

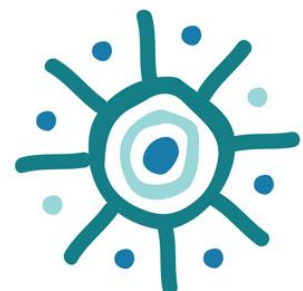


Government of **Western Australia**  
Department of **Communities**

# Have your voice heard



Carers self-advocacy handbook



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## Are you a carer

This handbook is for carers. You are a carer if you provide unpaid care or support to a person who requires assistance to look after themselves. You may be a carer for someone who:

- has a mental health issue;
- has a chronic or terminal illness;
- has a disability;
- has an alcohol or drug issue; or
- is elderly or frail.

A carer may be:

- a parent caring for a child who has additional needs;
- an adult caring for an elderly parent, adult child, partner, friend, neighbour or sibling; or
- a child or young person caring for a parent, sibling or relative.

As a carer, you can decide how much care you are able to give, and what services are best for you and the person you care for.

## Self-advocacy

To self-advocate means communicating in a way that makes your needs and desires known to others. You may need to self-advocate with people who provide health, disability and other services to the person you care for.

This handbook provides tips to help you to self-advocate as a carer and to look after yourself. It can also help you to speak up for yourself in stressful situations and provides information about services that may help you to look after your own health and wellbeing.

Information in this handbook is based on research, as well as contributions from Western Australian carers, Carers WA, Carers Advisory Council and other carer organisations.

You will find a list of agencies that can provide you with support or advice on page 12.

# Understanding your rights

There are State and Commonwealth laws that recognise and protect your rights as a carer.

The following steps can help you to self-advocate more effectively.

1. Know and understand your rights.
2. Develop an effective communication style.
3. Manage your emotions.
4. Look after your own health and wellbeing.

Western Australia was the first State to introduce a specific law for carers. The *Carers Recognition Act 2004* (the Act) and the Carers Charter recognise the rights and role of carers.

## **The Carers Charter states:**

- carers must be treated with respect and dignity;
- the role of carers must be recognised by including carers in the assessment, planning, delivery and review of services that impact on them and the role of carers;
- the views and needs of carers must be considered, along with the views, needs and best interests of people receiving care, when decisions are made that impact on carers and the role of carers; and
- complaints made by carers in relation to services that impact on them and the role of carers must be given due attention and consideration.

The Act and Charter support your right to self-advocate and be heard.

The Department of Health, Disability Services and organisations they fund to provide services must comply with the Act. They report on compliance to the Carers Advisory Council, which then reports to the Western Australian Parliament through the relevant Minister.

The Department of Communities administers the Act and supports the Carers Advisory Council.

## **What can I do if my rights are being ignored?**

- Speak to the service provider and refer to the Carers Charter to remind them of your rights.
- Contact the Health and Disability Services Complaints Office (HaDSCO). See page 9 about the complaints process.

## **Other laws to protect your rights as a carer:**

- Equal Opportunity Act 1984
- Disability Services Act 1983
- Disability Discrimination Act 1992
- Mental Health Act 2014
- Health and Disability Services (Complaints) Act 1995

## Tools for effective communication

As a carer you provide the day-to-day care needed by the person you care for. You also have a unique understanding of their needs. You often work with service providers, health professionals and family members to provide support for the person you care for. This handbook will help you to communicate more effectively with these people.

Effective communication can help you to get better outcomes for yourself and the person you care for. You can choose to communicate by phone, meeting face-to-face, writing a letter or by email.

Tips for effective communication include:

- make notes of what you need to ask; be specific and keep to the main message you want to get across;
- start slowly and keep calm;
- speak with someone who has the authority to make changes;
- raise your concerns in an orderly manner; avoid overwhelming the person you are speaking to with too much information at once;
- avoid being confrontational; explain your needs rather than demand action;
- ask for enough time to make decisions rather than feeling pressured to decide there and then;
- stand your ground on things that you need; focus on what you want to discuss and don't be afraid to ask again if you need to;
- if you don't understand what the person is saying, ask them to explain it again; and
- use positive body language; nod and look at the person talking and avoid interrupting them.

### **Always remember ...**

You can have a friend or supporter with you when you are talking to service providers or professionals. Explain what sort of support you need from them and let them know if they should speak or take notes for you.

### **Making a phone call**

Below are tips for effective phone communication.

- Make short notes about what you want to say and achieve before you make the call.
- Make sure you are contacting the right department that can assist you.
- Keep the discussion focussed.
- Keep a record of the discussion, if you can, including the name of the person you spoke with.

## **Writing a letter or email**

Written communication allows you to take your time and keep a record. Below are tips for effective communication.

- Have the correct name, title and address of the best person to contact about your issues.
- Write the topic of your email or letter in the subject heading.
- Keep your letter or email short and focussed on what you want and need.
- Write with care so that you explain yourself clearly.
- Avoid writing when you feel angry or emotional. Save a draft and come back to it when you've had time to calm down, reflect and think.

## **Effective communication**

Assertiveness can help you to communicate effectively. Being assertive means communicating what you feel, need or want with confidence, without offending others. You can be honest and direct but also respect other opinions. Being assertive may help you to feel more in control of the situation and help you to protect your rights and gain respect from others. Assertiveness can help to get the outcome you need and can encourage open and honest relationships.

## **Barriers to effective communication**

There may be times when you find it difficult to be confident or assertive and to stand up for your rights as a carer. This could be because you:

- are too busy to ask for something;
- put others before yourself;
- have had a bad experience in the past;
- think that it is your duty to do everything for the person you care for;
- find it hard to say no to people;
- feel that people aren't listening to you;
- feel angry, stressed, isolated or depressed; and
- feel exhausted or vulnerable.

## **Being assertive versus being aggressive**

Being assertive is a balance between standing your ground and respecting other opinions, showing restraint to avoid conflict and not becoming aggressive.

Aggressive behaviour, on the other hand, ignores the rights of others, is disrespectful of other opinions and can cause distress to the person you are communicating with.

## **Examples of aggressive behaviour.**

- Shouting and talking over the top of others.
- Swearing, personal insults and name-calling.
- Racial or sexual comments.
- Verbal threats and threatening gestures.
- Abusive or repetitive phone calls, letters, online messages.
- Talking down and insulting someone.
- Being scornful by sneering or mocking someone.

Thinking about your feelings and being aware of your own experiences can help you to control how you behave, as well as how you react to aggression.

## **Managing your emotions**

It is not always easy to stay calm and manage your emotions when you are caring for someone. It is common to feel frustrated, angry, sad, anxious, lonely or guilty. You may ignore these feelings to protect and support the person you care for. This can sometimes make it hard to keep things in perspective and make good decisions. When you feel and think this way, you may find it hard to communicate your own needs.

“I was afraid, sad and overwhelmed. Months later I also became very angry. All these emotions, and more, bubbled to the surface from time to time.”

Controlling these feelings and expressing them in a safe place may help you to communicate your needs assertively and effectively.

### **Below are examples of safe ways to let out frustration and anger.**

- Walking away from the situation before it becomes an argument.
- Asking for a five-minute break from a meeting so you have time to calm down.
- Using deep breathing or other ways to try and keep calm.
- Thinking about something happy for a few minutes.

In some situations, controlled anger can be a helpful and appropriate response. If it is focussed on the issues and doesn't involve aggressive behaviour, it can make people sit up and listen to you.

### **Ten tips to help you become a confident communicator.**

1. Be aware about how you communicate, your feelings, your triggers and your needs.
2. Be honest and direct about your thoughts and feelings, without getting angry.
3. Be specific about what you need from the other person and respect their rights and feelings.
4. Ask for help from friends, family or service organisations like Carers WA when you need it.
5. Be confident about your opinions and decisions without having to apologise.
6. Your rights and needs are important. Turn down requests that seem unreasonable or unfair.
7. Listen and try to understand the other person's point of view without interrupting them.
8. Take a problem-solving approach to conflict and be willing to compromise. See the other person as equal. They may have a more suitable idea or solution.
9. Maintain eye contact (if appropriate) and be confident to get your message across.
10. Be patient. Being assertive is a skill that needs practice. Start out small and in low risk situations.

## **Case study: Being heard and staying calm**

Bill is the sole carer for his wife Jean, who has dementia. Bill can't leave Jean alone for too long as she now needs more help with her personal care. Bill is starting to get tired and irritable, and sometimes feels unable to cope.

A friend suggests that Bill contact the aged care provider to see if Jean can go to a day activity centre during the week to allow Bill to have a break. The friend also encourages Bill to contact Carers WA to ask them how he can get Jean into the centre and seek their suggestions for any other help that he can access.

A social worker visits Bill and Jean at home. Bill thinks that this will be to reassess Jean's needs. However, the social worker says that it is an initial meeting to get to know Jean and Bill, as she has several clients that she must visit that day. Bill feels frustrated but stays calm, maintaining eye contact and lets her know that he needs to sit down and discuss the help he needs for Jean. He explains that he feels unable to carry on with things as they are.

In this situation, there was a difference in Bill's and the social worker's expectations. In being assertive and staying calm, Bill and the social worker agreed to continue the discussion about the help he and Jean need.

## **Working in partnership with professionals**

### **Negotiating and influencing**

Negotiating can help you to get what you want, or to reach an agreement with another person. You may want to negotiate to get access to a service or extra help for the person you are caring for. Negotiation can happen at meetings, by letter or email, or by communicating with a support worker or General Practitioner.

### **What if I don't have time to prepare?**

You might find yourself in a situation where you are negotiating but have limited time or information. You can ask for more time to decide rather than agreeing to something that might not work for you. You can also ask for help, support and information from family, friends or Carers WA. Remember that all parties should benefit from negotiating, so you may have to compromise.



Tips for effective negotiation.

1. Before you start negotiating, think about what you want to achieve and know how you may go about it.
2. Acknowledge your feelings before stating your case. For example, “I was frustrated by ... but I want to come to an agreement about...”.
3. Present your case with confidence. Make it clear that you want to reach an agreement. Keep to the facts.
4. Take time to make sure each person’s position is understood. Both parties should clarify anything they did not understand.
5. You may have to compromise to get an agreement. The aim is to be in a better situation than you were before you started negotiating.
6. When you reach an agreement make sure you understand what you have agreed to. Write it down for future reference.
7. In some cases, an agreement may not be reached. You can choose to accept this or take your concerns further (see below, Making a complaint).

Effective negotiation skills are important to get your voice heard. If you are not ready to negotiate, contact your local support service or Carers WA for information and advice.

The Activity Sheet on page 13 can help you to plan how you want to deal with an issue or concern.

## Making a complaint

If it is not possible to negotiate a solution, you may choose to make a complaint.

You may decide to make a complaint about:

- service providers failing to follow the Carers Charter;
- not having a service provided;
- the way a service was provided;
- denying or restricting your access to records; or
- not effectively dealing with your complaint.

### **Steps you can take to resolve your concerns:**

1. Raise your concerns with the service provider involved. Remember to communicate clearly and assertively.
2. If you are not satisfied with the result, you may make a complaint to the:
  - HaDSCO, which provides a free, impartial resolution service about health or disability services;
  - Aged Care Complaints Commissioner, which provides a free resolution service for anyone with concerns about service or quality in aged care;
  - Health Consumers’ Council, which can help carers understand the health system. They can also provide a free service to assist who are not able to self-advocate to make a complaint.

## Looking after yourself

Caring can be physically and mentally tiring. Many carers put their own needs last. However, it is important to keep yourself healthy and make your own mental and physical wellbeing a priority.

You may need to slow down and look after yourself if you have any of the following symptoms:

- Disturbed sleep or insomnia, tiredness and apathy;
- Racing heart or sweating, digestive problems, headaches and muscle tension;
- Overeating or loss of appetite, weight loss or gain;
- Feelings of tension, impatience or irritability, anger and resentment;
- Lack of self-esteem, depression and helplessness, anxiety or guilt;
- Forgetfulness and indecision;
- Misuse of alcohol, drugs, tobacco or gambling; or
- Negative feelings and withdrawing from people or activities you normally enjoy.

### Ideas to help you care for yourself

- Take one day at a time. Focus only on what you need to do on that day.
- Make a list of friends or relatives who you can ask to help you.
- Set aside some quiet time each day to clear your mind.
- Try to eat healthy, stay active and get enough sleep.
- Discuss flexible work options with your employer. Many employers offer flexible working arrangements for carers.
- Set up a roster system if more than one person is providing care for your loved one.
- Give yourself regular rewards. Take a break, do something special that lifts your spirits and makes you feel good.
- To save time, consider using the internet for online banking, shopping and to pay bills.
- Plan for longer breaks and use respite services if they are available.
- Seek professional help for yourself, if required.

### Getting help with difficult feelings

It is a positive and courageous step to admit that you can't do it all yourself. It can be the first step to a better quality of life for you and the person you care for.

Sharing experiences with other carers can help you maintain your mental and emotional wellbeing. People in similar family situations often know and understand what you are experiencing. It helps you realise you are not alone.

“I connected with a carers group who helped me understand the changes going on in our family and for me.”

Carer peers know and understand:

- what it is like when your loved one is diagnosed;
- the feelings of loss and grief;
- the different emotions that relate to the caring role;
- the frustration you feel when you are trying to, but cannot get support;
- what it is like to deal with difficult behaviours and situations; and
- what it is like to hide your issues from friends, family and work.

You might find counselling helpful. A trained counsellor who is not involved with you or the person you care for may be able to look at your situation objectively and can help you explore other ways to manage your situation.

Counselling can help you to:

- clarify your needs and goals;
- manage conflict, stress, grief and your emotional wellbeing;
- make sense of overwhelming and confusing feelings;
- develop healthy coping skills and build resilience; and
- improve your mental, emotional and physical wellbeing.

## Useful contacts and support services

### Department of Communities

Information about the Carers Recognition Act.

Telephone: 6217 6888

Email: [carers@communities.wa.gov.au](mailto:carers@communities.wa.gov.au)

Website: [www.communities.wa.gov.au](http://www.communities.wa.gov.au)

### Carers WA

Counselling, information and advice, young carer service, social support and wellness.

Telephone: 1800 242 636 (free call)

Email: [info@carerswa.asn.au](mailto:info@carerswa.asn.au)

Website: [www.carerswa.asn.au/](http://www.carerswa.asn.au/)

### HaDSCO

Complaints authority for health, disability services and the Carers Charter.

Telephone: 6551 7600 or 1800 813 583 (country free call)

Email: [mail@hadsco.wa.gov.au](mailto:mail@hadsco.wa.gov.au)

Website: [www.hadsco.wa.gov.au](http://www.hadsco.wa.gov.au)

### Aged Care Complaints Commissioner

Complaints authority for aged care services.

Telephone: 1800 550 552 (free call)

Email: [enquiries@agedcarecomplaints.gov.au](mailto:enquiries@agedcarecomplaints.gov.au)

Website: [www.agedcarecomplaints.gov.au](http://www.agedcarecomplaints.gov.au)

# Activity Sheet

To help you to self-advocate as a carer, please answer the following questions:

1. Do I know what the issue is?

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2. Do I know my rights?

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3. Who is causing the problem and who can I ask for support?

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4. What do I know?

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5. How am I feeling? Has this affected my health?

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6. What is my goal? What result would I like?

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7. What can I do to change it? What skills do I have and need?

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