

an
unrecognised
grief

loss and grief issues for carers

carer's guide

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a carer's guide**

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Preamble

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 unrecognized 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 wellbeing, 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.

Introduction

This booklet has been written primarily for caring families.

Throughout this booklet the term carer has been used in its broadest definition as someone who cares for a person with special needs. We acknowledge that there are situations which involve not just one carer and that other family members, friends or neighbours may contribute to significant care responsibilities. Anyone involved in caring for a family member or friend may experience loss and grief.

Grieving carers come from all walks of life and an infinite range of care situations. You may be parents coping with the diminished abilities and life choices of a child with a physical or intellectual disability. You may be family members dealing with the uncertainty, stress and sadness of watching your relative struggle with a debilitating mental illness. You may be daughters and sons, husbands, wives, lovers, friends and others adjusting to your loved ones gradual loss of their personality or independence due to strokes, head injuries, AIDS, Parkinson's, Alzheimer's or other diseases. One thing you share in common is that you all experience loss at different times and in different ways, as your journey unfolds.

Background

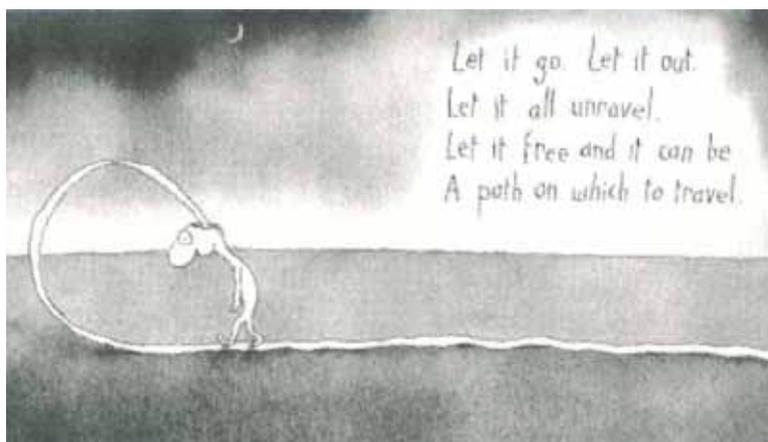
It can be hard to remain positive when you are undertaking a workload that is immense and demanding and offers little recognition. You may feel tired, unappreciated and depleted both emotionally and physically.

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 that you experience varies, this guide focuses on grief as the common response to loss which all carers' experience. Grief is experienced differently by individuals and may be expressed in a range of ways within different cultures. All carers experience loss and therefore are likely to experience some type of grief response. 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.

In producing this booklet, we hope that you will develop greater confidence in your abilities to recognize 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 of you 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 secure so that you can speak without fearing that 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 recognize it, name it and respond to grief, from the heart, can be a powerful, and life affirming experience.



1. Different carers different losses

When you hear the words loss and grief do you automatically think of death and dying? In many care situations, however, 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 burden of grief which may seem insurmountable. This grief is rarely articulated but instead can remain hidden beneath 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. It can usually be associated with unwanted change. One of the first changes you may notice might be the change in your relationships with others, your family members, friends and colleagues. Your relationship with the person you are caring for, the role that person played in your life and yours in theirs, may now be completely different.

Carers may experience some or all of the following:

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

Spousal carers may experience changes around issues of intimacy, companionship, communication, sharing of memories and tasks and recognition of a life lived together. **Daughters or sons** caring for a parent may experience an unwanted role reversal in becoming the parent to that parent. **Younger carers** may have never had the security of a loving parent and may have felt responsible for that parent and siblings.

Carers from **culturally diverse** backgrounds can experience layers of loss. You may be a **Koori, migrant or refugee carer** and may have experienced major personal and cultural losses such as separation from family, traditions, tribal community and language. If so, you are likely to be vulnerable to being 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 it is likely that you will 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 their absence may contribute to feelings of intense isolation and loneliness.

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

2. Carer loss and grief – a complicated business

Unrecognized 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 symptoms may not be immediately associated with grieving – indeed you may not recognize that this is actually what is happening to you.

You may instead describe yourself as feeling teary, sad, angry, frustrated, confused or resentful. These are all expressions and symptoms of grief. The grief may be so complicated and deep-seated as to be part of day to day living and therefore not recognized by yourself or others.

No definite starting point

Unlike bereavement there may be no definite starting point at which the 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 slowly accumulating over a period of many years. The future is uncertain and the grieving process may continue on and on alongside the caring, 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.

A carer's reflection

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

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 that the person would die, so that their suffering is relieved and some normality restored, then feelings of guilt may also be present and painful. However, be assured that you are not alone in these thoughts and that this is a normal response to an abnormal situation.

A carer's reflection

"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."

Disenfranchised grief

The stresses, isolation and other impacts of caring are not often recognized 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.

A carer's reflection

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

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

A carer's reflection

"I wanted to see him but couldn't cope with the aggression and stealing."

Cumulative losses

There is rarely a neat and tidy aspect to carer loss with 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 fully for a previous loss or any past unresolved issues in your relationship.

A carer's reflection

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

No final loss

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

A carer's reflection

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

Anticipatory loss

You might grieve not for just what has already happened but 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 offspring leading a lonely or unfulfilling life is an incredibly sad one.

You may grieve in advance at the devastating 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.

A carer's reflection

"Who will look after her when I'm gone."

3. 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

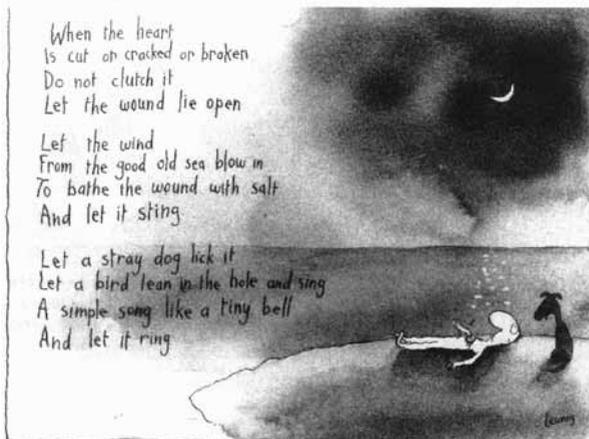
Emotional signs of grief may include:

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

Physical and emotional stress can easily be heightened from lack of sleep or support.

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

In addition spiritually 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.



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
- How many other losses you've experienced in your life
- Your age and health
- Your relationship with the person you are caring for
- The support system available to you
- Your personal background (e.g. religious, cultural and social)
- Your financial situation
- Whether you are male or female

This last factor is an important one that is often ignored. Society has taught males from an early age that to be manly it is best not to cry or show grief. Tears have been said to be a sign of weakness. Similarly, women are often taught not to show anger and often talk about having 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 intensity of the grief may ebb and flow but can be managed with help.

4. 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. Others may not understand the depth of emotion that you are experiencing, nor recognize the impact of your emotional rollercoaster 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 cognitive impairment you may feel that the real person 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 normal reactions to what is an abnormal 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 will find that responsibilities increase as the health of the person you are caring for changes and deteriorates.

You are likely to face difficult decisions about future care at some stage. Moving someone into residential care may be one of the most difficult decisions you ever have to make. It is usually a turbulent time and your mind 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 be at an all-time low. Many carers struggle to deal with the adjustment of having time on their hands. These issues and many more questions and thoughts may make the decision more difficult for you. They are normal feelings and you may find it helpful to discuss them, instead of having them go around in your own head day and night.

5. 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 the carer counselling service.** Don't wait for a crisis. Consider attending even if things are good at the moment!



6. 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. Realizing that others also share that deep sense of loss can help you to understand the depth and complexities of what is happening to you and help you to validate and legitimize your own grief.

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 Alzheimer's Australia, 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 when you are collecting information, 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, ring Lifeline or Griefline or arrange for some counselling with Carers Victoria so you can talk things over. Find someone who will listen and not be judgmental. All organisations respect your privacy and keep your information confidential.

- **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 you sometimes 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 that you have particular needs and act on it.
- **Counselling.** Going to see a counsellor, or talking to one on the phone, is now common. When you do, you are showing that you are in control of your life and know that you need for support. Look at the back of this booklet for some places to ring to arrange to see someone.
- **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. It is better to leave the ironing or washing up and sit and read the paper than to always be working. The ironing and washing up 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.
- **Physical self-care.** This can mean simple things like eating properly, sitting down for a drink, lying down for 10 minutes, having a bath with some lavender oil in it, wandering in your garden, or just sitting and staring out the window and watching the traffic 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

1. Organisations

Carers Victoria – 9396 9500

Times: Monday- Friday 9am to 5pm

Peak body representing all Victorian carers. Join up – it's free and receive the free regular newsletter, ebulletins and access the library service to borrow books, DVD's, articles which are posted to you.

2. Phone services

Carers Advisory Line - 1800 242 636

Times: Monday to Friday 8.30am to 4.30pm.

Talk to our friendly experienced staff who can provide information and emotional support. They can connect you to a range of services and make referral to other programs.

Lifeline Australia - 13 11 14

Times: 24 hour service

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

Grief Line - 9935 7400

Times: 12 noon to 3am

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

3. Counselling services

Carers Counselling Program - 1800 242 636

You don't need a referral from a doctor to access this service. Counselling is available statewide and can be accessed by individuals, couples or groups. The service provides specialized counselling with a carer focus.

4. Education

Carer Workshops - 9396 9500

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

5. Carers in transition programs

Carers in transition programs – 1800 242 636

For information about programs that target specific stages of the carer journey including bereaved carers contact Carers Victoria on the above number or email nccpadmin@carersvictoria.org.au

6. Respite services

Commonwealth Respite Centres - 1800 059 059

Call this number to access your local centre for information on short term respite and emotional support. They can also advise you as to what is happening for carers locally.

Emergency respite out of hours – 1800 059 059

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