

WITH A LITTLE HELP..

How family and friends
can support a Carer



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This resource was written as a collaborative project by the members of the Resthaven Carers Community Advisory Group.

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Max Jacquier passed away as this booklet was being written and is remembered with respect and fondness.

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WHY THIS BOOKLET?

This information is for family and friends of a Carer: to help you support someone you know who is caring for someone else.

Here is some information and practical ideas for family and friends about how to support a Carer in their important role.

Many Carers say that, while they value their role and it has its rewards, it can be demanding and that they need to be supported so that they can keep it up when things get difficult.

Some 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.

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'. Carers who we have spoken with said that they wished there was some information available to family and friends that would help them understand and better support the Carer. Carers don't call for special praise – just some recognition and understanding of what they are going through.

FOREWORD

With a Little Help... is the result of considerable thought and discussion by a group of experienced Carers who comprise the Resthaven Carers Community Advisory Group.

We all agreed if only this information had been available to us, it could have made family and friends more aware and softened our pathway on our caring journey.

We hope those people who find themselves treading this same path will obtain benefit from our book.

Beryl Ducray

on behalf of the Resthaven Carers Community Advisory Group

March 2011



WHAT IS A CARER?

A Carer is someone, such as a spouse, a partner, a family member or a friend, who provides regular sustained care to another person without payment. A Carer provides help in everyday activities and may care full time or for a few hours each day or each week. The support that a Carer gives will be quite varied, depending on the situation and the needs of the person they are caring for. People may not recognise themselves as a Carer – rather they see it as expected family role. Sometimes they do not have a choice. A Carer may live in the same house as the person they care for or they may live elsewhere. Some Carers are on call all day every day.

What things might a Carer do?

A Carer might support the person being cared for with many things – shopping, cooking, eating, house cleaning, clothes washing, personal care such as bathing and dressing, transport to appointments, shops, bank and bill paying, gardening, going out, keeping in touch with friends and family.



Why do Carers become Carers?

Carers value and take their role seriously. Some reasons given by Carers for taking on the role include love, friendship, commitment and a feeling that the person they are caring for is better off at home. (*Aged Care INsite Apr-May 2010 p3.*)

“Caring for someone who is very important to my life gives me some satisfaction and purpose and perhaps a sense of achievement.”

“In your own heart, you get satisfaction that you are looking after the person to the best of your ability.”

Carers have a practical role but also have an emotional involvement in their role as a Carer. Most have not planned to become a Carer but have found themselves in that position. While it’s a challenge, many people express a sense of privilege that goes with a big responsibility.

It’s important for family and friends of Carers to recognise that a Carer sees many positive aspects to their role and that the Carer needs support and understanding to continue supporting the person they care for. Friends and family of a Carer can assist through taking some of the load and recognising that with a little support, the Carer can keep on doing what they do.

WHAT DOES A CARER FEEL AND EXPERIENCE?

As well as Carers expressing a sense of commitment and privilege in their role, many often express other feelings that they experience:

- that the world has changed completely and forever, that they may as well be on another planet
- grief and a sense of loss for the person who they used to know, intimacy, the support of a partner, freedom, the plans that were in place for the future
- invisible – a loss of individuality and their own sense of identity
- lonely, isolated, cast adrift
- not understood, misunderstood
- undervalued
- guilty, frustrated, angry, powerless, sad, perplexed
- constantly in demand – time becomes a blur
- lack of sleep, tiredness, exhaustion





- an impact on health both physical and mental
- overwhelmed by paperwork
- burdened with responsibility
- a sense of role reversal such as that when a son or daughter is looking after a parent
- confused about the huge amount of information
- confused about the legal/bureaucratic nightmare
- on a financial tightrope
- that there is a stream of strangers in their life
- challenged spiritually, in their faith, and in their belief in people
- the need to pursue spiritual support
- it's difficult to accept help
- having to deal with unpleasant things like incontinence
- that there's no light at the end of the tunnel

HOW CAN YOU RECOGNISE A CARER UNDER PRESSURE?

- irritability
- anxiety
- feeling low
- withdrawal
- poor health or illness
- emotional outbursts – anger, frustration, sadness, tears, violence
- substance abuse
- paper work 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.



HOW CAN YOU SUPPORT A CARER?

Recognise 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

HOW CAN YOU SUPPORT A CARER?

What can you do for a Carer?

As a family member or friend you could...

- 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 – maybe to attend a Carer support group
- do your own research and discover what's out there
- support the Carer to keep up with their own life – to recognise that they have needs and that by meeting these needs they will be a better Carer.
- do some research so that you better understand what it's like to be a 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 gets to go for a walk or just go window shopping
- take the person being cared for on an outing.

How CAN YOU SUPPORT A CARER?

Supporting a Carer when someone is dying

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

Don't ask, just pop in with a meal. If you are comfortable, ask if they would like you to sit with them. If you're comfortable, 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; giving 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 ring people to inform them the person 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. Work provides a chance for a Carer to have another identity, gives them friends, a sense of identity, 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 of support:

- recognise and understand the role of 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 others
- 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



- It's important that Carers recognise their own limits.
 - It's OK for a Carer to seek support in their role as a Carer.
 - It's OK for a Carer to have a break from their role as a Carer.
 - It's OK for a Carer to seek help from others.
-
- It's OK for a Carer to have emotional support and acceptance from family and friends.
 - It's OK for a Carer to take care of their own health and well being.
 - It's OK for a Carer to enjoy life, achieve their own goals and fulfill their own potential.
 - It's OK for a Carer to maintain facets of their life that support their own individuality, interests, recreation, relaxation and leisure.
 - It's OK for a Carer to express their emotions.

WHERE TO GET HELP



Do you care for someone and need support? Then Freecall™ 1800 200 422*. This number can provide a link to a wide range of community, aged care and support services that are available locally, including carer support and respite services.

*Free call except from mobile phones.

Commonwealth Respite and Carelink Centres

1800 052 222

www.commcarelink.health.gov.au/

Carer Support Network

www.carersupportsa.org.au

Carers' Link, Barossa & Districts

(08) 8562 4000

Carers' Link, Lower North

(08) 8842 1988

Carers' Link, York Peninsula

(08) 8821 2444

South Coast Carer Support,

Southern Fleurieu Peninsula

(08) 8552 7419

Northern Carers Network,

Northern Suburbs (08) 8284 0388

Carer Support and Respite Centre,

Southern & Eastern Suburbs

(08) 8379 5777 or 1800 052 222

Carers SA

(08) 8291 5600 or 1800 815 549

www.carers-sa.asn.au

Resthaven

1300 13 66 33 www.resthaven.asn.au

Agedcare Alternatives 8271 3888

www.agedcarealternatives.net.au

Alzheimer's Association

(08) 8372 2100

or National Dementia Helpline

1800 100 500 www.alzheimers.org.au

Office for Carers

(08) 8207 0424

or type 'office for carers south

australia' into your search engine

Palliative Care Australia

(08) 8291 4137 www.pallcare.asn.au

Seniors Information Service (SIS)

8186 8776 or Country FREECALL

1800 636 368 www.seniors.asn.au

Centrelink

13 27 17 www.centrelink.gov.au

Contact details on this page are correct at time of publication, September 2011.

SOME ACRONYMS...

One of the things that Carers and their families come across are many acronyms for government-funded programs. These can add another challenging layer to the experience. Some that you may come across are:

ACAT Aged Care Assessment Team

HACC Home and Community Care

CACP Community Aged Care Package

EACH Extended Aged Care at Home

EACHD Extended Aged Care at Home, Dementia

NRCP National Respite for Carers Program



For more information about
Resthaven and the services offered,
visit www.resthaven.asn.au

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

It can be a demanding and lonely role and 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.

This easy-to-read booklet, written by the Resthaven Carers Community Advisory Group, aims to help the reader understand how a Carer feels, the role of the Carer, and how they as a family member or friend can support them.



Supporting older people and their carers