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Introduction

This booklet has been written primarily for those who work with carers in their roles as support workers, social workers, counsellors, residential care staff and volunteers.

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 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. They may, for example, be parents coping with the diminished abilities and life choices of a child with a physical or intellectual disability. They may be family members dealing with the uncertainty, stress and sadness of watching their relative struggle with a debilitating mental illness. They may be daughters and sons, husbands, wives, lovers, friends and others adjusting to their loved ones gradual loss of their personality or independence due to strokes, head injuries, AIDS, Parkinson’s, Alzheimer’s or other diseases. One thing they share in common is that they all experience loss at different times and in different ways as their caring journey unfolds.
**Background**

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 bereavement through death occurs or is expected to occur. Caring families are grieving for all sorts of different losses:

- the unfulfilled expectations they had for themselves or their loved one
- the changed relationship they may now have with the person with care needs
- changed relationships with other friends and family members
- choices relating to paid work and careers
- income security
- changes in lifestyle, status, intimacy, freedom and identity.

In recent years much has been spoken and written about loss and grief. We are aware of books, journals, videotapes, counselling services and conferences, all seeking to break the silence that for too long has stifled attempts to talk openly about loss, grieving and sadness. As useful as these resources are, most of them focus exclusively on the loss and grief issues that arise in response to an actual death or bereavement. This excludes the thousands of family carers who we know are experiencing profound loss, but without the finality and recognition that an actual death can bring.

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 the nature of losses that carers experience varies, this guide focuses on grief as the common response to loss which all carers experience.
In producing this booklet, we hope those reading it will develop greater confidence in their abilities to recognise and respond to the emotions that accompany the losses that carers experience. It is reassuring to know that professional help is there if we need it. Many carers do not want formal counselling, but they do want to be able to tell their stories without censure or judgement, and without feeling that the listener is watching a clock. Carers also need to feel secure that they can speak without fearing that the listener may not be able to cope with the depth of their emotions. Grief and loss are, after all, a normal part of life like joy. To name it and respond to grief from the heart, can be a powerful and life affirming experience.

Friend of a carer

“A friend was telling me about this heavy situation and without really thinking I found myself saying ‘That’s terrible. You should really talk to someone about that’. She stopped short and looked at me and said, ‘I thought that’s what I was bloody well doing’.”
1. Different carers, different losses

Most of us automatically associate grief with death and dying. Unfortunately this assumption excludes many people who are experiencing great loss in their lives within the caring context. 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. In these situations, the grief response may be both different to, or more complicated than that experienced after a death.

As the carer’s journey unfolds, 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.

There are as many types of illness and disability as there are types of carers and care situations. In naming any particular group or category, it is easy to run the risk of over-simplifying the diversity and complexity both of carers and their unique situations.

A carer’s reflection

“His personality changed after the stroke. He used to love the kids, he had so much patience with them. Now he’s always yelling at them. They’re terrified of him half the time - their own father!”
Summary of carer losses

It is useful to summarise some of the losses that typically occur in specific care situations.

These include loss of:

- Dreams
- Hopes
- Achievements
- Opportunities – educational and career
- Paid work
- Financial security
- Personal space
- Privacy
- Freedom
- Lifestyle
- Time
- Energy / health
- Friends
- Roles – carer and care recipient
- Relationships
- Sharing
- Companionship
- Intimacy
- Affection
- Sexual expression
- Choice
- Control
- Identity
- Peace of mind
- Personality
- Self esteem
2. Characteristics of carer loss

Unlike bereavement there may be no definite starting point at which the grieving can begin.

The person being cared for may have been exhibiting memory loss or slight behavioural changes for months or even years before a diagnosis of illness such as Alzheimer’s disease, Parkinson’s or a stroke is made with certainty. Even in the case of a baby born with a disability or an adult acquiring brain damage due to a car accident, it may take a long time before the extent of the problem can be established. These weeks, months or years prior to the diagnosis can bring great strain to relationships and give rise later to difficulties and regrets that further complicate the grieving process.

A carer’s reflection

“With loss there is grief. My personal definition of death is that it is a completion of life, a time to grieve. Dementia robs the person and partner of the dignity and comfort of participating in the dying process. When a person is diagnosed with dementia it is considered inappropriate to discuss death and saying ‘goodbye’ because the physical death may be years away. The loss of shared memories, sense of family and way of life places untold stress on a carer who often has been ill prepared for the manifestations of this illness. Too little information too late has left the partner grieving but not being seen to be grieving by the wider community, family and friends.”
No final loss

Unlike an actual death where the bereaved person can strive to accept a final and certain loss, there is no such end point for the carer. If the person with care needs has an illness such as motor neurone disease, Alzheimer’s or Parkinson’s disease, 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 religious occasions or anniversaries, or following major changes such as placement of the person in a home or facility.

A carer’s reflection

“I found myself wishing he would die and then feeling awful. I just wanted it to stop. I was so tired.”

Ambiguous Loss

These losses are often unrecognized as they do not fit our preconception of grief. Given that the person with care needs is still alive, carers may ask themselves is it appropriate to grieve or am I being disrespectful to this person? How much should I grieve? How do I know at which point to strive for acceptance?

When the losses are uncertain and when the person remains physically present but psychologically altered or absent the carer is faced with a more ambiguous and therefore more complicated grieving process. They are likely to feel overwhelmed, exhausted and confused by the lack of certainty. If they sometimes find themselves wishing that the person might die so that their suffering is relieved and some normality restored, then feelings of guilt may also be present and very painful.
A carer’s reflection

“People kept telling me how lucky I was to still have her with me. I didn’t feel lucky – the mother I knew was gone forever.”

Episodic or recurring loss

If the care situation involves a mental illness or any sort of episodic condition, the carer’s grief may be experienced in parallel. The family may enjoy good times while there is stability only to have their hopes totally dashed again by a major set back. The family 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.

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. 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

“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.”

Cumulative Loss

New losses have the tendency to bring up the pain of past losses. If the carer is already grieving a significant loss, then new losses and changes, even if relatively minor can feel devastating. The experience may be compounded by something as common as lack of sleep.
The grief may be particularly intense if for any reason the carer has been unable to grieve fully for the past loss or if the carer is confronted with unresolved issues such as family conflicts or regrets about the nature or quality of the relationship.

Koori, migrant and refugee carers are especially susceptible if they have experienced major personal and cultural losses such as separation from family, traditions, tribal community and language. They will be more vulnerable to being overwhelmed and isolated by the grieving process.

**A carer’s reflection**

“I lost my sister just before I began caring for Dad. I had to put my grief on hold and couldn’t talk about it for years. Then it all hit me together, like a rock.”

**Anticipatory Loss**

Carers 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 their offspring leading a lonely or unfulfilling life is an incredibly sad one.

Carers may grieve in advance at the devastating prospect of eventually having to relinquish or share the care with a facility.

**A carer’s reflection**

“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.”
**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**

“No one visited Mum when she was at home, but they called regularly when she was admitted to hospital.”

“I needed someone to give me permission to immerse myself in my grief.”
3. Unrecognised and unacknowledged

The grief could be so complicated and deep seated as to be part of day-to-day living and therefore not recognized or acknowledged by the carer, other family members and friends or workers.

“No one understands. They think I should be the one to do the caring as I live closest. My family thinks this is easy but they don’t know what my life is like now – there’s not much of me left. I’m disappearing too.”

The difference between bereavement and carer loss.

These diagrams may help to illustrate the difference between bereavement and carer loss. These differences can have a major impact on how the grief is experienced and will influence how the carer perceives and processes it.

**Bereavement**

The Plus (+) sign symbolises the living person and the Minus (-) sign symbolises that this person is no longer with us. The ‘X’ symbolises the physical loss of that person.

Death is a visible loss and the associated bereavement takes place within a social context. Family and friends may offer practical and emotional support.

Arrangements are made, rituals are observed and the deceased’s life is acknowledged and celebrated. Death is a recognised and final event.

![Diagram showing bereavement and carer loss](image-url)
Loss the carer’s journey

In contrast, the carer journey can be compared to a roller coaster.

Associated losses of personality, role, communication and companionship can feel as significant as death. Carers speak of having lost the person, even though the person is still alive. Bereavement gives legitimacy to and sanctions grief, whereas carers may struggle to justify grieving for someone still living.

Unlike the finality associated with bereavement, carer grief may have no identifiable starting or finishing point and losses accumulate throughout the carer journey.

Some losses (symbolised by an ‘X’) are more keenly felt at the peak or the good times, as the depth of what has been lost becomes more obvious. The troughs or low points bring their own associated grief.

The ‘razor wire’ likeness symbolises the complicated process that is carer grief.

The cyclical and episodic nature of the carer journey has extremes of effect and intensity. It can mask grief reactions which can hinder or disrupt the already complicated grieving process.
A carer’s reflection

“It’s unending. When you feel as if there is no more to lose, you lose a little more.”

The journey is often travelled in isolation without the associated rituals, sympathy, empathy or understanding that bereavement may bring. Any or all of these factors can combine to create a grief unique to carers.

A death may evoke a deep sense of loss, anguish and sadness, and the finality of the event and associated rituals such as funerals and wakes may go some way towards helping to process this grief.

But the carer journey of loss can be a much more complicated process. Stages, phases and tasks associated with bereavement have been well documented but this approach does not necessarily apply so readily to the complicated grief of the carer journey.

A carer’s reflection

“Sadness when you consider the person’s life will not be celebrated by friends and colleagues as the length of the dying process and the inability of many of these people to remain in touch causes a breakdown in the societal response.”

To summarise the grieving journey of carers

• The person with care needs is alive but is not how they used to be or not how the family would expect or want them to be

• A carer is grieving for their own loss and also the losses and /or suffering experienced by the person with care needs
• There may be no clear beginning or end. Instead, the losses may continue to accumulate or re-emerge as the person with the illness or disability progressively deteriorates or fluctuates between being well and unwell.

• In the case of a parent carer, new losses might be felt at each developmental stage, milestone, birthday etc.

• The grief may be marked by uncertainty and confusion. The losses may be more ambiguous because the situation is always changing, depending on the different phases of the illness or disability and the stages of the carer journey

• The grief may go on and on alongside the caring, sometimes for years and sometimes for a lifetime

• The losses tend to go unrecognized by the carer’s friends, networks and broader society and there are few, if any, opportunities to publicly grieve

• Grief may be noticed but avoided by people who feel uncomfortable with intense feelings of anger, sorrow, frustration or anxiety

• Feelings of sadness may be hidden beneath other emotions, or the many practical tasks the carer needs to do for day–to–day survival

• The process may be fraught with feelings of guilt for grieving for someone who is still alive

• There may be complicating factors such as a history of past abuse, unhappy relationships or family conflicts.

• The carer may be grieving for not only what was but perhaps for what should or might have been (for example a loving relationship rather than a violent one, or for lost opportunities to put things right)
• The mental and physical health of carers is likely to suffer due to the long term strain

• Individuals and families may attach different meanings to the same losses and may grieve entirely differently according to diverse factors such as personality, family culture, ethnic traditions, past history of loss and amount and adequacy of support from formal and informal networks

• It may be difficult or impossible to resolve the grief; however, once identified, many carers are able to integrate it into their lives whilst enjoying life outside the carer role

A carer’s reflections

“I never realized there was so much loss involved.”

“I didn’t understand that much of my anger and frustration with everything was to do with grieving.”
4. Working with the loss and grief of carers:

A worker’s reflection

“To respond appropriately to carers, we need first to be aware that loss and grief may be involved and that carers may appreciate an opportunity to express it. We need to understand that the grieving journey – always a lonely one – may be even more isolating for carers given the lack of recognition, the long term nature of caring and the many other complexities already discussed.”

It is important to understand that this grief may not always be expressed by overt sadness or tears. What we don’t see can be as important as what we do see. Grief can manifest in several ways:

- anger
- anxiety
- confusion
- bewilderment
- frustration
- isolation
- resentment
- betrayal
- desolation
- guilt

A sense of:

- failure
- self blame
- self criticism
- diminished self esteem
- feeling out of control

Grief can affect the carer and family, physically, emotionally, socially, financially and spiritually.
A carer’s reflection

“There is nothing that compensates a partner for these lost years. There is a sadness that envelops one forever.”

General Principles:

- **Allow the carer to tell their story.** They might like to begin at the time of diagnosis or long before this when changes may have been noticed or initial fears and uncertainties crept in.

- **Listen.** Use reflective listening skills and make sure the focus remains on the carer and his/her story.

- **Name the grief** and if relevant, acknowledge the ambiguity of the losses and how hard that must be.

- **Allow adequate time** for first and subsequent meetings with a carer. Appearing rushed may make the carer feel like their story is not important and reinforce their sense of isolation.

- **Try not to judge** or censor the carer’s experiences and feelings.

- **Avoid clichés and platitudes** such as ‘I know how you feel’ or ‘time will heal’.

- **Be aware that a grieving person may need to tell and re-tell their story.** This is a part of healing.

- **There may be times when you feel at a loss to know what to say.** Don’t be afraid to acknowledge this, or to sit with the silence.

- **Provide as much information as possible** about the illness or disability.

- **Resist the temptation to respond to strong emotions with a quick, ‘fix it’ approach.** There may be a time when problem solving is called for but it is probably not while the carer needs to vent their emotions. Instead it may be helpful to further explore the expressed
feelings by asking more questions, clarifying and/or reflecting back your understanding of what was said

- **Encourage the carer to look after themselves.** Discuss the health impacts of caring and grieving and, if desired, together try to develop some simple strategies aimed at looking after their own physical, mental and emotional health

- **Share the load.** Are there other family members, friends, neighbours, spiritual or religious affiliations or support services who could offer any practical or emotional support? Encourage the carer to share their feelings with trusted others, to ask for help and to accept support when it is offered.

- **If the carer comes from a culturally or linguistically diverse background** they may prefer referral to an appropriate bilingual worker.

- **Refer to available services.** See suggested resources and services on page 29.

**A carer’s reflection**

“Listening to others sharing the same thoughts and feelings, I realized that I wasn’t mad or a bad person.”
5. Basic counselling and support:

General principles

While the principles outlined previously are intended for all workers or volunteers, the suggestions below are geared more towards those health professionals who are expected to carry out some basic counselling and support or assessment work with carers. These are not intended to replace referral to more experienced expert loss and grief counselling if this is appropriate or requested.

- **Explore** the history of the illness or disability and the way the family and friends have responded to it. Allow the carer to identify the losses that have already occurred or which may be feared for in the future

- **Validate** the grief as a normal reaction to the losses that have been expected or are expected to be experienced. Together, explore the feelings and issues the carer has in response to these losses

- **Avoid** assumptions about what is good grieving or bad grieving. Be aware and supportive of the fact that individuals grieve differently. Instead, support the carer in identifying what is meaningful to them

- **Home visits** may be more suitable for offering emotional support to the carer than an office meeting. If it is a home visit, try to ensure that your discussion occurs in a room where the carer can speak freely

- **Respect** the fact that the carer may take time to build up trust in you, especially if they have already had contact with lots of workers over the years. It may also take longer if the carer is from a culture which does not usually talk about illness or grief

- **If you will be away** for a long period or leaving your job altogether, make every effort to ease the transition to a new worker. Give lots of advance notice and opportunities to talk about your departure
• **Inform** the carer about relevant support groups in their area. If they wish to attend but feel nervous about taking the first step, you could offer to ring the group facilitator for them.

• **Leave information brochures.** Make sure the carer is informed of relevant services such as disability organizations and of specialist grief telephone and counselling services. Remind the carer that some of these services operate out of office hours, at times when they may be most in need of a listening ear.

• **Discuss**, if appropriate, loss and grief counselling options with the carer. With the carer’s permission, you may be able to assist by arranging a referral, transport, respite and/or financial assistance to cover costs.

• **Affirm** what a good job the carer is doing; share any positive observations about the carer’s skills and commitment. Carers are sometimes only able to see their inadequacies.

• **Encourage** progress, milestones and/or the positives.

**A carer’s reflection**

“I finally understood that the whole thing was just very very sad.”

“Although it didn’t fix it, I felt better after I had talked to someone not personally involved.”
Carers who have relinquished caring at home or whose loved one has died

A carer’s reflection

“After two and a half years of no sleep I had to let go. The hardest day of my life was the day I signed Mum into a nursing home permanently.”

In these situations carers may experience additional strong feelings of guilt that they can no longer care at home or that they didn’t do enough while the person with care needs was still at home and/or still alive. If the person with care needs has been placed in a nursing home or other institution, there may also be guilt, anxiety and grief about the quality of care being offered. After months or years of caring, it can be tremendously difficult to let go. The carer’s whole identity may be bound up in the needs of the other person. They are likely to have lost friends and social outlets along the way due to their many care responsibilities and self esteem may be at an all time low.
6. Ideas for making the workplace more grief-friendly

As a first step, the team or workplace may need to decide to devote some time to develop achievable grief-friendly practices. Once a commitment is made, any or all of the following might be useful exercises to carry out as a team:

- **Organise some professional development around loss and grief.** This may mean attending training, or arranging for a guest speaker to visit. Alternatively, you may find that organising your own in-house session is a more effective way to get staff committed to developing grief-friendly practices that suit the idiosyncrasies of your own particular work or carer group. You don’t need to be a grief expert to do this, but rather to plan and facilitate the session well so that the collective expertise of the group can emerge. You can build the session around some of the exercises below.

- **Brainstorm all the losses** you can think of for the carers you know. Discuss the hidden and overt ways that the grief tends to manifest itself.

- **Present carer case studies.** What are the losses? Are they recognised? How is the carer grieving? What could be done to assist or affirm the grieving process for the carer?

- **Share ideas** for rituals that might be meaningful to a grieving carer. Discuss the suggested responses listed above. What might you add, leave out or modify in your work with carers? Share ideas about what you already do in terms of responding sensitively to loss and grief.
• **Discuss current assessment practices.** Are these sensitive to the fact that loss and grief may be a central part of the carer’s experience? How might they recognise or affirm this more fully? Is there sensitivity to the fact that people from other cultures may grieve differently and/or may experience exacerbated grief due to a past history of loss?

• **Circulate appropriate articles and books** about loss and grief. Make a note of particular concepts or ideas that may be worth discussing at a team meeting.

• **Discuss the impact that staff changes** and departures may have on carers. What are some standard practices that could be adopted to acknowledge and/or minimise the loss for carers?

• **Discuss some of your personal responses** to being confronted with so much loss and grief. What are some of the ways staff and management can support each other?
7. Self care for workers – general principles

Worker’s reflection

“Like so many workers I was never good at looking after myself. But I’ve learned to be better at it, to be more aware of it. I’ve learned to emotionally leave when I physically leave, to take time out, weekends off, go walking, take massages and so on ... I also share with my colleagues how to look after ourselves in tiny little things. It doesn’t have to cost money. It might be just making a pot of tea and putting myself in a nice environment.”

Being continually exposed to the pain of others can take a physical, emotional and spiritual toll on workers.

To respond effectively to the practical and emotional needs of others it is important that you find a way of monitoring your own emotional health and wellbeing.

- **Educate yourself** as much as possible about loss and grief. Feeling ill-informed about grieving can add to our feelings of stress during emotional encounters with carers. Similarly, knowing that anger may often be a sign of underlying grief can help you to maintain your compassion and sensitivity at difficult times.

- **Try to stay in touch with your own feelings** in response to the grief of the carers you work with. Be true to yourself. Do you have losses of your own that you need to acknowledge or grieve for? Are there situations that are a little too close for comfort or which you feel you would rather not tackle? Maybe these feelings can be taken into account at case allocation meetings?
• **De-brief with other workers** as much as possible, particularly after a draining day or support session. If an experience has been particularly distressing, there may be an opportunity to debrief with an outside professional.

• **Take breaks between interviews** with carers whenever possible. Try not to take work home or miss lunch breaks or holidays no matter how pressing your work appears.

• **Strive for a balanced lifestyle yourself** with adequate sleep, a nutritious diet and regular exercise. If possible, treat yourself to massages, yoga or other relaxing pursuits, especially at times when you feel weighed down by the pain of others.

• **Periodically review your work goals** and performance. How are you relating to carers? If you notice a significant increase in feelings of impatience and stress and a decrease in sensitivity, it may be time to take a holiday or to seek work in another area. Perhaps your workplace can offer a stint away from casework to do a specific project? A break may be all that’s needed to refresh the spirit.
Useful resources

Phone services

Carer Advisory Line – 1800 242 636

*Times: Monday to Friday, 8.30am to 4.30pm*

Provides information and emotional support and will connect carers to a range of services

Lifeline Australia – 13 11 14

*Times: 24 hours*

Grief Line – 9935 7400

*Times: 12 noon to 3am*

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

Counselling services

Carer counselling program – 1800 242 636

Counselling is available to individuals, couples, families and groups and can be accessed face to face, by telephone or web based.

Referrals can also be made on the number above, by fax on 9396 9595 or online at www.carersvictoria.org.au

Carers in Transition programs – 1800 242 636

A suite of three distinct programs:

Carers in Transition 1 – *Preparing for residential care*

Carers in Transition 2 – *Sharing the care – when the person has moved into residential care*

Carers in Transition 3 – *New Horizons – for bereaved carers*

For more information call the above number or contact nccpadmin@carersvictoria.org.au
Education and training

Carer Workshops – 9396 9500

For information about workshops specifically designed to support carers in their carer role or to obtain a copy of the current brochure contact Carers Victoria on the above number or email education@carersvictoria.org.au

Service Provider Workshops – 9396 9500

For information about quality training to enable your staff to work more effectively with carers and their families contact Carers Victoria on the above number or email education@carersvictoria.org.au

Respite services

Commonwealth Respite Centres – 1800 059 059

Please call the above number for your local centre

Reading


Cantwell-Bartl, Annie, 2000, *Caring about carers: focus on the complicated mix of emotions experienced by carers*, Self Published.


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Levine, Stephen, 2005, *Unattended sorrow: recovering from loss and reviving the heart*, Rodale, Emmaus, PA.


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