Caring for the carer
A guide for caregivers of an older person
Introduction

A carer is someone who provides unpaid care and support to another person who is unable to properly care for themselves.

The important role of caring for someone who is frail aged or is living with dementia, can give the carer satisfaction and even a sense of achievement.

However it can also present many challenges, often resulting in both physical and emotional exhaustion. Over a period of time, this can result in the carer burning out.

As a caregiver, it is important to acknowledge that you also have needs. Meeting these needs is essential to help you to stay in the carer role for longer and for improving the quality of time spent with your loved one.

This booklet provides guidance and practical advice to assist supporting carers. It also identifies agencies and organisations available to you. You can then decide what is most beneficial to support you in your caring role.
Self-care

Central to care-giving is the self-care for you as a carer. This will increase the longevity of care provision for another by helping minimise the carer burning out.

Helpful self-care strategies include:

- prioritise own health checks (including dental care)
- getting enough sleep (including power naps)
- including some exercise into your day
- scheduling regular time out
- ensuring a healthy, well-balanced diet
- knowing when and how to access outside support
- accepting assistance from other family and friends
- connecting to counselling and support networks.

Often, carers find it difficult to ask for assistance or support. This can happen for many reasons, including:

- feeling they should be able to manage
- believing it is their sole responsibility
- feeling embarrassed or guilty requesting help
- believing that others are more deserving
- fear of upsetting or disrupting the care receiver
- feeling others would not provide appropriate care.

These are normal feelings for care givers and completely understandable, however if the role is to be sustainable, caregivers’ needs should also be met.
Care-giving can be stressful

The demands of care-giving can often prove stressful. Normal feelings while care giving can include:

- anger
- guilt
- depression
- loneliness
- sadness
- fatigue
- frustration
- grief and loss
- resentment
- a sense of hopelessness.

Stress can mean different things to different people and can be experienced in different ways.

**Physical stress**
As a result of too much to do, heavy lifting, exhaustion due to lack of sleep, inadequate diet or an illness.

**Emotional stress**
Affects your peace of mind as you become anxious about the care receiver’s illness, finances, services and resources, accommodation, lack of support or concern about the future.

Stress is often a negative feeling and it can be hard to put your experience into words. Often it is felt as a loss of control.

Some of the highest carer stresses identified by carers include:

- night time wandering
- personality changes
- incontinence
- agitation
- lack of sleep
- aggression
- increased mobility
- personal care provision
- balancing important relationships.
Strategies to manage stress

If you feel overwhelmed—it is ok to say ‘no’. You may be taking on more than you can handle. There is only so much that can be done in a day.

Try not to expect perfection from yourself—or others!

When you reduce stress in your life, you are better able to cope with the pressures of being a caregiver.

• Tackle one task at a time. Choose the most urgent one first and be realistic about achievable timeframes.

• Celebrate your achievements.

• Avoid negative self-talk

• Include exercise and meditation to your routine

• Record your thoughts in a journal

• Stay focused on the bigger picture

• Be open to listening to others suggestions when you need help. Try to be flexible and open to trying new strategies

• Find time to relax—listen to music, meditate, visualise and continue with your hobbies and interests

• Sleep and rest whenever possible

• Accept love and support from your family and friends

• Seek help if you need it. If you feel symptoms of depression (sadness, difficulty concentrating, sense of hopelessness, inability to sleep) see your doctor and access counselling supports.
It’s ok to accept help from services, family and friends. You don’t have to do everything yourself. By allowing yourself the opportunity for some personal time, you increase your ability to sustain the carer role for a longer period. It is also important that you maintain social contacts and continue to foster friendships and relationships.

**Remember:** talk to someone who really listens to what you are saying.

**Support groups**
There are support groups in your area that provide contact with other caregivers. It can be helpful to share your experience with people who are living a similar experience. It can also assist you to gain and provide practical and emotional support.

Talking to others provides comfort and helps remind people they are not alone.

**Alzheimer’s Queensland** 1800 639 331 or **Carers Queensland** (07) 5451 1882.

**Advocacy**
Aged Care Advocacy can assist you in representing the rights of your loved one through support and advocacy regarding aged care services.

**My Aged Care** 1800 700 600

**Aged and Disability Advocacy** (07) 3637 6000
Accepting help

Counselling Services

Talking with someone professional about your experiences and feelings as a carer can help you to better understand and manage your situation. This can assist in minimising stress and lengthening the duration of the carer role.

**Carers Australia:** 1800 242 636  
**National Dementia Helpline:** 1800 100 500  
**Better Access Scheme:** via your G.P.

Dementia Behaviour Management Advisory Service (DBMAS)

DBMAS provides strategies and support for people caring for someone who is demonstrating behavioural and psychological symptoms of dementia and who is receiving support through aged care services.

**24 Hour Helpline:** 1800 699 799

QLD Younger Onset Dementia Key Worker Program

This program provides individualised case managed support and services for people living with younger onset dementia, their families and carers.

**National Dementia Helpline:** 1800 100 500.

Carers’ Advisory Service

Provides carers with information, support, planning and referral advice. This includes information about available services and supports, assistance in maintaining carer health and financial and legal information.

**Carer Advisory Service:** 1800 242 636
In-home services and supports

Services are available to support the frail elderly and people living with dementia, to enable them to remain independent in their community homes for as long as possible. This may include domestic support, nursing assistance, community connection, carer support, home modifications and more. Depending on the individual needs this can be organised as specific independent supports, or as a case managed package of care.

The My Aged Care Service can assist you in finding out more information about services that are right for you and your loved one. They will discuss care needs and will support you with the processes required to begin receiving in-home services.

This may require assessment by the Aged Care Assessment Team (ACAT) for a home care package (level one to four), or services may be provided by Commonwealth Home Support Program.

The Aged Care Assessment Team is able to assess eligibility and approve applications for residential care (permanent and respite) and community home care packages. ACAT also provide information and advice regarding aged care services.

Register: My Aged Care Service 1800 200 422 or www.myagedcare.gov.au
Respite can provide essential short term breaks for carers. This provides opportunity for carers to attend events and activities, enjoy social gatherings, stay involved in interest activities or simply relax and revive. Respite can be provided either informally, through friends and family, or more formally through the services such as those listed below.

**In-home respite**
A professional carer who comes to the home and provides support to the person requiring care, or takes the person out to provide the carer a break at home.

**Community-based day respite**
Centre-based group activities and events, organised by an aged care service and run from a residential facility.

**Emergency respite**
Available if an emergency arises and you are temporarily unable to continue in the carer role. Can be in-home or residential-based.

**Short-term respite**
Short stay in a residential aged care facility, planned or emergency. This requires assessment from the aged care assessment team for respite approvals (see details below). Once approved, you are eligible for up to 63 days of respite within a financial year, with potential to extend in special circumstances.

**Respite with a view to permanent care**
Short-term respite can sometimes be used as a lead-in to permanent residential care, while awaiting the finalisation of Centrelink assets and income details. In this instance, negotiations occur with the preferred aged care facility, to see if they can accommodate your loved one in a respite arrangement, with a view to this becoming permanent.
Register for respite services

**My Aged Care:** 1800 200 422 or www.myagedcare.gov.au

Contact for those already registered

**Commonwealth Respite and Carelink Centres:** 1800 052 222

**My Aged Care:** 1800 200 422 or www.myagedcare.gov.au

**Department of Veterans’ Affairs (DVA)**

The DVA can offer financial help and support to help carers and family members caring for a veteran. DVA can provide in-home assistance through their home care packages. This includes domestic support, help with personal/nursing care and respite support.

**Department of Veterans’ Affairs:** 1300 555 727

TY users phone 133 677 then ask for 133 254

Internet relay users via NRS then 133 254
Managing the home environment

Managing in the home can become difficult for the frail elderly and those living with dementia. Along with appropriate home-help there are a few changes in the home that may help both you and your relative, by reducing risks and enhancing comfort. It is important to try to balance safety, security and independence, this may include:

• Establish a daily routine. Your loved one may feel more reassured by following a predictable pattern of familiar events.

• Involve your loved one in some simple tasks and activities in the home. This will help in preventing boredom and associated behaviours, such as wandering.

• Minimise the number of visitors (at once) and background noises, as this can be unsettling and over-stimulate your loved one.

• Maintain comfortable room temperatures, to minimise stress.

• Keep up physical exercise for your loved one if possible, including daily walks or other physical activities. This may aid sleep patterns.
• Good lighting is important to prevent falls and disorientation. Also consider a night light in hallways or bathrooms.

• Remove trip hazards such as mats, rugs and extension leads, to reduce falls.

• Modifications in the bathroom such as rails, shower chairs and raised shower floors can minimise falls.

• Assess safety, including risk of fire (i.e. check toaster, kettle, stove and consider turning off gas stoves). Use automatic cut-offs for electric appliances to ensure safety. Turn down hot water to reduce risk of scalding.

• Smoke detectors are essential for safety—install, with regular checks on batteries.

• Other electrical devices are also available to maximise safety, including mat and door alarms, as well as personal alarm jewellery.

• Gates can prevent wandering. Install and check catches are secure.

• An identification bracelet can be useful for people who wander.
Managing agitated behaviour at home

If the person you are caring for becomes agitated, try to stay calm. Remember that behaviour is a form of communication and may be a response to fear, pain or frustration. Try to identify what may have caused the behaviour (triggers) and what message is trying to be conveyed.

The following helpful tips have been adapted from the Alzheimer’s Australia, 12 tips in caring for a person with dementia:

1. **Remember the person**: understand their likes and dislikes. Provide photos, mementos, pictures and discuss memories.

2. **Smile**: The person will notice your emotional state. Remain relaxed, using slow, soft tones and positive body language.

3. **Slow down**: Help the person to do things for themselves and avoid hurrying the person. Keep it simple.

4. **Help with orientation**: Remind them of people, places and routines. Use cues, words, signs and pictures.

5. **Communicate clearly**: Speak clearly and use simple language that the person will understand. Take time to understand.

6. **Step back**: If the person is angry, keep yourself safe. Consider why the behaviour happened, provide space and try again later.

7. **Keep it quiet**: Reduce conflicting noises (TV, radio) and avoid crowds and over-stimulating environments.

8. **Don’t argue**: Go with the flow. Acknowledge and respect the person’s choices and opinions.

9. **Engage and encourage**: Get the person started with an activity and then set them up to succeed. Thank them for their help.

10. **Distract**: Discuss their life experiences. Provide activities and a relaxed environment. Encourage reminiscence.

11. **Talk with others**: Seek support when needed and consider what is or isn’t working for your loved one.

12. **Be aware of sudden changes**: Such as pain, dehydration and infections. If illness is suspected. Seek medical advice.
Financial concerns

Deciding to become a carer can have financial consequences relating to changes in employment, living arrangements and outgoings. As a caregiver, you may be eligible for financial assistance from Centrelink. Payments that are available include:

**Carer payment**
This payment is for carers providing constant care and requires referral from your G.P. or other health professional. Carer payment eligibility requires income and assets assessment.

**Carer supplement**
An annual payment, made automatically to carers who receive another qualifying payment.

**Carer allowance**
This payment is in addition to other Centrelink payments, including the aged pension and is a supplement for carers who provide additional daily care and attention. This payment can be accessed if the person you are caring for resides separately.

**Pharmaceutical allowance**
Help with the cost of buying prescription medicines.

**Rent assistance**
If you are paying rent and receiving a Centrelink payment, you may be eligible for rent assistance.

**Bereavement payment**
If your loved one passes away, you may be entitled to a bereavement payment. If receiving the carer’s payment when your loved one passes away, you may be entitled to up to 14 weeks payment after the death.

As payments and allowances change regularly, please use this information as a guide only and contact your local Centrelink office on 13 27 17 (multilingual 13 12 02) for further information on eligibility and entitlements.
As we age, it is sensible to consider planning ahead regarding financial, medical and legal matters. Documenting our preferences and wishes alongside allocating an appropriate substitute decision-maker, helps ensure that our wishes are carried out in the event that we are not able to make decisions ourselves.

It also helps to minimise stress for those supporting us. This is particularly important for people diagnosed with dementia and those frail elderly, who are at higher risk of acute illnesses and delirium.

**Advance care planning**

This involves a series of steps that can help a person ensure their wishes are respected at a time when they are unwell or dying. Making these wishes clear can also help provide peace of mind to family and friends in knowing what is wanted, should the person not be able to communicate it themselves.

Advanced care planning means thinking now, about what medical treatment is wanted in the future and provides opportunity to communicate and record these wishes for others.

1. **Creating an Enduring Power of Attorney (EPOA):** allows you to pre-organise someone you trust to make decisions for you, in the future event that you are unable to do so yourself. This can include financial and/or personal and health decisions. When considering your EPOA, it is important to think of the person, or people, who would most understand your preferences.

2. **Completing an Advance Health Directive (AHD):** This is a legal document that provides a detailed record of a person’s preferences and directions regarding future medical care. This document needs to be completed when the person still has decision-making capacity and in conjunction with their G.P. specialist health staff or treating doctor.
3. Completing a Statement of Choices: This is a document focused on a person’s wishes and choices regarding future health care provision. This document can be completed when no advanced health directive is present, or can be used to compliment a completed Advance Health Directive. The form can be completed in the community, or in hospital.

4. Completing an Acute Resuscitation Plan (ARP): This is a Queensland Health clinical document completed in hospital between doctors, patients and their families about appropriate resuscitation planning. This includes whether cardiopulmonary resuscitation (CPR) should be performed.

Making a will

Allows for your wishes to be known and carried out in the event of your death. Making a will also allows you to pre-determine what will happen to your assets when you pass away.

It is important, when completing a will, Enduring Power of Attorney or Advanced Health Directive, to consider whether you or the person completing the paperwork, truly understand what the paperwork includes. It is normally recommended that any person who has recently been acutely unwell, refrain from completing any legal paperwork until a later date.

If you are unsure whether your loved one has capacity to complete legal paperwork, encourage and help them to contact their lawyer, G.P. or specialist for further advice.
Family and other relationships can sometimes be complicated, especially at a time when a loved one is unable to act on their own behalf and difficult decisions are required. During these times there may be conflicting ideas about what is in the best interests of the person requiring the support, leading to questions about who should make these decisions.

The following are the most common decision-making pathways.

**Enduring Power of Attorney (EPOA)**

An EPOA document appoints a previously arranged legal substitute decision maker, as outlined within the limits of the document. This may be for health, personal and/or financial decisions.

**Statutory Health Attorney (SHA)**

When there is no legally appointed decision-maker, medical decisions can be made by the person’s closest relative or relationship who is over 18 years of age.

**Queensland Civil and Administrative Tribunal (QCAT)**

Where there is no Enduring Power of Attorney and a formal decision maker is sought, application can be made to QCAT for appointment of a formal guardian. QCAT also provides advice and information regarding assisted decision-making and/or administrator support.

**Office of the Public Guardian and Public Trustee**

The Public Guardian and/or Public Trustee can be appointed by QCAT to act as an substitute decision maker or administrator for a person with impaired capacity. This may be at the request of the person and their family/support people, or because there is no other identifiable person able to fill the role at the time the support is needed.

**Investigating appointed decision-makers**

Where there is conflict or concerns that an appointed Enduring Power of Attorney is not acting in their charge’s best interests, the Office of the Public Guardian (OPG) is able to investigate. The OPG may refer some complaints onto QCAT.
Useful websites

Advanced Care Planning Australia: www.advancecareplanning.org.au

Alzheimer’s Australia: www.fightdementia.org.au

Beyond Blue: www.beyondblue.org.au

Carers Australia: www.carersaustralia.com.au

Carers Queensland: www.carersqld.asn.au

Dementia Behaviour Management Advisory Service: www.dbmas.org.au

Department of Veteran’s Affairs: www.dva.gov.au

Legal Aid Queensland: www.legalaid.qld.gov.au

My Aged Care: www.myagedcare.gov.au

National Dementia Helpline: www.fightdementia.org.au/national/helpline

Queensland Civil and Administrative Tribunal: www.qcat.qld.gov.au

Aged and Disability Advocacy: www.adaaustralia.com.au
This booklet is produced by:
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Standard 2
Partnering with Consumers

Standard 11
Service Delivery

Standard 12
Provision of Care

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