Carer Awareness in General Practice webinar content

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Part 1: Recognition of the carer role

Who is a carer?

One in eight people in Australia are carers. For context, if we identify patients in our practice with certain health conditions, one in eight is significantly more than people who have diabetes or asthma, which are conditions that we would all quite routinely recognise and record in our practice.

One in eight people works out to 2.6 million Australians who are caring for a family member or friend.

People become carers in many different ways. It can happen gradually as a person's health and independence get worse over time, or it can happen suddenly after a health crisis or accident. Many carers feel that it is what they should do and that they don't really have a choice.

It is important not to confuse carers with paid care workers, such as Community or Aged Care workers.

Many people don't identify with the term carer. There may be other words they use to describe themselves. Some people dislike the label carer believing it can detract from their identity as a parent, child, partner, relative or friend to the person they care for.

The Victorian Carers Recognition Act 2012 defines a carer as someone who provides care to another person, and includes carers under the age of 18. Carers can provide care for a person who:

- has a disability
- has a mental illness
- has an ongoing medical condition or
- is an older person with care needs.

Carers do not:

- need to live with the person they care for
- need to be the main source of care and support
- have to provide care every day or over many years
- have to receive the Carer Payment or Allowance from Centrelink

Some carers provide continuous care – providing up to 24-hour support and aid to someone with high care needs, helping with daily activities such as preparing meals, bathing, dressing, toileting, moving around and taking medicine. Others have more intermittent carer roles – looking after people who are mostly independent but might need help with tasks such as banking, transport, shopping or housework.

Tips for identifying carers in your practice

- Include questions on your registration form, such as *Do you rely on someone for your care?* and *Does someone rely on you for their care* or *Do you assist someone who has health, disability, or age-related support needs?*
- Consider patients who are frail and elderly, have dementia, a mental illness, a disability, chronic illness or complex needs, or receive palliative care – identify if they have a family member or friend who is providing unpaid care and support

- Diagnosis or first appointment for patients with a longer-term illness is a good opportunity to ask who their main support person is, even if they do not yet identify as needing a carer
- Utilise your practice management software or other information systems to promote the identification of carers
- Make sure you record that someone is a carer in both the patient and the carer's file
- Many people don't identify with the term 'carer' – ask open questions about the things they do and support they provide (e.g. *What sort of things to you do for <name>?*)
- Other questions that may help identify carers include:
    - *Do you worry about leaving <name> home alone?*
    - *Do your responsibilities at home mean you often miss out on doing other things you enjoy, or would like to do?*
    - *Have you given up work or reduced your hours so you can give more support to someone at home?*
    - *Do you regularly arrange hospital and other appointments, provide transport, or help someone manage their affairs so they can maintain their independence?*
- Recognise that the carer may change over a patient's lifetime (e.g. from parent to spouse)
- Remember that every carer situation is different
    - Some people provide care all the time, while others do so only occasionally
    - A person might be a carer for multiple people
    - Someone receiving care may have multiple carers

Issues faced by carers

There are many rewards experienced by those caring for a family member or friend, but caring can be very demanding and often restricts the lives of individual carers and their families.

Many carers miss out on important life opportunities, particularly for paid work, a career and education. Caring can take the freedom and spontaneity out of life.

Physical and mental health and wellbeing impacts of being a carer:

- Caring can be emotionally taxing and physically draining
- Carers have the lowest wellbeing of any large group measured by the Australian Unity Wellbeing index
- Carers often ignore their own health and are 40% more likely to suffer from a chronic health condition
- Some health problems, like back problems, anxiety and depression, can be directly linked to caring
- Many carers are chronically tired and desperately need to refresh with just one night of unbroken sleep, a day off or an extended period with no caring responsibilities

There are also social impacts, including stigma, isolation and on relationships:

- Many carers feel isolated, missing the social opportunities associated with work, recreation and leisure activities
- The demands of caring can leave little time for other family members or friends
- Carers often have to deal with strong emotions, like anger, guilt, grief and distress, that can spill into other relationships and cause conflict and frustration

There are also often financial hardships being a carer:

- Carers often have diminished financial resources as they have reduced or given up work
- 50% of primary carers are on a low income and many find it hard to cover living expenses, save money or build up superannuation
- The extra costs of caring can be enormous. Caring families often have to find money for extra expenses like heating and laundry, medicines, disability aids, health care and transport.
- Not all carers live with the person they care for, but may still need to support some of their housing expenses

Tips for supporting carers in your practice

- Listen, support and facilitate
- Consider utilising checklists or question prompts to help identify issues and opportunities for support (e.g. Carer Strain Index)
- Utilise MBS items to assess and manage carer health (e.g. 75+ health check, 45-49 health check, mental health plan, chronic disease management items)
- Encourage and enable carers to have an annual influenza vaccination as a priority group
- Provide adequate safety-netting and follow-up arrangements for carers and family members to reduce risk and improve care
- A significant number of carers experience considerable psychological distress – consider depression screening and referral to either a clinical psychologist or counsellor
- Promote carer education sessions and support groups
- Consider the financial impact of services
  - Is it possible for your practice to bulk bill carers?
  - Be aware of the financial impacts of referrals
  - https://www.carergateway.gov.au/financial-help
- Value the views of carers and acknowledge the barriers they face to providing effective support for the person they care for. Appreciate that factors affecting a carer’s health may affect his or her ability to care.
- Be alert to the presence of carers under the age of 25 and provide support when a young carer is identified. Consider if they are undertaking caring duties inappropriate to their age (this may be a safeguarding issue).
- Be mindful of potential abuse. Both care recipients and carers can be susceptible to abuse.

Part 2: Identifying and supporting carer needs

Working with carers to support their needs

According to the Carers Recognition Act 2012, a carer should:

- be respected and recognised:
  - as an individual with their own needs
  - as a carer
  - as someone with special knowledge of the person in their care
- be supported as an individual and as a carer including during changes to the care relationship
- be recognised for their efforts and dedication as a carer and for the social and economic contribution to the community arising from their role as a carer

- have their views and cultural identity taken into account, together with the views, cultural identity, needs and best interests of the person for whom they care, in matters relating to the care relationship. This includes when decisions are made that impact on the carer and the care relationship.
- have their social wellbeing and health recognised in matters relating to the care relationship
- have considered in decision making the effect of being a carer on their participation in employment and education.

Opportunities to identify and support carer needs will vary depending on whether they are also your patient. When you see carers in your practice, consider whether they are also a patient at your practice or if they attend another practice as a patient.

If they are a patient at your practice, consider whole-practice opportunities to identify carer needs. Utilise practice systems and include non-clinical staff.

If carers are only attending in their caring role, create opportunities to see them independently. Carers may have difficulty leaving the person they care for to attend appointments, so it is important to offer some flexibility.

Offer carers consultations at times when their caring duties permit them to access the practice, and ensure they have access to after-hours medical support information. Consider offering carers first appointments to minimise waiting time or adding on an appointment when the person they care for comes in for an appointment. Consider booking longer consultations for carers to allow as much as possible to be done to reduce the number of visits required.

If the carer is a patient at a different practice, it is still important to check in and ask if they are receiving the support they need. There may still be opportunities for your practice to provide them with support and services.

Carers from culturally and linguistically diverse communities

Carers from culturally and linguistically diverse communities may be harder to reach. They may not understand the concept or identify with the term ‘carer’ as caring for family members can be a strong part of the culture.

Carers of culturally and linguistically diverse backgrounds may face additional barriers, such as language and communication difficulties, lack of knowledge or understanding of the mainstream health care system, and inadequate access to culturally safe services.

Carers in Aboriginal and Torres Strait Islander communities

Aboriginal and Torres Strait Islander people are more likely to be carers than non-Indigenous Australians. Aboriginal and Torres Strait Islander carers are also more likely to need assistance with their own care needs, including self-care, mobility and communication.

The impacts of caring may be greater for Aboriginal and Torres Strait Islander carers due to the higher incidence of caring, lower engagement with mainstream health and disability services, and inadequate access to culturally safe services.

Carers in LGBTIQA+ communities

Many LGBTIQA+ people care for a partner, friend or family member. Carers in the LGBTIQA+ community can face particular challenges in their caring roles because of invisibility, discrimination or exclusion. A lack of recognition of a person's experience, sexuality, gender identity or care relationship can add stress to carers in already challenging circumstances.

Many carers may be isolated from others in their communities by distance, social isolation, financial disadvantage, stigma and/or demands related to their role. Limited access to affordable inclusive services and fear of discrimination can prevent LGBTIQA+ people from seeking services or disclosing their sexuality, gender identity or intersex status.

The caring role can be challenging for all carers, but it might be particularly challenging for LGBTIQA+ carers because of:

- Experiences of discrimination and fear of discrimination in the community, including from family, friends and peers, employers or other carers
- Fear of exposure or judgemental attitudes from service providers
- Lack of traditional supports through loss of contact with family/culture
- Lack of social and legal recognition of relationships and ‘family of choice’
- Invisibility in caring situations can lead to isolation and exclusion from decision making (meaning they are unable to advocate for the person they care for)
- Inability to maintain intimate relationships or to ‘be themselves’ in care situations
- Judgemental attitudes from service providers or other service users

Tips for a carer-friendly practice

- Improve the physical accessibility of your practice so carers can bring patients with a mobility condition or disability into your practice
- Offer carers consultations at times when their caring duties permit them to access the general practice
- Ensure carers have access to after-hours medical support information
- Regularly obtain feedback from carers on your appointment booking, referral and communication systems and use this information to improve access and continuity of care
- Provide adequate safety-netting and follow-up arrangements
- Write down information and clinical advice given in consultations for the patient and carer to take home
- Understand that having an identified health professional to liaise with or the same GP to provide care can be immensely helpful for carers. It reduces repetition, saves time and is reassuring for the carer knowing the healthcare professional is familiar with, and understands the situation they’re dealing with (even when the patient is not present).
- Examine barriers to carer support and ways in which they could be overcome within your field of practice
- Use professional interpreters when communicating with patients and carers who are not fluent in English
- Put together and provide an information pack for carers and family members to help them in their roles. Include culturally relevant and multilingual resources, where available.

Referral pathways for carers including support services

- HealthPathways
- Carer counselling services, such as Carer Gateway and Cares Victoria
- Mental health services
    - Consider a mental health care plan, if appropriate. Where possible, refer to services with experience working with carers.
    - PHN-led mental health services (e.g. CAREinMIND for NWMPHN)
- Respite services vary widely across Victoria. Carers may need to talk to several organisations to see what they offer and how they can help, but Carer Gateway is a good starting point https://www.carergateway.gov.au/respite Remember, help is always available in an emergency.
- Peak bodies often have information about support for carers, as well as for navigating the NDIS and other parts of the health system, if relevant. E.g. Dementia Australia, MS, Amaze, Cancer Council Victoria
- Peer support
    - Local carer support groups can be found through Carers Victoria
    - Switchboard Victoria provides peer-driven support services for LGBTIQA+ people, their families, allies and communities http://www.switchboard.org.au/

Life after caring

When caring responsibilities come to an end, carers may question what else they are able to do, with education, employment and relationships inevitably affected during their time caring. Ongoing support is required during this time.

Some problems commonly seen when carers stop caring include feelings of emptiness, loneliness, low self-esteem, depression, anxiety, and poor health as a result of years of self-neglect, stress and the physical impacts of caring.

Every caring experience is different. How a person copes with life after caring depends very much on the length and complexity of the caring responsibility and the relationship between the carer and the cared for person. It also depends on how it ends.

Death of the care recipient may result in a sense of shock, even if the person has been ill for a long time. Carer payments often come to an end within a few weeks of death and there may be housing issues if the person who has died owned or was leaseholder for a joint home.

Admission into residential care also results in a sense of bereavement. The carer may experience feelings of guilt and anxiety, even though the move is often the only feasible option. Even though the carer will continue to be a carer, albeit from a distance, they may feel a sense of failure. In addition, there may be financial implications and, after many years of rarely being able to leave home, the carer may lack confidence in seeking a life away from their caring responsibilities.

Varying care needs may result in carers moving in and out of a caring role. For example, where a family member misuses alcohol or drugs, has a mental health issue or an eating disorder, carer responsibilities will vary according to the current state of health of the person they care for. Even when that person appears to be coping well, the carer might always have the stress of wondering what the future will bring and uncertainty of not knowing when their help will be needed urgently.

Part 3: Involving the carer in patient care

Carers as partners in care

Carers know the people they care for better than anyone and their knowledge is extremely useful in planning patient care and in the identification of problems that require intervention.

Engagement and co-operation with carers is an essential part of good patient care. When care is planned without the input of carers, research has shown that outcomes for the patient include more frequent hospital admissions, poor medication management and a lack of integration of care.

Co-operation may be needed from carers to effectively implement a patient care plan. Involving carers and listening to their views when devising a care plan is likely to result in much better co-operation and agreement.

Respect for privacy and confidentiality as well as the self determination of patients is critical, however there may be benefits in involving a carer in information sharing and treatment decisions.

- Talk to patients routinely about the issues surrounding information-sharing and seek their permission for appropriate information about their care and treatment to be shared with their carer
- When planning patient care, where possible ask carers first about any problems they may be having and their views about the best course of action to support the patient
- Where a patient is reluctant for all information to be shared, talk through the consequences of this decision; there may be some aspects of their condition they are comfortable to share
- Where a patient does not want any information given to their carer, ensure there is general information on relevant health conditions available, for example leaflets on medical conditions or the effects of medication
- Introduce agreements on information sharing and record them prominently in the patient's notes so other members of the team are aware of them
- Ask the carer to feedback any difficulties encountered once a new care plan has been instituted

In some cases, patients lack the mental capacity to make a decision about sharing their personal information with carers. A person should be able to:

- Understand the information relevant to the decision
- Retain that information long enough to make a decision
- Use or weigh that information as part of the process of making that decision
- Communicate his or her decision using verbal or non-verbal communication.

If this is not possible and you need consent for treatment or a decision around disclosure of information you may need to turn to the person responsible or guardian. The carer may also hold these roles and functions, but not automatically, so you need to check.

Tips for incorporating carers in care treatment and planning

- Explore the ideas, concerns and expectations of carers and other family members. Be aware of the relationship between carer and patient and consider that they may not always be completely honest in front of each other.
- Adopt a problem-based approach with carers to clarify and prioritise clinical and non-clinical issues that need to be addressed
- Use medical records and information tools to enhance and inform the shared decision-making with patients, carers and multi-disciplinary teams

- Include the carer in multidisciplinary case conferences, or provide a summary and discuss the outcomes of the conference (if appropriate and the patient agrees)
- Actively involve carers in the planning and implementation of long-term management plans of those they care for, particularly when developing Advance Care Directives and discussing aspects of health Advance Care planning
- Develop holistic and shared decision-making approaches to treatment plans with patients and carers
- Co-ordinate and integrate the agendas of carers and other family members with that of the patient and your own agenda. Enable shared decision-making and agree on management plans.
- Recognise that carers may need different information and support depending on where they are on their caregiving journey. Consider providing information about carer education, specialised advice or training for specific aspects of their role (e.g. advice about lifting and transferring a patient).

Working with carers of people with a mental illness

The Chief Psychiatrist's guideline: Working together with families and carers provides specialist advice about involving family and carers in the treatment and care of people with a mental illness. The following are key messages and general advice about privacy, confidentiality and information sharing with carers. The full guideline should be consulted for further information and clarification.

- Families and carers should be recognised, respected and supported as partners in providing support and care to consumers
- Families and carers should be identified and engaged as soon as possible in assessment, treatment, care and recovery
- Services must have clear processes and practices that support open communication with consumers, families and carers regarding information sharing, privacy and confidentiality
- Services are required to have regard for the impact of mental illness on family members and to assist families and carers to identify their needs, including in relation to the caring role
- Families and carers should be engaged in organisational practice and governance

Sharing information is important to support open, collaborative relationships between clinicians, consumers, families and carers. A challenge for clinicians can be meeting the privacy preferences of consumers and the need to keep family members and carers informed and involved in supporting the consumer's recovery.

The Mental Health Act recognises that carers need information to assist them in their caring role and authorises clinicians to provide this information in specified circumstances. Openly communicating with consumers, families and carers about privacy, confidentiality and information sharing is fundamental, particularly because this is an area where misunderstandings and difficulties can arise.

Consumers have the right to privacy and should have the opportunity to decide what information can be shared with their families and carers. Families and carers need information to assist them to provide sufficient support to the consumer. Clinicians will need information from consumers, as well as carers and family members, to provide treatment and care to the consumer.

In certain circumstances, such as where family violence or family trauma is disclosed, it may not be appropriate to share information with some family members. Allow for respectful communication with the consumer about their communication preferences.

The Mental Health Act also includes specific obligations for clinicians to consult with and inform carers where actions will directly affect the carer and the care relationship. Details of these obligations and when they apply can be found in the guideline, accessible in the Resources section.

Families and carers should be provided with general information on available supports and information about the service. Providing general information and hearing from a carer or family does not breach privacy or confidentiality.

Medical decision making when a patient cannot consent

A patient must be an adult, and able to understand, retain, use or weigh up information about the general nature and effect of the proposed medical treatment and communicate their decision to consent to the treatment.

The Medical Treatment Planning and Decisions Act 2016 provides a framework for making medical treatment decisions when people do not have capacity to make their own decisions. The Act allows people to complete an advance care directive, appoint a medical treatment decision maker and appoint a support person.

The Act also sets out the process for health practitioners when a patient does not have decision-making capacity to consent to medical treatment.

A person may only create an advance care directive if they have decision-making capacity in relation to each statement in their advance care directive. There are two forms of statement a person may include in their advance care directive:

- an instructional directive
- a values directive.

If medical treatment is clinically indicated and a person does not have decision-making capacity, a health practitioner must obtain consent through an instructional directive, or if there is none, obtain consent from a medical treatment decision maker. An adult may appoint a medical treatment decision maker when they have decision-making capacity.

If an adult does not have decision-making capacity, the medical treatment decision maker will be the first willing and available person from the list below (there can only be one medical treatment decision maker at a time):

- an appointed medical treatment decision maker
- a guardian appointed by the Victorian Civil and Administrative Tribunal (VCAT)
- the first of the following with a close and continuing relationship with the person:
    a) the spouse or domestic partner
    b) the primary carer of the person
    c) the first of the following and, if more than one person fits the description in the subparagraph, the oldest of those persons:
        i. an adult child of the person
        ii. a parent of the person
        iii. an adult sibling of the person.