

# WITH A LITTLE HELP..

How family and friends  
can support a Carer



THIRD EDITION 2018

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#### Acknowledgements

This resource was developed as a collaborative writing project in 2010 by members of the Resthaven Carers Community Advisory Group, based on the observation that there was a gap in resources available to Carers that could be used to let family, friends and the community at large know a bit of what it was like to live as a Carer.

Original contributors were Beryl Ducray, Philip Ellison, Max Jacquier, Mary Jarvis, Vicki Kelly, Myra McGinn, Carole Matthews, Valerie Sandlant, Shirley Sheppard, Pat Smytherman and Tony van Kalken.

Members of all Resthaven Community Advisory Groups contributed to the 2015 and 2017-18 reviews ahead of the revised editions.

Max Jacquier passed away as this booklet was being written and Beryl Ducray passed away since the publication of the second edition; they are each remembered with respect and fondness.

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## WHY THIS BOOKLET?

*With a Little Help ... How family and friends can support a Carer* is the result of a great deal of thought and discussion by experienced Carers. It has been written to be read by family and friends of a Carer: to help in building your understanding of and support for someone you know who is caring for someone else.

Many Carers say that they sometimes experience a sense of isolation – that those around them, family and friends, can't quite 'get' what it is that the Carer is going through.

Along the way, the focus is, understandably, often on the needs of the person who is being cared for. There is a sense that the Carer can or should be strong and 'just get on with it.' But, Carers give enormously of themselves and, at all stages of the journey, Carers face challenges to leading a rewarding and fulfilling life for themselves.

While Carers value their role and it has its rewards, many say that it is demanding and that they need to be supported so that they can keep it up when things get difficult. Carers don't call for special praise – just some support and acknowledgement and understanding of what they are going through.

Carers we have spoken with said that they wished there was some information available to their family and friends that would help them understand and better support the Carer.

Here you will find information and practical ideas to support a Carer in their important role.

## FOREWORD

No-one volunteers to become a Carer; it is something that happens when someone we know becomes dependent on us. Often this is someone we love – in a marriage or partnership. Sometimes the person is a family member; at other times, a friend. It sometimes means 24/7 care, every day, very often without a break.

Immediate family, and friends, often don't have much idea of the physical, emotional and mental strain on the Carer, which is why this booklet was created, and it is very pleasing to see it going into a third edition.

Tony van Kalken

on behalf of the Resthaven Carers Community Advisory Group, June 2018

## WHO IS A CARER?

A Carer is someone of any age who provides unpaid support to a spouse or partner, a family member, or a friend who could not manage without this help. This support includes caring for someone who is ill, frail, has dementia, has a life-limiting illness, or someone who has any of a range of other support needs.

Carers may be holding down a job; working full time or part-time, or may have stopped paid employment to fulfil their role.

Carers may live in the same house as the person they support or they could visit that person's home.

## WHAT SORT OF THINGS DOES A CARER DO?

The support a Carer gives depends on the situation and the needs of the person they are caring for. Help may include personal care, like taking a shower or bath or getting dressed, cooking, eating, laundry, housework, getting to appointments, help with managing money and paying bills, gardening, arranging social activities and keeping in touch with other family and friends.

The support a Carer gives could be for a few hours each day or a few hours each week. Some Carers are on call all day, every day.

## WHY DOES SOMEONE BECOME A CARER?

Anyone can become a Carer and most Carers have not planned to take on the role, but sometimes feel that they have no choice. Carers take their role seriously, and express a sense of privilege in providing vital support to the person they care for. A person may become a Carer because of family relationships, friendship or compassion, and the feeling that the person they care for is better off living at home.

Many Carers feel that they are just getting on with doing what anyone else would do in the same situation.

While caring for someone is important to the life of a Carer and often provides satisfaction and a sense of achievement, it is a big responsibility that needs close emotional involvement and personal resilience. It takes a great deal of energy.



## HOW DOES IT FEEL TO BE A CARER?

Each Carer is different but there are some common things they experience. There is an impact on physical as well as mental wellness. Often a Carer feels that they are in constant demand; time becomes a blur – the ‘36-hour day’.

Often Carers experience thoughts and emotions such as bewilderment, frustration, anger, and even guilt. Many feel isolation, hopelessness, powerlessness and exhaustion. There may be a sense of loss and grief for the person they knew, the intimacy and support of a partner, and plans that had been made for the future – what might have been.

The role will often mean that a Carer's financial security, career, independence, sense of self, identity and individuality are negatively affected.

A Carer may feel misunderstood, undervalued, overwhelmed by paperwork and responsibility, confused by bureaucracy and the amount of information that they are expected to absorb.



Most Carers never expected that they might need to provide personal and intimate support to another adult and deal with unpleasant things like incontinence. It's challenging to some Carers to feel that role reversal of being a daughter or son looking after a parent.

Some Carers feel challenged in their personal values, their faith, and their belief in others. Carers often talk of feeling the need for moral support or spiritual support; for a listening ear.

A little ironically, sometimes it's difficult for a Carer to accept help. They may have a sense of being invaded by a stream of support from outside professional providers.

That's why it's important to become aware of and understand the challenges faced by Carers. Family and friends can reach out and help by taking some of the load and recognising that, with a little help, the Carer can keep on doing what they do.



## HOW CAN YOU RECOGNISE A CARER UNDER PRESSURE?

Some signs that a Carer might be under pressure could include:

- irritability
- anxiety
- feeling low or depressed
- emotional episodes – anger, frustration, sadness, tears, violence
- ongoing poor health or illness
- substance abuse
- paperwork and bills piling up.



## SOME COMMON MISCONCEPTIONS THAT PEOPLE HAVE ABOUT CARERS

- 'The Carer is making too much of it.'
- 'They'll come good in time.'
- 'They're just having a "bad day".'
- 'As a family member or friend, I don't have the right to intervene.'



## ACKNOWLEDGING AND RECOGNISING A CARER

Be aware that a Carer needs:

- acknowledgement and recognition of
  - the Carer
  - the situation
  - your own feelings as a family member or friend
- understanding and empathy – try to put yourself in the 'Carer's shoes'
- emotional support
- encouragement – don't patronise
- practical support
- a break every now and then to recharge their batteries
- their own space – affirmation of their individuality beyond being a Carer.

## SOME SIMPLE AND PRACTICAL WAYS YOU CAN SUPPORT A CARER

- be a listening ear – do this openly and without judgement
- keep advice to the minimum
- take it easy on the Carer
- treat the Carer as an important person
- share the load
- have a laugh – bring some humour into the day
- share the highs and the lows
- give the Carer a break on a regular basis so that they can relax, be themselves, recharge, pursue a hobby, get a good night's sleep. Respite should be 'me' time for the Carer.
- provide some practical help – do the shopping, go to the bank, cook a meal, assist with paying bills and official correspondence, help with the cleaning
- keep in touch
- offer help – don't wait to be asked
- be willing to accept that your offers of help may not be accepted... but offer again another day
- sustain your support, even through the hard times



- help the Carer to keep in touch, with family, with the community, socially, with reality
- encourage the Carer to seek help and support – e.g. seek respite from a service provider or attend a Carer support group
- do your own research and discover what's out there so that you better understand what it's like to be a Carer
- support the Carer to keep up with their own life – to recognise their own needs and that by meeting these needs, they will be a better Carer
- arrange for an unexpected surprise – make some home baked biscuits, cook a meal, give the Carer a ticket to the movies, a handwritten card with some encouraging words, offer to stay at home while the Carer goes for a walk, or just goes window shopping
- take the person being cared for on an outing.

## SUPPORTING A CARER WHEN SOMEONE IS DYING

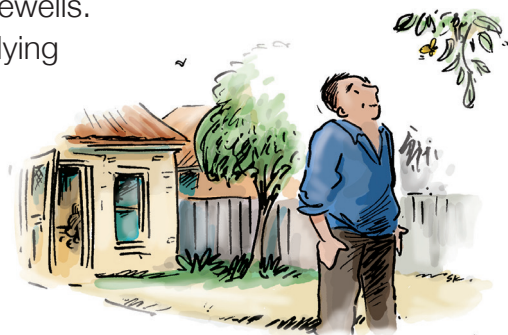
During the end-of-life stage of someone who is being cared for, Carers can become overwhelmed and exhausted. It's very easy for all of the Carer's thoughts and energy to go into the person who is dying, and to forget about their own needs. This is understandable, since Carers just want what's best for the person they are caring for.

Don't ask, just pop in with a meal. If you are comfortable, ask if they would like you to sit with them. Offer to stay with the person who is dying and suggest the Carer goes for a short walk or gets outside in the fresh air, even if for just a few minutes.

Ask the Carer how they are; give them the opportunity to talk if they want to, but realise that it's OK to sit in silence. If you don't know what to say, tell them so; it's OK not to know and it's OK to cry together. Ask if there is anything you can do e.g. to call people to inform them the person who is dying is in the final stages of life. If the Carer doesn't want to be alone, and if you are able, offer to organise a roster of family and friends to be with them.

Don't be afraid to ask on their behalf, if this is what they need. Be aware that at times, the Carer may want to be alone with the person to say their farewells.

Show that the person who is dying is important to you and say your own farewells.



## HOW AN EMPLOYER CAN SUPPORT A WORKING CARER

Carers who are in paid work need support in their role. Having a job is important to working Carers – to have income so that they and the person being cared for can live. Paid employment gives Carers a chance to have an identity beyond being a Carer. It gives them friends, a sense of individuality, self-esteem and, surprisingly, respite. With some support from an employer, the working Carer will experience less stress, contribute more to their job and be a more loyal and reliable employee.

Some practical ways in which an employer can be supportive:

- recognise and understand the role of a Carer
- provide access to Carer Leave
- flexible work arrangements e.g. working from home or with more flexible hours
- flexible access to unpaid leave.

## SOME CARERS FIND IT HARD TO ACCEPT HELP - WHY?

It may be difficult to understand, but some Carers might find it hard to accept your help. There could be many reasons for this, including:

- not wanting to burden you
- this is their obligation – not yours
- this is something that only they can do
- they feel that they won't be able to return the favour
- the person being cared for doesn't want anyone else helping
- the Carer thinks they will be seen as incapable if they admit to needing support.



## SOME IMPORTANT THINGS To REMEMBER



- A Carer can seek support and help from others in their role as a Carer.
- A Carer has the right to have a break from their role as a Carer.
- It's important that Carers recognise their own limits.
- A Carer has the right to express their emotions.
- A Carer can seek and get emotional

support and acceptance from family and friends.

- A Carer has the right to take care of their own health and wellbeing.
- A Carer can maintain facets of their life that support their own individuality, interests, recreation, relaxation and leisure.
- A Carer has the right to enjoy life, achieve their own goals and fulfil their own potential.

The Australian Government and various state governments such as the Government of South Australia have recognised Carers through legislation; Commonwealth *Carer Recognition Act 2010* and *South Australian Carers Recognition Act 2005*. You can search on line for more information about Carers and Carer's rights in Australia

## WHERE TO GET HELP

Carers and their family and friends can find out about home care and support, including respite, from **My Aged Care**, Freecall™ 1800 200 422\* or at [www.myagedcare.gov.au](http://www.myagedcare.gov.au)

**Carer Gateway** is a national online and phone service that provides practical information and resources to support Carers. Freecall™ 1800 422 737\* or at [www.carergateway.gov.au](http://www.carergateway.gov.au)

### You could also contact:

**Carer Support Network**  
[www.carersupportsa.org.au](http://www.carersupportsa.org.au)

**Carers' & Disability Link**  
Adelaide Hills  
Barossa Valley  
Fleurieu Peninsula  
Yorke Peninsula  
(08) 8562 4000  
[www.carersanddisabilitylink.support](http://www.carersanddisabilitylink.support)

**Northern Carers Network**  
Northern Metropolitan Adelaide  
(08) 8284 0388

**SA Country Carers**  
Mid North Country SA  
1300 686 405  
[www.sacountrycarers.org.au](http://www.sacountrycarers.org.au)

**South Coast Carer Support**  
(08) 8552 3173

**Carer Support and Respite Centre**  
1800 052 222

[www.carersupport.org.au](http://www.carersupport.org.au)  
Centres at Campbelltown,  
Glandore and Morphett Vale

**Carers SA**  
1800 242 646  
[www.carers-sa.asn.au](http://www.carers-sa.asn.au)

**Carer Advisory Service – Carers Australia**  
Nationwide Freecall™ 1800 242 636

**Resthaven Inc.**

1300 13 66 33  
[www.resthaven.asn.au](http://www.resthaven.asn.au)

**Agedcare Alternatives**  
(08) 8271 3888  
[www.agedcarealternatives.net.au](http://www.agedcarealternatives.net.au)

**Dementia Australia –  
National Dementia Helpline**  
1800 100 500

[www.dementia.org.au](http://www.dementia.org.au)  
**Dementia Australia, South Australia**  
(08) 8372 2100  
[www.dementia.org.au/contact-us/sa](http://www.dementia.org.au/contact-us/sa)

**Palliative Care, South Australia**  
(08) 8271 1643  
[www.pallcare.asn.au](http://www.pallcare.asn.au)

**Catalyst Foundation –  
seniors information**  
(08) 8168 8776 or  
Country Freecall™ 1800 636 368  
[www.catalystfoundation.com.au](http://www.catalystfoundation.com.au)

**Centrelink**  
13 27 17  
[www.centrelink.gov.au](http://www.centrelink.gov.au)

If you need help in another language, many of these services will provide help in community languages – just ask.

Contact details on this page are correct at time of publication, June 2018.

\*1800 numbers are free calls except from mobile phones.

## SOME ACRONYMS ETC.



One of the things that Carers and their families come across are many acronyms and names of services. These can add another challenging layer to the experience. Some that you may come across are:

**My Aged Care** the main entry point to the aged care system in **Australia**. Through a website, [www.myagedcare.gov.au](http://www.myagedcare.gov.au), and a national contact centre, 1800 200 422, My Aged Care aims to make it easier for older people, their families, and Carers to access information on ageing and aged care, have their needs assessed and be supported to find and access services.

**Carer Gateway** national website, [www.carergateway.gov.au](http://www.carergateway.gov.au), and phone service 1800 422 737 that provides practical information and resources to support Carers.

**ACAT (ay-cat)** the Aged Care Assessment Team or the Aged Care Assessment process itself. You might hear about, 'the ACAT team,' or, 'having an ACAT assessment.'

**HCP** Home Care Package. Australian Government-funded support for older people who want to stay at home with access to a range of ongoing services and support, including access to a range of respite options.

**CHSP** Commonwealth Home Support Programme. Australian Government-funded 'entry-level' support for older people who want to keep living independently in their own home – including respite.

**RAS (razz)** Regional Assessment Service carries out face-to-face assessments of people needing support through the Commonwealth Home Support Programme (CHSP).

For more information about Resthaven and the services offered, visit [www.resthaven.asn.au](http://www.resthaven.asn.au) or call 1300 13 66 33

## **CARERS FULFIL A VALUABLE AND IMPORTANT ROLE IN OUR COMMUNITY; SUPPORTING THE PEOPLE THEY LOVE, FAMILY MEMBERS AND FRIENDS TO LIVE A BETTER LIFE.**

It is a demanding role and can be lonely. Carers can feel like they go it alone in an environment where few understand what it is that they actually do and what life for a Carer is like. There is little information that helps Carers explain to their family, friends and the community what it's like for them.

Now in its third edition, this easy-to-read booklet has been developed based on the wealth of knowledge and experience of Carers who have lived the experience.

Taking the opportunity to read this engagingly written and illustrated resource will help you understand the Carer role, how a Carer feels and how you, as a family member or friend, can support a Carer.



Working together: outstanding care and support for older people and their carers.

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