

AN UNRECOGNISED GRIEF CARERS GUIDE

LOSS AND GRIEF ISSUES FOR CARERS



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EVERYONE EXPERIENCES LOSS DURING LIFE

This booklet is about loss and grief that arises not only through death but also from a range of other losses.

If you are a carer there is loss. These losses are often unrecognised and unacknowledged by those around you and perhaps even yourself, but these losses can have a great effect on your feelings, your physical health, your mental well being, your financial situation and so much more.

This booklet aims to help you understand the significance and impact of not only what you do, but also the bond you share with others who are in the same situation and how to find appropriate help and support.

Carers experiencing grief or loss come from all walks of life and an infinite range of care situations. You may be parents adjusting to the differing needs of a child with a physical or intellectual disability and the impact on the family. You may be members of a family dealing with the uncertainty, stress and sadness of watching your relative struggle with a mental illness. You may be daughters and sons, husbands, wives, lovers, friends and others adjusting to your loved one's gradual loss of or change in personality or independence due to stroke, acquired brain injuries, AIDS, Parkinson's, Alzheimer's or other diseases. Anyone involved in caring for a family member or friend may experience loss and grief. One thing in common is the experience of loss at different times and in different ways.

BACKGROUND

It can be hard to remain positive when you are providing care that can be intense and demanding and offers little recognition. You may feel tired, unappreciated and depleted both emotionally and physically.

The purpose of this booklet is to acknowledge and raise awareness about the fact that loss and sadness are indeed a central part of the caring experience – whether or not an actual death occurs or is expected to occur. You may be grieving for all sorts of different losses:

- › The unfulfilled expectations you had for yourself or your loved one.
- › The changed relationship you may now have with the person with care needs.

- › The impact on your relationships with friends and family members.
- › Reduced choices relating to paid work and careers.
- › Income security now and in the future.
- › Changes in lifestyle, status, intimacy, freedom and identity.

Although the nature of losses you experience varies, grief is the common response to the loss that all carers experience. Grief is experienced differently by individuals and may be expressed in a range of ways within different cultures.

Although grief is commonly associated with the loss of a loved one through death, it is actually a natural response to any unwanted change or significant loss.

This guide will enable you to develop greater confidence in your abilities to recognise and respond to the emotions that accompany the losses you may experience. It is reassuring to know that professional help is there if you need it. But many carers may not want formal counselling. You may however, want to be able to tell your story without censure or judgement and without feeling that the listener is watching a clock.

Many of you may also need to feel that you can speak without fearing the listener may not be able to cope with the depth of your emotions. Grief and loss are, after all, a normal part of life, just like joy. To recognise it, name it and respond to grief, can be a powerful, and life affirming experience.

"I didn't realize I had been grieving for years".

A carers reflection

DIFFERENT CARERS, DIFFERENT LOSSES

When you hear the words loss and grief do you automatically think of death and dying? In many care situations, the prospect of death is a long way off and very uncertain. In the case of many disabilities, mental illnesses, and/or other injuries death may not be an expected part of the picture at all.

As your carer journey unfolds, many changes occur and losses may accumulate at a varied pace. This can result in a sense of grief that may seem insurmountable. This grief is rarely talked about but instead can remain hidden among other emotions or the day-to-day practical concerns that caring for someone with an illness or disability presents.

It may be useful to identify where carer loss begins. This may be associated with unwanted change. One of the first changes you may notice might be the change in your relationships, such as your family members, friends and colleagues. Your relationship with the person you are caring for, the role that person played in your life and theirs in theirs, may now be completely different.

Carers may experience some or all of the following losses:

- › time with own family
- › economic security
- › study or job possibilities
- › normal role
- › friends
- › freedom to socialise
- › spontaneity
- › personal space and privacy
- › future dreams and plans
- › identity
- › choice and control
- › peace of mind
- › ability to plan for own interests.

Spousal carers may experience changes around issues of intimacy, companionship, communication, sharing of memories and tasks and recognition of a life lived together.

Daughters and sons caring for a parent may experience an unwanted role reversal in becoming the parent to that parent.

Young carers may feel responsible for their parent and/or siblings.

Carers from **culturally diverse** backgrounds can experience layers of loss. You may be an **Aboriginal or Torres Strait Islander, migrant or refugee carer** and may have experienced major personal and cultural losses such as separation from family, traditions, community and language. If so, you may be vulnerable to feeling overwhelmed and isolated by the grieving process. If you are a carer who has come from another country and have had to leave behind people and things that were familiar to you, you may feel isolated and perhaps unsupported. If English is not your first language, you may struggle to understand the system and find services.

Many of these losses are fundamental to our sense of self and may contribute to feelings of intense isolation and loneliness.

When carer loss and grief are unrecognised, the physical and emotional impact over an extended period of time may be misunderstood and underestimated. This may affect your ability to make sense of your circumstances and thereby access any help that may be needed.

CARER LOSS AND GRIEF: COMPLICATED BUSINESS

Unrecognised grief

Recognition of the extent of losses and associated grief experienced by carers is recent, but we now understand that it is encompassed in the whole carer journey. The signs may not be immediately associated with grieving – indeed you may not recognise that this is actually what is happening to you.

You may instead describe yourself as feeling teary, sad, angry, frustrated, confused or resentful. These can be expressions and signs of grief. The grief may be so complicated and familiar as to be part of day to day living and therefore not recognised by yourself or others.

No definite starting point

Unlike bereavement, there may be no definite starting point at which grieving can begin. If the person with care needs has an illness such as Motor Neurone Disease, Alzheimer's disease, Parkinson's disease or an acquired brain injury for example, the changes and losses may continue to accumulate over a period of many years. The future is uncertain and the grieving process may continue on alongside the caring role, perhaps intensifying at meaningful times such as anniversaries, milestones or major changes such as placement of the person in a residential care facility.

You may be the parent of a baby born with a disability and it may take a long time before the extent of the problem can be established, thus delaying and complicating the grieving process. There may be no final loss so you may feel as you have no ability to begin or conclude the grieving process.

Ambiguous grief

When the losses are uncertain and the person remains physically present but psychologically altered or absent, you may feel faced with a more ambiguous and therefore more complicated grieving process. You may feel overwhelmed, exhausted and confused by the lack of certainty. If you find yourself sometimes wishing the person would die, so their suffering is relieved and some normality restored, then feelings of guilt may also be present and painful. However, be assured you are not alone in these thoughts and that this is a normal response to an abnormal situation.

"Sometimes I think that I want him to die - so it will all be over. I feel guilty for thinking this and I have to keep my thoughts to myself as my family wouldn't understand."

A carers reflection

Disenfranchised grief

The stresses, isolation and other impacts of caring are not often recognised or understood by family, friends or the community. Unlike when a person has died, there are no rituals to publicly celebrate the uniqueness of an individual's life and the ways in which they will be remembered and missed. There is little practical and emotional assistance such as friends dropping in or symbolic support in the form of cards or flowers.

I had lost the wife I knew without the luxury of having a funeral.

A carers reflection

Episodic or recurring grief

A person with cognitive impairment may improve briefly and may have a glimmer of insight into their illness, only to deteriorate once again. This may occur several times. If the care situation involves a mental illness or any sort of episodic condition, your journey may be experienced in parallel. Your family may enjoy good times while there is stability only to have your hopes totally dashed again by a major set back. Alternatively, you may function under a heightened level of anxiety, awaiting the next episode and therefore be unable to enjoy any peace that might accompany an improvement in the condition or behaviour.

Your feelings may fluctuate between confusion, anger and disappointment. It is common for the effects of the loss to be felt more keenly when the person improves, as this highlights what has actually been lost. This roller coaster of emotions can be difficult to manage.

"When my son's mental illness was under control, I could not relax; I was just waiting for the aggression and the stealing to begin again."

A carers reflection

Cumulative losses

There is rarely a neat and tidy aspect to carer loss, or a defined beginning, middle and end.

New losses have the tendency to bring up the pain of past losses. If you are already grieving a significant loss, then new losses and changes - even if relatively minor - can feel devastating. The grief may be particularly intense if, for any reason you have been unable to grieve for a previous loss or any past unresolved issues in your relationship.

"Dad died 18 years ago and now I'm looking after mum. I thought here we go again."

A carers reflection

No final loss

Unlike a death, where the bereaved person can strive to accept a final and certain loss, you may be struggling to manage the changes and losses that can accumulate slowly over a period of many years. The future is uncertain and the grieving process may continue on alongside the caring. Grief may intensify at meaningful times such as religious occasions or anniversaries, or following major changes such as placement of the person in a residential care facility.

"There was no light at the end of the tunnel"

A carers reflection

Anticipatory loss

You might grieve for what has already happened and also for what is likely to happen or not happen in the future. Many parents experience strong anxiety over what will happen to their child after they die or are unable to care any longer. The prospect of your son or daughter leading a lonely or unfulfilling life, or relying on others for care and support can be incredibly sad and worrying.

You may grieve in advance at the prospect of eventually having to relinquish or share the care with a facility. You may wonder how you will cope with the impending death of the person or feel frightened at the thought of being alone.

"I try not to think about what will happen to him when I die. There is no one else to take care of him. I can't get sick but I'm so stressed about it. There's nowhere for him to go."

A carers reflection

SIGNS OF GRIEF

Grief can affect us physically, emotionally, socially, financially and spiritually.

Physical signs of grief may include:

- › Shortness of breath.
- › Tightness in the throat and chest.
- › Changes in eating patterns.
- › Changes in sleep patterns.
- › Tiredness and fatigue.
- › Lack of energy.
- › Vulnerability to illness.

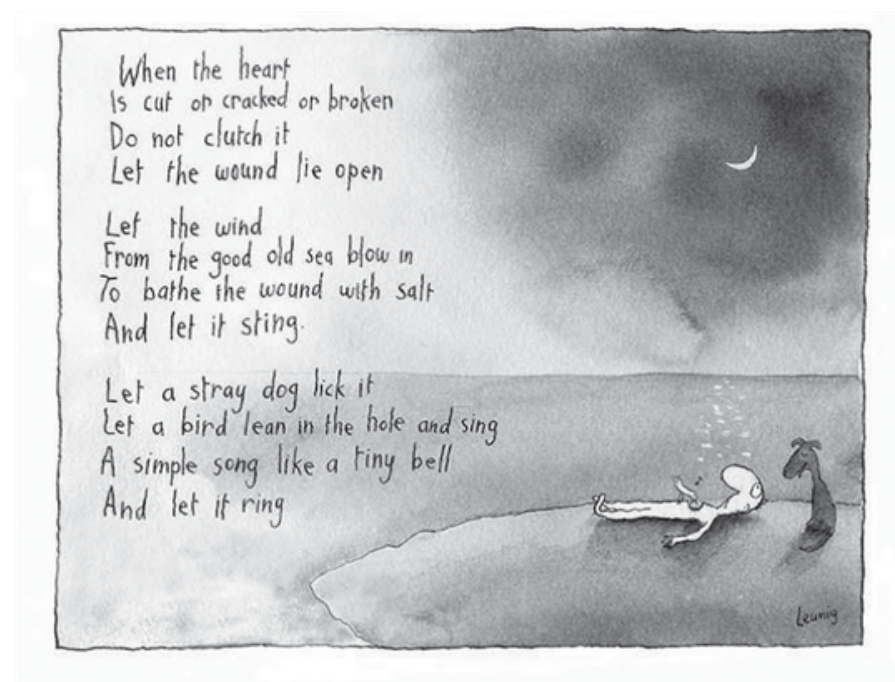
Emotional signs of grief may include:

- › Loneliness and isolation.
- › Feelings of confusion.
- › Deep, ongoing sadness.
- › Feelings of anger or rage.
- › Resentment towards the care recipient and others.
- › Deep feeling of aloneness.
- › Feelings of guilt.

These signs of physical and emotional stress can easily be heightened by lack of sleep or support.

Many of these signs can be related to other problems as well, and must not be overlooked. When you speak to your doctor remember to mention you are a carer so she or he understands the stresses and added responsibilities in your life.

On a spiritual level, you may begin to question why these things have happened to you or to someone you love; you may try to make sense of what has happened and may even question deeply held views of life. As a carer you may feel the need to protect others from pain and sadness and may find yourself trying to hold and manage everyone's grief as well as your own.



How long should I grieve?

There is no right or wrong way to grieve just as there is no specific time limit to the process. You may feel that you are not grieving enough or too much because you seem to be responding differently to other carers you know. However, everyone grieves in his or her own way.

Some of the reasons for this are:

- › How you have coped in the past with a loss.
- › The number of other losses you have experienced in your life.
- › Your age and health.
- › Your relationship with the person you care for.
- › The support system available to you.
- › Your personal background (e.g. religious, cultural, social).
- › Your financial situation.
- › Your gender.

Gender is an important factor that is often ignored. Some societies teach males from an early age that to be 'manly' is

to not cry or show grief. Tears are seen as a sign of weakness. Similarly, women are taught not to show anger and feel they have to stay strong.

Hopefully, as we learn more of the importance of acknowledging our grief openly we will understand that to be able to cry, or get angry, is not a sign of weakness, but of love and concern. Remember the impact of the grief may ebb and flow but can be managed with help.

THE CARER JOURNEY

The carer journey is often travelled in isolation, as you tend to lose touch with friends and may struggle to find time for social interaction. Other people may not understand the intensity of emotion that you are experiencing, nor recognise the impact of the emotional roller coaster of loss.

Most people understand the need to grieve when someone we care about dies. The associated rituals, sympathy, empathy or understanding that bereavement may bring, helps to process emotions and gives validation to our grief. However, if you are caring for a person with a degenerative cognitive impairment you may feel the person you knew has disappeared over a period of time. Communication, sharing of memories and companionship may also have been lost; this can feel like bereavement.

When the losses are uncertain and when the person remains physically present but psychologically altered you may feel overwhelmed and confused by the lack of certainty. It is important to understand that these are common reactions to what may be an uncommon situation.

Any or all of these factors can combine to create a grief unique to carers. Your journey as a carer will involve twists and turns and constant changes. It may begin with extra duties but you may find that responsibilities increase as the health of the person you are caring for changes or deteriorates.

FUTURE CARE

You are likely to face difficult decisions about future care at some stage. Moving someone into residential care, for example, may be one of the most difficult decisions you ever have to make.

Considering residential care is a turbulent time for carers and you may be trying to cope with many feelings and thoughts all at once.

For example:

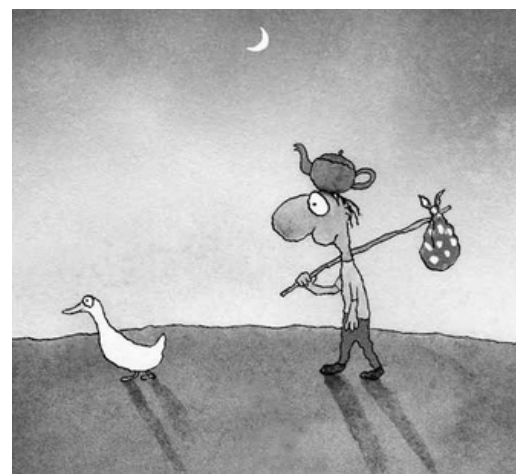
- › Will the person I am caring for be looked after properly by others?
- › What will other people think of me?
- › Have I done everything I could?
- › Am I a failure as a child/parent/sibling/partner/ friend because I can't give the care anymore?
- › What will I do with my life when I am not so busy?
- › I feel guilty for wanting some time for myself.

After months or years of caring, it can be tremendously difficult to let go. Your whole identity may be bound up in the needs of the other person and self-esteem may seem at an all-time low. Many carers struggle to deal with having extra time on their hands. These issues and many more questions and thoughts may make the decision about residential care more difficult for you. They are common feelings and you may find it helpful to discuss them, instead of having them go around in your own head day and night.

HELPFUL TIPS

While grief and loss are an integral part of the carer journey the following tips may be good initial steps to help you manage your feelings.

- › Learn as much about the condition as possible. Most condition specific organisations run information days and workshops.
- › Attend workshops and educational programs for carers. The value in talking to other carers in similar situations cannot be underestimated.
- › Find an appropriate carer support group. These can provide wonderful social interaction and emotional support.
- › Communication is essential. Talk to family members, friends and service providers about what you need.
- › Use a carer counselling service. Don't wait for a crisis. Consider attending even when things are going well!



CARING FOR YOURSELF

Sometimes you may find yourself thinking that caring is your whole life, and your whole life is caring. As your life is affected by your caring role, it is important to pay some attention to your own needs and to work to maintain your own health and well being. Carers say that having the opportunity to talk about their caring experience and to express how they feel, can help to reduce their sense of feeling alone. Realising others also share that deep sense of loss can help you to understand the complexities of what is happening to you and help you to validate and legitimise your own experience.

The following may provide some things worth considering to assist you in caring for yourself. In addition you will find a helpful list of people, places and contact numbers at the back of this booklet.

- › **Information** Find out what and who is available to support you. Contact organisations such as Carers Victoria, your local council, charitable organisations, the professional workers who assist you, and condition specific organisations such as Dementia Australia, Wellways (previously Mental Illness Fellowship), Cancer Council or the Association for Children with a Disability.
- › **Support groups** It helps to talk with other carers. Join a support group. These groups are supportive and provide time out from your caring role. Find out where these are using the numbers over the page and consider going along.
- › **Listening voice** If you don't have anyone among friends and family who can listen to you in the way you want, phone the Carer Gateway on 1800 422 737 to arrange counselling.

- › **Assertiveness** Ask questions, say how you feel, tell people you need some support and learn to say no. No matter how much you love the person you care for, you have needs too.
- › **Be aware of your feelings** When you are caring for someone else, it is easy to ignore how you are feeling. If you ignore feelings, they can sometimes cause you ill health. Listen to your heart and your body for signs you have particular needs and act on them.
- › **Companionship** Everyone needs to have time for talk, fun and laughter. Try to have contact with other people to bring some of the good things into your life.
- › **Taking breaks** You may think this is impossible but it isn't. You don't have to do everything all the time. For example, it is better to leave the ironing or washing up and sit and read the paper than to always be working. Those tasks will still be there, but you will feel stronger for the break. Be firm about not being interrupted by the person you are caring for unless it is urgent. Use respite services to take planned, longer breaks.
- › **Physical self-care** This can mean simple things like eating properly, sitting down for a drink, lying down for 10 minutes, having a bath, wandering in your garden, or just looking out the window and watching the world go by.
- › **Sometimes it can be difficult to take a break**, but remember to be as gentle and kind with yourself as you are for the person you're caring for. Try not to get to the point where you are emotionally and physically exhausted. Remember the people and places listed in this booklet (and many more) are there to help you.

WHERE TO FIND HELP

Carers Victoria

Phone 1800 514 845

www.carersvictoria.org.au

Carers Victoria is recognised and funded as the leading body for carers and caring families in Victoria. We work collaboratively with Carers Australia and the other state and territory-based Carer Associations to represent, advocate for, and provide carer services on behalf of carers throughout Australia. Join up as a member (it's free for carers) and keep informed about carer issues through our regular free ebulletin 'The Voice'.

Carer Gateway

Phone 1800 422 737

(8.00am to 6.00pm - Monday to Friday)

www.carergateway.gov.au

The Australian government gateway to information, advice, support, services, counselling and carer community connections.



Education

Carers Victoria Carer Workshops

Phone 1800 514 845

For information about workshops and programs specifically designed to support carers in their caring role contact Carers Victoria on the above number or email education@carersvictoria.org.au

Services

Lifeline Australia

Phone 13 11 14 (24 hours - 7 days a week)

Access to crisis support, suicide prevention and mental health support services.

Grief Line

Phone 1300 845 745 (Midday to 8.00pm - 7 days a week)

A free and anonymous telephone counselling service to people experiencing personal crisis or any type of loss or grief.

Beyond Blue

Phone 1300 224 636 (24 hours - 7 days a week)

Beyond Blue provides information and support to help everyone in Australia achieve their best possible mental health, whatever their age and wherever they live.

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Carers Victoria

1/485 La Trobe Street
Melbourne Vic 3000

PO Box 13305
Melbourne Vic 3000

Phone 1800 514 845

Email reception@carersvictoria.org.au
www.carersvictoria.org.au

 /carersvictoria

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