

Working with Carers, Family and Kin

A Guide for Healthcare Professionals

- Identify and acknowledge the role of carers
- Establish open lines of communication
- Support understanding of confidentiality
- Provide essential information

Funded by



**Queensland
Government**

The [name of the project] was produced by Arafmi Ltd with funding from the Department of Child Safety, Seniors and Disability Services.



Disclaimer

This guide is intended solely for informational purposes and does not provide professional advice or recommendations. The content of this guide has been developed in consultation with healthcare professionals and carers to offer accessible tools and resources that support healthcare professionals in their interactions with carers.

The information presented in this guide is provided on an “as is” basis, without any guarantees or warranties, express or implied. We do not guarantee the accuracy, completeness, or reliability of the information contained within this guide. We assume no liability or responsibility for any errors or omissions in the content.

Use of the Guide

You may download, display, print and reproduce this guide, either in its entirety or in part, in an unaltered form for personal use. If you are part of an organisation, you may reproduce it for internal use within your organisation, provided that the reproduction is not used for any commercial purpose. Additionally, you must retain this copyright notice and disclaimer as part of the reproduction. All other rights are reserved, and reproduction of the whole or any part of this guide in any manner (electronic or otherwise) is strictly prohibited without obtaining prior written permission from Arafmi Ltd.

Please direct reproduction and rights inquiries to Arafmi or via email at info@arafmi.org.au.

Acknowledgments

This guide acknowledges the substantial contribution of “A practical guide for working with carers of people with a mental illness, March 2016,” authored by Mind Australia, Helping Minds, Private Mental Health Consumer Carer Network (Australia), Mental Health Carers Arafmi Australia, and Mental Health Australia. We express our sincere gratitude for the previous work undertaken to develop that resource.

We extend our heartfelt appreciation to the many contributors of this guide who graciously dedicated their time and expertise to provide invaluable insights and feedback. Their contributions have greatly enhanced the quality and relevance of this resource.

Funding Acknowledgment

We appreciate the Queensland Carers Advisory Council for their generous funding, which enabled the development of this resource.

Suggested Citation

Working with Carers, Family and Kin – A Practical Guide for Healthcare professionals, June 2023, Arafmi with funding from Queensland Advisory Council.

¹ https://www.mindaustralia.org.au/sites/default/files/publications/A_practical_guide_for_working_with_people_with_a_mental_illness.pdf

Contents

Carers, Family and Kin	00
Working with carers	00
Legal Frameworks	00
Steps for including carers in consumer care	00
1 Identify and acknowledge the role of carers	00
Resources and further reading	00
2 Establish open lines of communication	00
Resources and further reading	00
3 Support all parties' understanding of privacy and confidentiality	00
Communicating confidentiality, privacy, and consent with consumers	00
Communicating confidentiality, privacy, and consent with carers	00
Resources and further reading	00
4 Provide essential information	00
Resources and further reading	00

Carers, Family and Kin

Carers, refers to family members, friends, and kin, who voluntarily provide unpaid care and support to their loved ones with disability, mental illness, chronic or terminal conditions, substance abuse, or are frail aged. The term carer will be used throughout the document to refer to any family member, friend or kin who have unpaid caring roles. It is estimated that 2.6 million, or one in eight Australians are carers.

It doesn't matter how many hours are spent each week providing support. Carers are people who invest time, energy, and support, generally in an unpaid capacity. However, some may receive Centrelink benefits to enable them to continue in their caring role.

Carers may live with the person they are caring for, assisting with daily needs, or may visit the person regularly. The types of caring role could include:

- Continuous care (up to 24 hours support a day) or
- Intermittent roles that support a person with specific tasks (e.g., support for decision-making, attending health appointments etc)

Carers are often 'hidden', or do not see themselves as a carer. They can become carers in many different ways, suddenly through a recent diagnosis or gradually through deterioration of a condition or diagnosis, and often they don't get a choice.

Children who become carers face particular difficulties in being recognised and having their needs met. And in culturally diverse communities, responsibility for the provision of care may involve the entire community and may provide additional challenges during the process of identifying who is a carer.



The primary role of a carer is, and will continue to be a person's wife, husband, partner, son, daughter, parent, family member, neighbour, friend or in some cases their child or children. They have unique expertise and knowledge of the consumer's situation and needs. This knowledge should be recognised and valued by clinicians.

Working with carers

Carers have an essential role to play in consumer health and well-being and in most cases, have the desire to be helpful. They can play a crucial role as a valuable source of collateral information for healthcare professionals. Often, they have a lived experience in recognising:

- Early warning signs of change in a person's health,
- What management strategies have worked in the past,
- The impact of medication or treatment.

Involving carers in planning and discharge discussions allows for a more holistic approach to care support. Carers contribute valuable input regarding the consumer's preferences, routines, and specific care needs. Their involvement can facilitate a smoother transition during the discharge and planning processes as they provide support and ongoing care for the consumer beyond clinical settings.

It can also be beneficial to the wellbeing of the carer/s to be included in the treatment process.

Legal Frameworks

Recognising the role carers play in supporting consumers is an important aspect of healthcare provision. In Australia, there are several legislative frameworks that have been established to ensure the involvement of carers in healthcare settings.

The Carers Recognition Act of 2010 serves as a cornerstone legislation, emphasising the significance of acknowledging and supporting carers. It is intended to increase recognition and awareness of carers and to acknowledge the valuable contribution they make to society and includes “The Statement for Australia’s Carers”

- 1 All carers should have the same rights, choices and opportunities as other Australians, regardless of age, race, sex, disability, sexuality, religious or political beliefs, Aboriginal or Torres Strait Islander heritage, cultural or linguistic differences, socioeconomic status or locality.
- 2 Children and young people who are carers should have the same rights as all children and young people and should be supported to reach their full potential.
- 3 The valuable social and economic contribution that carers make to society should be recognised and supported.
- 4 Carers should be supported to enjoy optimum health and social wellbeing and to participate in family, social and community life.
- 5 Carers should be acknowledged as individuals with their own needs within and beyond the caring role.
- 6 The relationship between carers and the persons for whom they care should be recognised and respected.
- 7 Carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.
- 8 Carers should be treated with dignity and respect.
- 9 Carers should be supported to achieve greater economic wellbeing and sustainability and, where appropriate, should have opportunities to participate in employment and education.
- 10 Support for carers should be timely, responsive, appropriate and accessible.

Additionally, various other legislative frameworks, such as the National Safety and Quality Health Service (NSQHS) Standards and the Health Services Act 1991 (Qld), provide guidelines to encourage the active engagement of carers in patient care. These legislative measures aim to foster collaboration between healthcare providers and carers, recognising their unique expertise and knowledge of the consumer.

A list and links to relevant Laws and Policies relating to the involvement of carers in patient care can be found in the References and further reading section.

Steps for including carers in consumer care

This guide outlines four steps aimed to improve collaboration with carers in consumer care. By identifying and acknowledging the role of carers, providing them with essential information, establishing open lines of communication and supporting their understanding of confidentiality, healthcare professionals can build strong partnerships with carers and improve health outcomes for consumers.

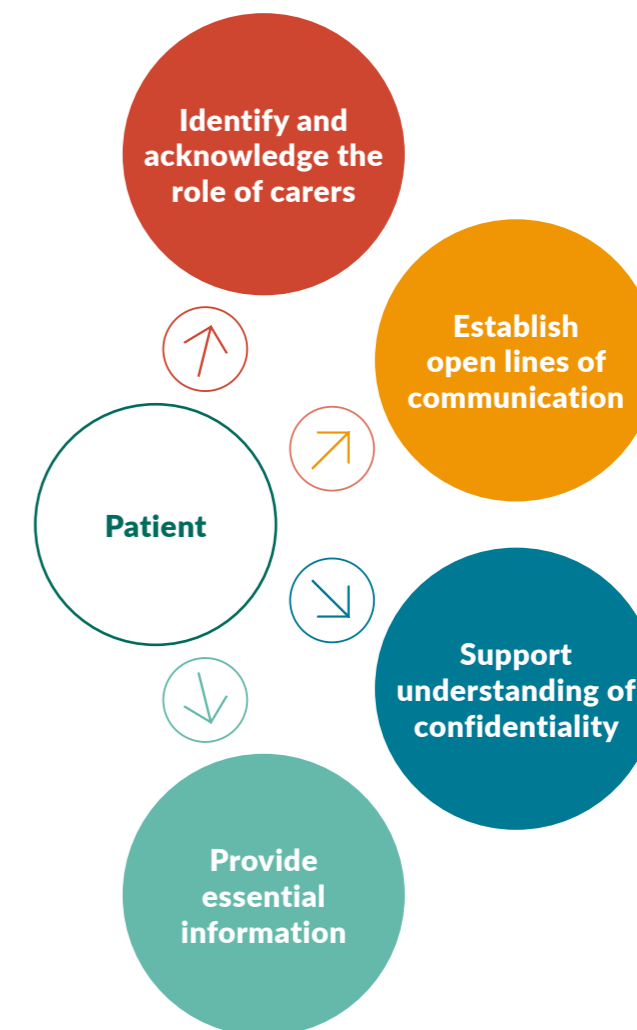
Steps:

1
Identify and acknowledge the role of carers

2
Establish open lines of communication

3
Support understanding of confidentiality

4
Provide essential information



1. Support all parties' understanding of privacy and confidentiality

The first step in effective collaboration is to identify and acknowledge the carers' role. By validating their expertise and understanding the unique perspective they bring, healthcare professionals can foster a collaborative environment built on mutual respect and shared decision-making resulting in better health outcomes for consumers.

At first contact, or soon after,

- ask the consumer who the important people are in their life, and the nature of their involvement and relationship;
- seek permission to involve them in the consumer's care,
- record the extent to which information can be shared with carers,
- consider if there are any specific considerations and requirements associated with the carer's age (including children as carers), gender, indigenous status, culture, language, religion, sexual orientation, disability.

When carers attend healthcare visits with the consumer, it's a great opportunity to:

- ✓ connect,
- ✓ acknowledge their role as a carer,
- ✓ provide information about their rights, health conditions, and other relevant information for their wellbeing,
- ✓ answer any questions they might have.

Remember a carer may not identify with the term "carer" as they are often family members, friends or kin, It is important to recognise the relationship they have with the consumer first, e.g., daughter, son partner, friend, aunty etc. and aim to use the preferred term/s relevant to each individual situation.¹

Resources and further reading

- Tips for including carers in consumer care [→ Sheet 1](#)
- Questions to identify carers [→ Sheet 2](#)
- Carers First Contact Tool: Question Guide [→ Sheet 3](#)
- phn Victorian-Tasmanian Alliance: Educational kit offering guidance for GPS to identify and support patients who are carers. <https://vtphna.org.au/news-and-education/online-learning/carer-awareness-in-general-practice/>



2. Establish open lines of communication

Establishing and maintaining open communication with carers is crucial for building trust and achieving a shared understanding of the consumer's needs. Regular communication can take place through in-person meetings, phone calls, or digital platforms. It's important to recognise that carers are partners who share responsibilities and possess valuable information that can contribute to the consumer's care.

To effectively engage with carers, it's essential to emphasise the importance of sustained and regular communication. This ongoing engagement allows for the sharing of insights, updates, and concerns, ensuring that everyone is informed and on the same page.

Open communication also entails respecting confidentiality, ensuring that all personal data is kept confidential and shared only with consent. Maintaining confidentiality is a critical aspect of building trust and protecting individuals' privacy. For more information on confidentiality, please refer to the next section on support all parties understanding of 'privacy and confidentiality.



Steps to Establish Open Lines of Communication with Carers

- 1 Invite and Encourage Communication**
Create an environment that welcomes and encourages carers to communicate their thoughts, concerns, and observations. Let them know that their input is valued and essential for providing quality care.
- 2 Active Listening**
Practice active listening when engaging with carers. Pay attention to their words, emotions, and non-verbal cues. Demonstrate empathy and understanding, ensuring that carers feel heard and acknowledged.
- 3 Discuss Confidentiality Boundaries**
Engage in open discussions with carers about what information can and cannot be shared, emphasising the importance of respecting confidentiality. Address any concerns or questions they may have regarding privacy, including the carer's privacy.
- 4 Negotiate Ongoing Contact**
Discuss and agree upon the frequency and mode of ongoing contact between carers and healthcare professionals. Determine how updates, progress reports, and queries will be communicated, ensuring that all parties are comfortable with the agreed-upon arrangements.
- 5 Identify Communication Channels**
Identify and establish the preferred communication channels for carers, considering their preferences and accessibility. This may include options such as phone calls, text messages, emails, or face-to-face meetings. Flexibility in communication methods helps accommodate individual needs.
- 6 Foster Open Communication**
Strive to maintain open and transparent communication throughout the care process. Encourage carers to share their perspectives, ask questions, and provide feedback. Create a safe space for open dialogue, promoting collaboration and shared decision-making.

Practical Tips for Communication

1 Active Listening

Practice active listening by giving your full attention to the carer. Make eye contact, avoid interrupting, and demonstrate empathy. Listening attentively creates a sense of trust and respect, encouraging carers to share their perspectives openly.

2 Ask Open Questions

Use open-ended questions that encourage carers to elaborate on their thoughts and experiences. Open-ended questions give people the chance to talk rather than give one-word answers. For example, you could ask “how are you? rather than are you ok?” This approach allows for a deeper understanding of the situation, helps to clarify information, and facilitates shared decision-making.

3 Summarise

Summarise the main points of the conversation to ensure that you’ve understood the carer’s perspective correctly. Summarising also helps to clarify information, confirm agreements, and demonstrate that you’re actively engaged in the conversation.

4 Use Language Carers Understand

Use simple and concise language that is appropriate to the individual’s needs and abilities. Avoid using jargon or acronyms that only make sense to people with specialist knowledge. Adapt your language to suit the carer’s communication style to foster clear and effective communication. This could also mean providing a translator or interpreter where required. In some cases, the role of carer will be taken on by children and adolescents.


5 Consider Different Communication Methods

Consider different communication methods based on the carer’s preferences and needs. For example, you may need to use easy or plain English or sign language to communicate effectively. Flexibility in communication methods helps accommodate individual needs.

6 Document Conversations

Keep accurate records of conversations, capturing important information, decisions, and action points. Documenting discussions helps maintain clarity, allows for future reference, and ensures that all parties are on the same page. Accurate documentation also helps to avoid misunderstandings and miscommunications.

Resources and further reading

- Say this, not that:
A guide to communicating with carers. 
- OARS approach
https://rhntc.org/sites/default/files/resources/rhntc_oars_model_job_aid_12-20-2021.pdf
- Active Listening
<https://www.verywellmind.com/what-is-active-listening-3024343>
- Open Questions
<https://pdtraining.com.au/blog/effective-communication-course-2/effective-communication-skills-training-good-questions/>
- Simple language
<https://www.healthliteracyplace.org.uk/toolkit/techniques/use-simple-language/>



3. Support all parties' understanding of privacy and confidentiality

Openly communicating with carers and consumers about confidentiality and sharing of information is key to ensuring misunderstandings and difficulties do not arise.

In situations involving consumer confidentiality and carer engagement, it's essential to strike a balance between respecting consumer privacy and involving carers in the care process.

When a consumer does not provide consent for information to be shared with their support network, it is still possible to share general information without breaching privacy or confidentiality. General information includes non-personal, factual information that builds on the carers existing knowledge. It is still important to record the information that was discussed, with whom and when.

Carers have a legal right to be informed and receive information that supports them in their caregiving role. Healthcare professionals can engage with carers by actively listening to their concerns and providing general information about health conditions, treatment plans, medications, and available services.

Communicating confidentiality, privacy, and consent with consumers

In seeking consent, it is important for healthcare professionals to:

- explain the purpose and benefits of sharing specific information.
- communicate in a way the consumer will understand, using clear and concise language.
- assure the consumer they can withdraw their consent at any time.
- ask consumers for carers' input into planning consumer care,
- talk through any consequences of not sharing information. There may be some information the person is comfortable to share,
- close the discussion by clarifying the shared understanding of what has been agreed.
- document the agreed outcome of the discussion in the consumer's clinical record.

Where a consumer provides general consent to share information with those involved in their treatment and care, consent does not need to be sought before every instance of information sharing.

Communicating confidentiality, privacy, and consent with carers

Ideally, the consumer has had the opportunity to discuss and consent to the information that they agree to share with carers. However, if consent has not been provided, for any reason, healthcare professionals can still listen to carers and provide them with general information.

Where a consumer does not want any information given to their carer, ensure there is general information available. Ask carers to feedback any difficulties encountered with a new routine/health care plan.

Resources and further reading

- The consent conversation [Sheet 6](#)
- Sharing confidential information [Sheet 7](#)
- Confidentiality flyer (for carers) [Sheet 8](#)

4.

Support all parties' understanding of privacy and confidentiality

Carers provide support and care to consumers once they return home after healthcare visits. Empowering carers with essential information is crucial for their ability to provide appropriate support. Healthcare professionals can contribute to the successful transition home and ongoing health and wellbeing of consumers by equipping carers with the knowledge they need to make well-informed decisions.

Carers are better able to support health outcomes if they have:

- ongoing opportunities to ask questions, give feedback, and discuss concerns,
- information to support them in their caring role,
- the opportunity to see a health clinician on their own,
- confidentiality in communication with and to a clinician,
- referrals to additional information and support, if necessary,
- an assessment of their own needs and written care plan when required.²

It is important to recognise that a carer's own well-being and needs can change over time, which can impact their role and the support they require. They may also have significant health problems of their own, and it is not uncommon for them to engage in "co-caring." It is essential to acknowledge the complexity and diversity of caring roles.³

Here are some suggested questions to ask carers

What has happened since we last met?

- How are you going?
- Have you had a chance to look at the information I left with you last time?
- Is there anything you don't understand/want to clarify?
- What effect has the medication/intervention/treatment had from your perspective?

Resources and further reading

- Carer Resources



² http://www.chiefpsychiatrist.wa.gov.au/wp-content/uploads/2015/11/Carers_Guide_Information_Sharing.pdf

³ https://www.ranzcp.org/files/resources/college_statements/practice_guidelines/ppg-20-information-sharing.aspx

Practical Templates and Resources

The tools and resources in this guide aim to support healthcare professionals to work with carers in their consumer's care.

How to use the templates and resources in this practical guide

The final section of this guide provides a range of downloadable and printable templates and resources that you can use as they are or modified to suit your business and needs.

You will find the following templates:

1. Tips for including carers in consumer care.
2. Conversation starters to identify carers.
3. Carer first contact tool.
4. Your caring role (form).
5. Say this, not that: A guide to communication with carers.
6. The consent conversation (consumer).
7. Sharing confidential information.
8. Confidentiality Flyer (for carers).
9. Carer Resources.

References and further reading

Laws and Policies

- Carers Recognition Act 2010
- Carers (Recognition) Act 2008 Qld
- Hospital and Health Boards Act 2011
- Health Services Act Qld
- National Safety and Quality Health Service Standards (NSQHS)

Privacy and Confidentiality

- Privacy Act
- Information Privacy Act 2009 (Qld)
- Australian Privacy Principles
- The Health Privacy Principles contained in Schedule 1 to the Health Records Act 2001

Mental Health

- The Consumer, Carer and Family Participation Framework
- National Standards for Mental Health Services (NSMHS)
- Mental Health Act 2016 QLD

ⁱ <https://www.dsdsatsip.qld.gov.au/our-work/carers/queensland-carers-advisory-council>

ⁱⁱ <https://www.carersaustralia.com.au/about-carers/who-is-a-carer/>

ⁱⁱⁱ https://www.mindaustralia.org.au/sites/default/files/publications/A_practical_guide_for_working_with_people_with_a_mental_illness.pdf

^{iv} https://www.ranzcp.org/files/resources/college_statements/practice_guidelines/ppg-20-information-sharing.aspx

^v https://www.mindaustralia.org.au/sites/default/files/publications/A_practical_guide_for_working_with_people_with_a_mental_illness.pdf

^{vi} https://www.ranzcp.org/files/resources/college_statements/practice_guidelines/ppg-20-information-sharing.aspx

^{vii} <https://www.legislation.gov.au/Details/C2010A00123>

^{viii} <https://www.safetyandquality.gov.au/standards/nsqhs-standards>

^{ix} <https://www.legislation.qld.gov.au/view/pdf/inforce/2000-11-08/act-1991-024>

^x <https://www.health.vic.gov.au/sites/default/files/migrated/files/collections/policies-and-guidelines/c/chief-psychiatrist-guideline-working-with-families-and-carers.pdf>

^{xi} https://www.health.qld.gov.au/_data/assets/pdf_file/0026/444635/info_sharing.pdf

^{xii} <https://www.legislation.gov.au/Details/C2022C00361v>

^{xiii} <https://www.legislation.qld.gov.au/view/html/inforce/current/act-2009-014>

^{xiv} <https://www.health.vic.gov.au/legislation/health-records-act>

