Past Caring
THE END OR
THE BEGINNING?

You care for someone, we care for you.
Our Mission

Carer Support is a recognised leader in providing flexible and responsive services to carers, families and individuals.
INTRODUCTION

Being a carer is often a challenging and difficult journey. As a carer most of your time and emotional energy is focused on caring for someone else. When circumstances change there can be a real feeling of loss. There are usually two major ways the caring role transforms – the person you care for may move into a residential care facility or they may reach the end of their natural life.

This resource will be helpful to both situations with information for you for specific strategies for each of these circumstances.

Carer Support has supported a group of past carers to come together and share their experiences firstly, as carers and secondly, their personal journeys to provide advice and suggestions how to get through this difficult time.

All quotes in italics are from real past carers and content is closely based on their own words to us.

“When I was caring, my wife was number one, I became so involved with caring for her, I shut everything else out. I didn’t want to leave her with a care worker or in respite. When she passed I was devastated, there was a huge void in my life. I didn’t have anyone or anything in my life. I should have tried to get out and make connections while I was caring”.
WHILE YOU ARE STILL CARING

Being a carer for someone can take over your life. This can happen immediately or increase gradually over time. Your focus is on the needs of the person you are caring for, with all their doctors and specialists appointments to the point there is no time left for yourself. You can’t get out of the house as they need you there to ensure they are safe; assisting with meals, cleaning, showering and emotionally supporting them. Often caring can make you take on new tasks you haven’t had to do before; carers may have to learn how to cook, clean, do gardening or DIY and financial planning that their partner used to do before they became unwell.

“Join a group so you can meet people with similar interests WHILE YOU ARE STILL CARING. This is so important, as it gives you links to the outside world”.

During the caring role many friends disappear, this is often due to people not knowing what to say or do. The person you care for may have impaired speech or ability or challenging behaviour. Your friends drift away either because they don’t know how to deal with the person you care for, or it just gets too hard for them. Often family can fade away for similar reasons. So it is just you and the person you care for. You know they may pass away one day, but it’s too hard to think about, you just concentrate on getting through another day.

“Focus on the problem, ask health professionals to give you the truth as this helps you to accept, prepare and focus on your future”.
While you are still in your caring role, it is important to discuss yours, and your partner’s wishes, if either of you were to pass away.

“Make sure the person you care for has a Will”.

“Review both your and your partners Will regularly”.

“Do not leave a Will somewhere the executors can not access it” “Make sure you have a good, trustworthy solicitor to assist with all the arrangements prior to losing your partner”.

“Complete an Advance Care Directive for both yourself and your partner when you are both deemed mentally capable (or a Guardianship order up to July 2014). If either one of you is deemed mentally incapacitated, your Will or Advanced Care Directive can not be changed”.

PLANNING AHEAD
PLANNING FOR RESIDENTIAL CARE

MAKING DECISIONS

Am I still a carer? You are still a Carer although the tasks will be different. Keep in mind that your caring does not cease at the door of an aged care facility.

You are no longer eligible for respite but you are welcome to still attend Carer Support events and activities.

How do I tell the person I care for? It’s important to prepare them, but keep in mind their unique needs and capacity to understand. It can be quite difficult to talk about the approaching move.

“Start reaching out and make plans while you can, this is your future now and will progress as such”.

QUESTIONS

- How and when should you bring the up the question of moving?
- Who should tell the person you care for that he or she is moving?
- What should you say? Plan what is to be said ahead of time. Write it down. Think about the person’s reaction and plan your responses.
- Who should be present and involved in the discussion?
- How will you deal with your feelings about this decision?
- What sort of reactions might be expected? (e.g. changes in mood or behaviour)
- How will you deal with the feelings of the person you are caring for? Acknowledge their feelings. Listen and offer reassurance. They may be angry, sad and resistant: don’t discount their feelings.

CHECKING FACILITIES

Preparing: Be aware, it is not unusual to feel overwhelmed when visiting facilities. It may be your first time inside this type of facility, it may trigger past memories, or the visit may confirm that it is time for this move and this could be difficult to cope with.

Emotions: It may be beneficial to have another person with you to offer emotional support and to share reactions. It is not unusual to feel emotions such as relief, sadness, shock, guilt etc.

Experience: You will witness residents with a broad range of abilities and needs. You will see residents who may be more confused or physically frail than your relative and others who may appear less impaired.
A carer shares that he “put his wife in a different respite home each time I had a break, to allow my wife to find somewhere she liked for full time care. This made the finding of quality care, and somewhere she liked for full time care, much easier”.

Facilities: Due to the nature of the residential facility business, disruptions and unpredictable situations can occur. For instance, staff may be called away at a moment’s notice to cater to resident’s needs, or an emergency. Even the best places have bad days. If you are unsure or uncomfortable about what you are seeing, you may want to ask questions or arrange to visit again.

Check the facility’s mission statement and previous accreditation files. This gives you an idea of the company’s values and official views on the service they have been giving. Also, don’t just make pre-arranged visits. It is good to go to the home with no prior arrangements; this way you will see the “real” home.

AFTER YOUR VISIT

Reflect: Ask yourself how you feel. Did you get all the information you wanted? You may need to make another phone call if there are still some unanswered questions.

“When transitioning your loved one into care you have to be one step ahead at all times”.

Make notes: Jot down words to describe how you felt being there: comfortable or uncomfortable, welcomed or neglected (keep in mind; it may be difficult to separate out your feelings about having to move your relative versus how you feel about the residence).

Talk about your visit with other family members and friends. This is understandably a very emotional time. Give yourself permission to do whatever you need to do to get through this period.

TRIAL THE FACILITY

Where possible it is sometimes helpful for the person you care for to have respite in your chosen facility.

One carer told his wife “that she had bought a new home (the nursing home) as I wasn’t able to care for her anymore, and I had to stay in the other house. The nursing home was her new house that she had purchased, she seemed to accept this”.
SETTLING ON A RESIDENTIAL FACILITY

Consider what you can do to minimise stress. Firstly, plan ahead. Divide the task into three areas, before, during and after the move.

- Seek assistance from family and friends with the practical tasks.
- Query with the facility to see if you can decorate the room to suit your family member or friend before they arrive. This way it will be welcoming and have some familiar items displayed.
- Choose items such as a favourite chair, bed cover, books, photographs, cosmetics etc. Check with the staff to ensure that there is adequate space for the chosen items.
- Prepare a ‘personal profile’ about your relative or friend covering their interests, likes and dislikes. Provide information that will assist the staff to provide quality and comfortable care.
- Put together a photograph album of important people, pets and places. Providing topics for conversation and happy memories for your relative or friend.
- Seek assistance from a staff member to help prioritise what needs to be done before the move and what can be left until they have moved in.
- Seek out someone you trust or a legal representative to check it over before you sign any contracts as legal paperwork for the retirement home can be complicated and full of small print.
- Check with the facility to determine their preferred time of arrival. Try to coordinate with them to ensure that it is also a good time for your relative or friend a) when are they most rested? b) when are they at their physical best? c) is there a time when they are in a better mood?

MOVING IN DAY

- Seek support from a trusted person to accompany you on moving day. It will be comforting for you and the person you care for to have a familiar person with you and if you need to complete the moving tasks, they can give their attention to the person you care for.
- Consider how you might assist your family member or friend feel more relaxed about moving day. It may help to maintain their regular routine or it may be better to do something special.
- Dedicate the whole day to the move remembering that you will be emotionally and mentally fatigued. Once the move is complete use the remainder of the day to care for you.
• Plan what you will do when you leave the facility. You may like to have some quiet time for yourself or you may choose to debrief with a friend.
• Be aware that you may experience mood swings from relief to doubt about your decision once the move is completed. You may also be more fatigued than usual. These are very normal feelings.
• Be aware that you may be quite exhausted having spent time and energy in caring for your relative or friend and undertaking the move. It is emotionally draining, so allow ‘healing time’.

SETTLING IN
You can visit the residential facility whenever you like. There should be no restrictions. Residents are encouraged to participate in center activities and group events, so if your family member or loved one are not in their room, check with carer staff.

GETTING THINGS IN ORDER
As there are many matters of personal preference, you may like to consider them in advance and discuss with the person you care for prior so you are sure of what they want. It will give peace of mind that you make the right decisions on their behalf.

Power of Attorney (POA): You may wish to discuss becoming the Power of Attorney for financial and medical reasons if you are not already. This is a legal document appointing a person or trustee organisation of your choice, to manage your financial and legal affairs while you are alive. This person or organisation is then known as your attorney.

Advanced Care Directives: Replacing the previous Enduring Power of Guardianship or Medical Power of Attorney, this directive helps provide a clear understanding of needs and wishes should your loved one lose the ability to communicate them for themselves.

Will: If this still hasn’t been organised, it is prudent to ensure one is in place. A Will is a written document that sets out your wishes for the distribution of your property (sometimes called your ‘estate’) when you die. It looks after your family and it is your opportunity to make sure things go smoothly on your death. There are strict legal formalities to be complied with in making a Will. If these are not complied with then this creates many difficulties on your death and the risk that the paper that you signed will not be accepted as your Will.

Funeral: If a pre-paid plan is not already in place, the following are questions to be considered when
discussing arrangements with funeral directors:

a) Will the person be buried or cremated?
b) Will the funeral be private or public?
c) Will there be flowers or donations?
d) What clothing and cosmetics will the person wear?
e) Does the person wear glasses and/or false teeth?
f) What music will be played?
g) What will be the content of the ceremony?
h) Will it be religious or civil?
i) Where will it be held?
j) Who will be involved?
k) Do you want to play a DVD or have photos up of them?

“I had the foresight to see once my husband became ill; my life was going to change forever. I was no longer the lover carer; I was now the mother carer. I went to the bank, to Centrelink, my G.P and asked: my husband is ill and he is never going to get better, what can we do now to prepare for the future? I discussed our mortgage, our pension, our future income and received advice to assist us to prepare for the future. Preparation is the key while you are still caring”. 

Then it happens, the person you love and care for passes away. Once the funeral has passed, others may understand your grief at the loss of the person you cared for however they may not understand the loss you feel no longer being a carer.

It could be overwhelming to consider where you begin to pick up your life. You may not only be dealing with the loss of your loved one, you may also be dealing with the impact of previously losing social contact with the outside world and regular social activities during your time as carer.

“Be honest with both yourself and your situation”.

Let Carer Support continue to support you through this time of loss and change.

If you feel lonely and isolated, it can add to the grief and loss you are feeling.

The following are resources from other past carers who have been through exactly what you are going through at the moment and some advice to help you get through this difficult time in your life.
THE FIRST MONTH

IMMEDIATELY AFTER LOSING THE PERSON YOU CARED FOR

There is a long list of people you have to inform. Some need to be informed immediately while some can wait.

“If you find this too hard to do by yourself, get a family member or a trusted friend to support you. You may need to sit with them while they do the calls as many companies will insist on speaking to the account holder for permission to take the details from your support person”.

After close family and friends,

• Bank/direct debits (to close accounts or stop direct debits or change access to your money),
• Centrelink/Veteran’s Affairs,
• Mortgage/Rent,
• Pension,
• Funeral Plan/Insurance,
• Services - for example Home care provider, Domiciliary Care, Disability Services etc.

A comprehensive check list of who to call can be found on page 20 and on Carer Support website.
THINGS TO DO
Request approximately 10-12 certified copies of the death certificate as this may need to be sighted/ kept by businesses and other organisations and agencies (you can get this done at local libraries, council offices, Pharmacy or by a J.P /M.P).

As time progresses, it is important to remember to contact the rest of the services that your loved one used: to close accounts, cancel appointments, to change names on accounts or re-organise finances. See Carer Support website for a full list.

THEIR BELONGINGS
Going through your loved one’s belongings can be difficult to face. There is no right or wrong time or way to do this. You do what you have to, when you can. You can leave it for two years then give everything away. You can start going through it bit by bit quickly after they have passed. Try to give what you don’t need to charities, this way the person you cared for is helping others. Get help; ask family members or friends to help you, they maybe able to go through the belongings with less attachment and emotion.

“Remember how fortunate you have been to have had this person in your life, however short. Celebrate their life by living the rest of your life to its fullest.”
THE FUNERAL

The funeral is a huge responsibility. Initially, it can keep you so busy you don’t realise the extent of your loss. Consider sharing the responsibilities with family and friends who rally around.

AFTER THE FUNERAL

After the funeral, life returns to normal for your family and friends and this can mean people stop calling. People go back to work, families go back to their lives and you can be left home alone. The reality of your loss may now be overwhelming and the pain can have the opportunity to engulf you.

It is particularly important to take care of yourself at this point. Call services and seek out help when needed.

The grief process affects everyone differently, at different times. You may feel physically unwell, such as shortness of breath, loss of appetite, tiredness and sleep problems. It can cause emotional feelings such as loneliness, anger, fear, resentment, confusion, fear, guilt, rage, ongoing sadness, not wanting to go out or do the things you normally do. These feelings can be frightening however this is a normal reaction to grief.

“Let yourself grieve, let yourself cry, as it helps release pressure. Your friends will understand, but if they don’t, they are not your friends”.

Recognising your grief and talking about how you’re feeling can help. Seek professional support through your GP who should know someone trained in bereavement, grief and loss. Or contact one of the many online or telephone counsellors trained to assist you at this difficult time.

Exercise can help. As can walking the dog around the block. Trying relaxation methods such as deep breathing or writing a journal can be safe ways to release feelings of anger, blame or resentment. Good days and bad days may come and go. It may take some time for you to get used to this new routine.

“The first Christmas, birthday and anniversary of death after losing your loved one will be hard, it hits you regardless of how prepared you think you are. Just get through it, you’re going to feel sad, you’re going to cry, but it’s OK, it’s part of the grieving for your loss. Accept that and allow yourself to mourn them and miss them”.

Your financial situation may change, there are financial organisations who can assist with this. See our resource page on Carer Support website.
Staying at home while you are grieving can seem the safest place to be. You may find it easier to not deal with other people and their questions. But over time, the more you stay at home the harder it is to get back out into the world.

It is important for carers to make outside social connections while still caring for the person they care for. Even though it may seem impossible to get time out, it is very important to ensure you get a set time each week/fortnight/month to meet with other friends or people with similar interests. This makes it easier when you are no longer caring.

One carer told us “Choose to become a victim or choose to fight”.

“Alcohol can initially help to numb pain and block everything out. Over time this becomes a crutch, which in itself stops you enjoying life. Face the pain and grief and accept it. It celebrates your life together and the love you shared. Over time the pain will lessen, but you will never forget them. You can then look back over the time you had together with a smile, laughter and be grateful for the time you had together”

Advice from past carers is to build networks for you while still caring.

“People you haven’t seen for a while will ask how your wife (husband/partner) is; it’s really difficult to explain several months after the event that your loved one has passed. You need to accept people don’t know they have passed and are just caring”.

One carer joined a croquet club, giving him respite while caring and provided a support network for him when his wife passed away. If you weren’t able to do this while you were caring, there are ways to build new friendships and networks regardless of your age, the length of time you have been caring or the amount of time since you were actively participating in life.

“It is important to grieve for the loss of your partner but it is equally important to start to plan and move forward. It is a time to start looking at what you need in your life to feel happy again and who can help you do this. There are services, groups and people in your life that can help you with this, but you need to tell them what you need”.

GETTING BACK ON TRACK
BACK ON TRACK IDEAS

What did you used to like to do before you were caring? Did you use to go walking, swimming or singing? Or did you enjoy tennis or bowling? Write down everything you used to like to do or would like to try.

What are you good at? What qualities do you have? Organising, accounts, caring or craft - where could you use these skills to help others? Make a list of your skills and look it over. Could you join a local service group? We have listed local service groups in our resource page on the Carer Support website.

What is in your local community? Are there groups in your local community centre that offer clubs or classes? Have you looked at what is run in your local church or religious community? Contact your local Council or Library.

Do you want to learn a new skill? How about learning a new language? Or learn how to email using the internet so you can keep in touch with family who live interstate or overseas?

“Smile, even if you don’t feel like smiling. Not only does it make you feel happier, it will make others you pass smile too”.

Research: Start to pick up leaflets in your library, community centre, G.P’s office. If you can, use the internet to go online and google what is on in your area. Read local papers, listen to the radio for local events. Your local council has a directory of services they offer online or a paper copy can be picked up from your local library.

Go: Don’t think about it too much or procrastinate due to worry that you won’t know anyone, be brave and go. Initially it can be very daunting, but once you get there people start talking to you. It gets easier each time you do it.

“It took 6 months to adjust from no longer being a carer; I just didn’t know what to do with myself”

Ring up old friends: Old friends may have struggled to deal with the demands of your caring role but they do miss you and want to support you in your loss. Make the first move, call them.

Make an appointment to see a careers counsellor: Chat about what skills you have and what you would like to do.
Look outside the square and try different things: Museums, art galleries, tai chi, pottery, you don’t have to be an expert, you just need to try.

“I didn’t have any friends; they all disappeared over time as they didn’t know how to cope because my wife could no longer speak. I had to rely on myself”.

Mending old family quarrels: Time passes and things that made others or yourself angry can lose importance over time. Try to reach out and mend old relationships or create new ones where you can.

Sharing memories and laughing: When you can, pull out the photo albums and look back on all those happy times with your family and friends. Tell stories about the times that you’re loved one made you laugh and the gifts they left you. As the pain subsides rejoice and celebrate the love and fun you had together.

Don’t be afraid to ask others out: Go for coffee or dinner and don’t take it personally if they can’t come, they may have issues of their own, or it isn’t a suitable time for them.

If you’re nervous about joining groups: Try going out to events in your community such as the cinema, football or cricket matches. This way you are re-adjusting to being out in public without the pressure of having to chat if you’re not ready for it.

“Get a dog, take him for a walk. Believe it or not this can build up connections and friendships in your local area. Reach out, use any tool you can to break the ice with others”.
CONFIDENCE

Confidence is the key in being able to make new friendships and networks. This is why it is important to join a group of people who have similar interests or values as you. If you aren’t confident try counselling or confidence training.

“I had never lived by myself before; I was scared when my husband died. I gave SAPOL home assist program a call, and they sent a Police Coordinator around to look at my home and they conducted a free security audit of my home. They gave me advice on what to do to improve my homes security. It made me feel safer and more confident being home alone”.

AS YOU BEGIN TO FEEL MORE LIKE YOURSELF

Give back. Help other carers through various mentoring services like Weavers (a service where past carers support existing carers with their role). You have amassed a huge amount of knowledge and experience while caring; this information can make a huge difference in other carer’s lives who are struggling. You have been there and came out of the other side. You may know what services would help them, what help they can receive; this can make a huge impact in someone else’s life. Or look at getting back into employment or volunteering for an organisation that gives back.
VOLUNTEERING AND EMPLOYMENT

When looking for volunteering role, think about the job you would like to do and not simply being grateful for the first thing that comes along.

Volunteers at Carer Support are an integral part of our organisation. They have the understanding of what carers are facing, empathy and know what support they need. By volunteering here you will make new friends and visit new places. Volunteering helps you improve your confidence and skills.

Volunteer in a variety of other services. Local hospitals are always looking for volunteers to come and read to patients, cuddle the babies or just make a cup of tea.

Visit elderly people in nursing homes. Many older people don’t get many visits from family as they are all working and friends have passed away. The Community Visitors Scheme is an organisation that supports people, like you to visit older people in their own home or in nursing homes for visits, chats and companionship. Details are on resources page on Carer Support website.

Volunteering can give people who feel a bit lost, a reason for getting up. It can help you feel like you have a place in society and that you are needed.

“When I go out to join a group or help someone else, I am like a rock that is thrown into a lake; you don’t know where the ripples will reach.”
HOLIDAYS AND SHORT BREAKS

Going on holiday by yourself after losing your partner can be very difficult. You may feel lonely and isolated. The carers we interviewed suggested others look at companies offering holidays that cater for single people. You can then choose how much or little you mix with others. These holidays are for single people, so everyone on the trip is in the same position as you: on their own and looking for company when they want it.

“Give yourself permission to be happy again”
WHO YOU NEED TO NOTIFY WHEN A LOVED ONE HAS PASSED AWAY, INCLUDING SUGGESTED TIMEFRAMES

Immediately
- After telling close family and friends
- Arranging funeral
- Funeral insurance
- Financial institutions
- Centrelink
- Life insurance
- Solicitor
- Banks
- Services i.e. Disability SA / Domiciliary care

Later on
- House and contents insurance
- Car insurance
- Loan Company
- Credit cards
- Store cards
- Medicare
- Electric
- Gas
- Water
- Council rates
- Phone/internet
- Mobile phone
- Dentist
- Doctor
- Hospital
- Specialist
- Chemist
- Electoral office
- Trust house/landlord
- Home medical aids on rental or loan
- Blood bank
- Store cards – Myer etc.
- Lay-bys
- Accountant
- Tax adviser
- Public trustee
- Tax office
- Superannuation
- Employer
- Ambulance
- Car registration
- Driving licence
- RAA
- Dog registration
- Clubs/groups/organisations
- Health benefits fund
- Religious/church
- Hairdressers
- Ladies – nails
- Post office
- Community bus
- Organised taxis
- Meals on wheels
- Vets
- Emergency services levy
- Concession
- Seniors card
- Home care assist/nursing
- Volunteers
- Carers support
- Library
- Home delivery services/newspapers
- Subscriptions to magazines
- Optician
- Podiatrist
- Radio rentals
THANKS TO EIRWEN WIGGINS - ONKAPARINGA CARER, PAST CARER WORKING GROUP AND SOUTHERN SERVICES REFORM GROUP (SSRG)

THE PAST CARER WORKING GROUP

Left to right; Barrie Anderson, Noela Krahn, Cliff Barreau, John Matthias, Alan (John) Robinson, Don Allen, Russell Martin, Uwe Heggblum

Not in the photograph; Mick Dawkins, Darryl Mulberry, Graham Rowe, Jill Rowe, Helen Smith and Coral Nagel
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