical examination
- An interview with a psychiatrist
- Make someone a nominated person, who will then have the same rights as a carer of close family member
- A second opinion from another psychiatrist



See Involuntary Inpatient Rights & Community Treatment Order Rights Handouts

Involuntary Patient Rights

Mental Health Advocacy Service: A free service who help with understanding rights, explaining wishes to treating team, apply and support you through the Mental Health Tribunal and make complaints

Mental Health Tribunal: The Tribunal's main job is to review every new involuntary treatment order made by psychiatrists and decide if they meet the criteria laid down in the legislation

Mental Health Law Centre: Provides legal advice and legal services to mental health consumers which can include representation before tribunal and courts



Carers

- A carer is a person who provides ongoing care to a person with a disability, mental health illness, chronic illness or frail person **for free**
- All health services must recognise the role of carers, and their views and need must be taken into account
- Carers must be treated with respect and dignity, and must be included in assessment, planning, delivery and review of anything that might impact them



Rights in Hospital

While in Hospital there are staff that consumers can call for help

- Aboriginal Liaison Officer
- Patient Liaison
- Nurse Unit Managers
- Senior Doctor
- Mental Health Advocacy Service
- Health Consumers Council

Consumers call also ask for an Emergency Medical Review



Department of Health
WESTERN AUSTRALIA

Aishwarya's CARE Call

Are you worried?
Don't wait!

If you or one of your mob gets sicker, tell us now.

Step 1 Worried that you or one of your mob is getting worse? Tell us.

Step 2 Still worried? Tell a senior staff member.

Step 3 If you need help urgently, call your hospital's Aishwarya's CARE Call line or use the Aishwarya's CARE Call phone installed in some emergency departments.

You know yourself and your mob best. We will listen to you.

healthywa.wa.gov.au

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Rights in Prison

Aboriginal and Torres Strait Islander prisoners make up 29% of all prisoners

In WA when you enter prison you no longer fall under the Department of Health system, but part of the Department of Justice system instead. This means you lose access to Medicare & most things through the PBS.

There are inadequate mental and physical health services, and often rights to access, safety, respect, privacy are taken away.



If any rights are not being upheld, you can lodge a complaint with:

1. an authority within the prison
2. the Administration of Complaints Compliments and Suggestions (ACCESS)
3. the Western Australian Ombudsman
4. the Health and Disability Services Complaints Office (HaDSCO)
5. the Office of Inspector of Custodial Services.

Mental Health Emergency Response Line (MHERL)

Mental Health Emergency Response Line:

A 24 hour telephone service for people in the Perth metropolitan area experiencing a mental health crisis

It is available for:

- Individuals experiencing a mental health crisis who feel they need urgent assistance
- Families, friends & carers of people with a mental illness
- Members of the general public who witness a mental health crisis and need assistance
- Health & community welfare service providers

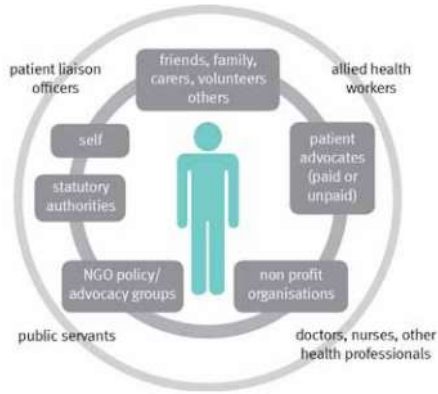


Adult Service: MHERL

Rural Service: Rurallink

Child Service: Crisis Connect

Health Advocacy



Consumers should be at the center of all their care and have rights to open communication of any issues or concerns they might have.

Advocacy empowers consumers and their advocates to actively participate in decision making around their healthcare and the broader health system.

<https://hic.org.au/wp-content/uploads/2019/11/HIC-The-Advocacy-Toolkit-for-Consumers-Queensland-Health-2011.pdf>



What does an advocate do?

Unless self advocating, as an advocate you will be someone who has been given the authority to speak on behalf of someone else

This means as an advocate you might:

- Liaise between the consumer and medical staff / health service
- Do research and apply for medical records
- Write complaints on behalf of the consumer
- Attend meetings with the consumer
- Refer more appropriate services to the consumer



Key Principles

Principle	Description
Consumer centred	The consumer is at the centre of the interaction.
Opportunities	Stakeholders promote and support opportunities for both individual and systemic advocacy.
Recognition	Stakeholders recognise that advocacy is legitimate and that it can take many forms.
Relationships	All those involved work together with respect and recognise each other's roles and contribution to the process.
Response	Matters raised are acknowledged and responded to.
Resolution	The aim of all parties is to find a solution which is acceptable to the consumer.

<https://hic.org.au/wp-content/uploads/2019/11/HIC-The-Advocacy-Toolkit-for-Consumers-Queensland-Health-2011.pdf>



Conflicts of Interest

Avoiding conflicts of interest should be standard practice.

It is vital to ensuring we act ethically, and ensures:

- We can retain our integrity
- The patient has someone 100% on their side



Tips for Communication

Often when consumers need someone to advocate for them, they feel like they have not been listened to or heard in the health system. To communicate effectively with Aboriginal and / or Torres Strait Islander people, you need to recognise that there might be barriers.

To overcome these, you might need to work on your cross-cultural communication skills. This is important because if you don't understand the message, you might not be able to provide a meaningful response – this can cause misunderstandings and complications.



For more information see the communication handout

Tips for Gathering the Information

- Ask the consumer about details you are not clear on
- Make sure you read your notes back to them to ensure you have captured their issue correctly
- Confirm the issue they want addressed
- Confirm the outcome they want (apology, explanation, meeting etc)



Decide on your Actions

When helping consumers decide on actions in order to reach their goals, it is important to remember that you are there to help them get the best outcome possible.

Giving them the opportunity to discuss what outcome they want is about upholding their right to be heard.

Most consumers want acknowledgement of their experience from the service, an agreement plan for future appointments or rectification of a mistake.



Decide on your Actions

Some things to consider:

- Ask consumer to do as much as within their capacity
- Get authorisation from the consumer to do the actions you both agreed on
- If identification is needed, check with service what ID they require
- If you are writing letters on their behalf, ask them to sign them if possible
- If you are signing on their behalf, ensure a signed copy of the consent form authorising you to act on their behalf, is included



Recording your Actions

Having a copy of the actions taken is important. The consumer may need this information to pass on to another organisation if the case is passed on elsewhere.

When you start taking the actions, make sure you take notes and record dates. For example

- 01/01/2000 – Complaint letter sent to Saturn Base Hospital
- 01/01/2000 – Called Rebecca at SBH and discussed complaints process
- 01/01/2000 – Text consumer and updated
- 28/01/2000 – Letter received from SBH, sent to consumer
- 05/02/2000 – Met with consumer, happy with response, issue closed



Closing the Case

Closing the case effectively means you have done all the actions you agreed on with the consumer and a satisfactory outcome was reached.

It is important you:

- Return all the documents back to the consumer
- Do not keep copies that could put the clients privacy at risk
- Debrief what you have learnt during this case so you can build your knowledge base
- Keep a list of contacts for future use



Referring the Case

Occasionally issues can be very complex or challenging

There may be times where

- Their desired outcome might not be possible for you to achieve
- You do not have the resources or capacity to continue to assist the consumer
- A specific body or organisation needs to take over the case to achieve the desired outcome

In these situations, it is possible to contact Health Consumers Council or another advocacy service for advice



Compassion Fatigue & Vicarious Trauma

Compassion Fatigue describes the physical, emotional, and psychological impact of helping others. It occurs when your work experiences start to impact your thoughts, mood, and wellbeing. Compassion fatigue is common among people who work in a helping capacity.

Vicarious Trauma is trauma you may get as a result of working with trauma survivors and experiencing their traumatic material. Just as you can get trauma from an abnormal event, vicarious trauma is a normal reaction to exposure to traumatic incidents. Anyone who empathetically engages with survivors of trauma is at risk of vicarious trauma.



Self Care

Without advocacy, many tough things would not be able to be achieved. But it is hard and sometimes disappointing work, which can start to take a toll on your mental health.

Even symptoms like jaw clenching, headache, having a hard time sleeping or a constant feeling of being overwhelmed, you may need some self care.



Where to go for Help

Some services consumer may want to go to for help, feedback or complaints are

- Care Opinion
- Health and Disability Services Complaints Office (HaDSCO)
- Hospital complaints process
- Equal Opportunity Commission
- Australian Health Practitioners Regulation Agency (AHPRA)
- Local member of Parliament
- Advocacy organisations



Hospital Complaints Process

WA Health has a complaints Management Policy

- Complaints about provision of health care (or lack of) can be made by anyone
- They can be made at any time
- They must be acknowledged within 5 working days
- Usually resolved within 30 working days, but if it will be longer than that consumers must be updated every 15 working days



Government of Western Australia
Department of Health



Care Opinion Australia

Care Opinion is an independent, not-for-profit organisation

- Anyone can anonymously share their stories about their experiences of care
- You can see what other people are saying about services which might help you choose the best care provider
- It covers health, aged care & community services in Australia & WA Health has signed all health services to it
- Services can respond, so you can find out which services have made improvements because of feedback



Health and Disability Services Complaints Office

HaDSCO is an independent authority set up under the Health and Disability Services Act 1995 who look to improve the delivery of health and disability services

- They assess, negotiate and investigate complaints and offer an impartial resolution service for complaints relating to health, disability and mental health
- They work collaboratively with their stakeholder to resolve and prevent further complaints and contribute to improving systems





The Commission has 2 main roles

- To encourage the understanding of equality of opportunity
- To provide a means of redress for people who allege they have been victims of unlawful discrimination

Complaints must be made in writing and must refer to one of the grounds of discrimination and an area of public life that is covered by the Act



Australian Health Practitioner Regulation Agency

AHPRA works in partnership with 15 National Boards to ensure the community has access to a safe health workforce across all professions


They regulate:

- Policy and professional standards
- Registration and eligibility to practice
- Notifications of complaints and concerns
- Compliance to board requirements
- Accreditation



Complaints can be made to AHPRA if you think

- A practitioner's behaviour is placing the public at risk
- A practitioner is practicing in an unsafe way
- A practitioner's ability to make safe judgements about their patients is impaired because of their health



If you are raising this concern for:

- an explanation
- an apology
- a refund or compensation
- access to your health records or to amend them
- change in policy or practice at a hospital, medical/dental practice, pharmacy, ambulance, community health service.


Submit a complaint to a **health complaints organisation**

If you are raising this concern because you think:


- a practitioner's behaviour is placing the public at risk
- a practitioner is practising their profession in an unsafe way, or
- a practitioner's ability to make safe judgements about their patients might be impaired because of their health.

Submit a concern to **Ahpra**


<https://www.ahpra.gov.au>



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Local Member of Parliament

Contacting a local member of Parliament can be an effective way of having an issue resolved or a complaint heard when other avenues haven't been successful

There are no guidelines to this, but calling and speaking to their office staff is a good start



Legal Action

If Medical providers breach their duty of care, you may be able to make a medical negligence compensation claim.

Some common issues that get claimed are:

- Misdiagnosis or failure to diagnose
- Making an existing condition worse
- Failing to provide the appropriate treatment, referral, surgery or post-op care
- Incorrectly reporting test results



Remember

- Advocacy can be hard
- The health system is huge and complex
- Even people who work in the system can be frustrated by it
- You tried your best
- Celebrate the wins
- Build your networks
- Ask for help

