



An Unrecognised Grief

Loss and grief issues for carers:

A carer' guide



**Annie Cantwell-Bartl
January 2001**

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**An Unrecognised Grief - Loss and grief issues for carers:
A carers guide**

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Acknowledgements

About the Author

Annie Cantwell-Bartl has a background as a nurse who worked in palliative care with patients and their families. She is now a consulting psychologist who does counselling, writing and education. She works closely with many people whose lives have been challenged and changed through losses brought about by accident, illness and other trials of life. She is married to Bernd Bartl and has four children: Ben, Anthony, Anna and David. In 1986 Anthony, aged six, was struck by a car and rendered a quadriplegic and is ventilator dependant. He is now twenty, lives at home and has a full life. The journey of adjusting to his disability and attempting to give him opportunities has been fraught with difficulties and stumbling blocks. That continues.

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Introduction

Why a booklet on Carer's grief?

Everyone experiences loss during life. However, for carers many of the changes and losses experienced can come quickly and often.

“The tree changes as it grows. It is torn by wind and lightning, scarred by frost and snow. Branches die and new ones emerge. The drama of existence has its way with the tree but still it grows; its roots reach down into the darkness; still its branches reach down into the sap and reach upward and outward into the world.”

M. Leunig

If you are reading this booklet then you are probably a carer. That means that you have volunteered to care for someone, a family member or friend, who has a long-term illness or a disability. You may be caring for a child with a physical disability, a spouse with HIV/AIDS or Hepatitis C, a parent or spouse with Alzheimer's, a brother or sister with a brain injury arising from an accident, a friend who has had a stroke. As a parent, child, lover, friend or spouse you are faced with another person's pain and frustration every day, and this can easily make you feel vulnerable too.

Michael Leunig's words suggest that even in times of suffering there is potential for hope and new life. Often this can seem impossible when you are caring for someone. However, if you are able to find support and some space to be yourself, then you may well be able to manage the situation more easily.

It is hard, sometimes, to be positive. As a carer you may often feel tired, depleted, exhausted, and perhaps self-critical. You may feel crushed, as if your “sap of life” is being diminished. You are undertaking a workload that is immense, and our society needs to be offering more respect, understanding and assistance to you in that work and added role.

This booklet is about loss and grief that arises not only through death, but also from a large range of other losses. If you are a carer there is loss. These losses are often unacknowledged by those around you, be they professionals or other family members and friends, but the losses have a great effect on your feelings, your physical health, your mental wellbeing, your financial situation and so much more.

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

What is grief?

Grief is the emotional reaction to any loss that is painful. It is as much a part of the emotions as joy. Sometimes grief is short-lasting; other times it overwhelms the whole self. There is always loss where there is love, particularly where one person is now the carer.

As you feel the emotions which come as part of grieving, you are going through what specialists in the field call a 'grief process'. It's called that because the intensity of grief actually has a beginning, a middle, and an end. The intensity of grief ebbs and flows but can be lived with. Sometimes it diminishes with support. Those who do not express the emotions can often experience health problems – both physical and mental – from bottling them up inside.¹

There are many reactions to grief. Grief affects the whole person: physically, socially, emotionally and spiritually. You may feel ill, feel you are going mad, experience a change in how you relate to others and question deeply

held views of life and God. Your feelings may be all over the place and there may be different feelings happening at the same time. Eg. You may feel both tender and protective of the person you are caring for and angry that you now have a huge job to do.

What are some signs of grief?

If you are grieving you may experience some or all of the following signs:

- ★ Shortness of breath
- ★ Weakness
- ★ Dryness of mouth
- ★ Changes in sleep patterns
- ★ Tightness in the throat and chest
- ★ Feelings of confusion
- ★ Deep, ongoing sadness
- ★ Feelings of anger and rage
- ★ Resentfulness towards the care recipient
- ★ Deep feeling of aloneness
- ★ Tiredness

Because some of these signs can sometimes be symptoms of other problems too, they must not be overlooked but always checked out with a doctor.ⁱⁱⁱ However, it is important that you inform the doctor you go to that you are a carer, so that she or he understands the stresses and added responsibilities in your life.

Remember that no matter what the feeling, there are ways of dealing with it. Feelings of anger and resentment can easily be heightened from lost sleep. Our community has acknowledged this for a long time with such organisations as Parents Anonymous^{iv}, so if you feel like this you are not alone and there is someone to listen to you.

Why people experience grief differently

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 and how many other losses you’ve experienced in your life
- ★ What the loss actually is
- ★ Your age and health
- ★ Your relationship with the person you are caring for
- ★ The support system available to you
- ★ Your personal background (eg religious, cultural and social)
- ★ Your financial situation
- ★ Whether you are male or female

This last factor is an important one that is often denied. Our society, with an Anglo/Celtic/Saxon basis, 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. 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.

Chapter One – Loss: The Beginning of Grief

A very common experience

The history of Australia shows us that loss is a very familiar experience to all. When white settlers came from the Northern Hemisphere, the Australian Aboriginal people, who had nurtured and revered this continent for many thousands of years, found themselves marginalised, facing death and imported diseases, forced from their own land and often separated from their own families.

Those same white settlers were also often experiencing many losses. For those who came as convicts, they had lost not only freedom but also contact with families, with no hope of meeting them again.

For those who came freely, both then and more recently, the losses were still many: family, friends, a familiar landscape, and a whole way of living.

And so our whole nation, like so many others, is one that is built on a vast number of losses – and yet we rarely acknowledge the sadness, anger and frustrations that can be passed from generation to generation as a result of the grief that accompanies them.

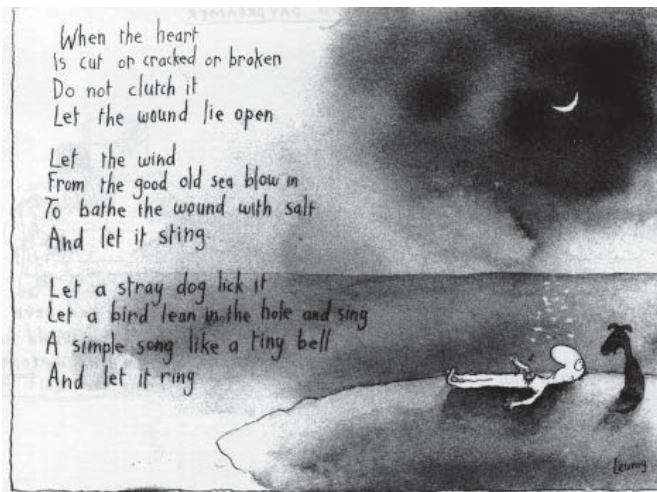
Our community, generally speaking, finds it much easier not to speak about sadness or pain than to show it. Different cultures have different ways of expressing feelings. If you are from a background where tears are readily expressed when you are sad – regardless of whether you are a woman or man – then you will recognise that those from other cultural backgrounds don't always feel that same sense of freedom to cry. If you come from a background that is religious you may find great comfort in your beliefs and the sacraments of your church. If you do not hold those beliefs you may draw comfort from your own firmly established values and belief in the power of the human spirit.

At the same time as experiencing your own losses and the grief that comes from them, you may come to see that often those around you find it is easier to deal with your situation by ignoring or denying its impact on you.

I would go down the street and I would see people cross the road, because they saw me coming. Eventually, I bumped into a friend as we were coming around a corner. She said, "Marie, I didn't know what to say to you, so I kept away." I said to my friend, "I don't know what to say either. There's nothing to say. But I'm glad you spoke to me."

Marie, mother of a child injured in a car accident.

Does that sound familiar to you? Or perhaps you experience people coming along with 'answers' to your situation, or 'reasons'. "God only gives this situation to special people. I know your child will be all right. I can just feel it" someone else told Marie. This may help you, it may not. And if it does not help you then not only do you not feel comforted, but you may feel even more alone in your experience. You quickly learn that very few people want to share you experience and understand how it is for you.



Before you became a carer, you had a whole lifetime of other experiences. Some of these would also have contained loss - you may find these are recalled. You have had your own way of dealing with those changes and transitions and now, with the additional responsibility of being a carer, you may be feeling overwhelmed.

When we hear of a person living through a traumatic situation we are not surprised to hear that they experience a great deal of stress.

It is often the same situation when the realisation 'hits home' that you are to have the additional role of carer added to all of your other roles and responsibilities.

There was the shock of our son being in an accident and learning the extent of his injuries. The accident changed things dramatically, with no hope of getting back to where we were. Suddenly we were highly dependent on others. The assumption that the world was a good place to be was suddenly in question. His disability affected everything: where we lived, our work, how much money we earned, our friendships, where our children went to school, where we went to church, whether we could have holidays and leisure, and how. Most relations with relatives and friends changed for the worse or ceased; a very few relationships brought welcome support. Things that were no longer possible kept cropping up. The additional tasks of living with him eventually settled into a routine, but new tasks kept coming up. Crises come and go. There have been gains. Real gains. Each day is an achievement. But the losses nevertheless go on accumulating.

Bernd, father of a boy with head and physical injuries arising from a car accident.

Regardless of whether or not you are caring for someone with similar disabilities, you can probably 'read between the lines' of Bernd's comment and recognise many of the losses which you yourself have experienced. There are others too.

Common losses experienced by carers:

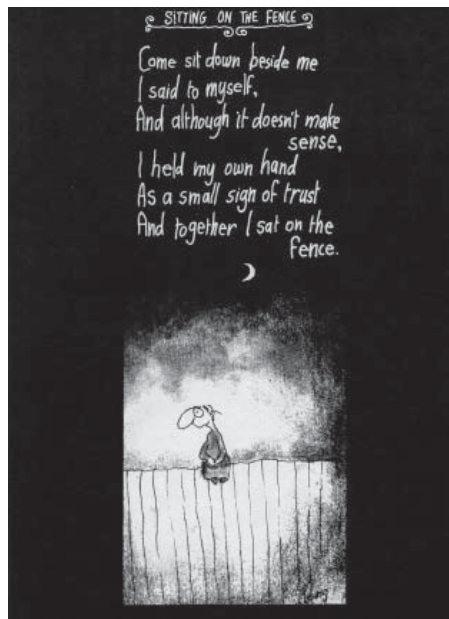
- ★ Loss of company and a social life, perhaps even friends
- ★ Lack of privacy because of constantly being scrutinised and assessed by professionals
- ★ Loss of freedom: being on call 24 hours a day
- ★ Loss of peace of mind as pain from other losses from the past seem to accumulate
- ★ Loss of personal identity: the focus is usually on the care recipient
- ★ Loss of financial security: arising from changed employment arrangements and the additional costs incurred by the needs of the care recipient
- ★ Loss of physical health arising from poor eating habits and lack of rest and recreation.

Chapter Two – Disenfranchised Grief

Disenfranchised grief is the ‘invisible’ or ‘unrecognised’ grief that you may be experiencing.^v “Disenfranchised grief is when a grief cannot be openly acknowledged, publicly mourned, or socially supported.” Along with all of the losses you are experiencing, there may be a sense of frustration or even anger that no one really understands what you are going through. To be honest, no one does know exactly what you are going through – but some do travel similar pathways. You are not entirely alone.

I looked after my husband for seven years. He had a stroke and then developed cancer. The family would come in and tell me what to do. The professionals would relate to him, and never ask me about him, even though I was with him 24 hours a day. People would come to my house and say, “How’s John?” No one ever asked about me. I felt like putting my hand up and saying “I’m here too, you know.”

Pat.



No one asked Pat what she was experiencing. No one seemed to recognise that she had lost many things in her own life, as a carer, while at the same time watching her husband lose mobility, independence and his usual personality. Pat's husband moved from being an easy going, independent man to a dependant, sometimes abusive demanding person. The loss was huge.

Perhaps you also experience the feeling that you have already 'lost' the person for whom you care. You are no longer able to 'just be' a sibling, spouse, lover or friend. You have taken on additional roles such as nurse, answerer of the telephone, domestic worker, chauffeur, exerciser, and so many more. [It can be hard to still feel 'romantic' about someone for whom you have almost taken on the parent or 'mothering' role.]

Some care recipients in our society do not receive the same amount of acknowledgement or sympathy as others. If the person you are caring for, for example, has HIV/AIDS or Hepatitis C, or a mental illness, then a feeling of social stigma may mean that you do not tell people of your added responsibilities for fear of their judgements. This will be adding to your loneliness, and sense of lack of recognition.

Chapter Three – Different Carers: Different Losses

There are many circumstances that bring specific losses for the carer.

Specific losses arise from:^{vi}

- ★ Illness or disability that may be chronic, progressive or cyclical
- ★ Changes in relationship with the care recipient
- ★ Different cultural and language groups
- ★ Geographical location
- ★ Indigenous carers

If we examine some specific situations we can see more readily how particular losses can arise in the life of a carer.

1. Illness or disability (chronic/permanent, progressive or cyclical)

If you are caring for someone who is affected chronically, then you will know the feelings of constant tension around the safety and well being of the person for whom you care. Various stages of the person's life will almost certainly raise different issues depending on such circumstances as:

- ★ Where your home is situated: in relation to professional and social support
- ★ Attitudes and responses of professionals to you and the care recipient
- ★ Availability of community resources to assist you
- ★ Degree of feelings of social isolation for both you and the rest of your family
- ★ Ready access to entertainment venues for you and the one you support

- ★ Demands of health care needs on your purse
- ★ Intrusion into private space by professionals leaving you with a feeling of no place which is really private
- ★ Questions as to what sort of accommodation is best for you and the person cared for. Eg community based hostel, nursing home.

As a carer you probably know the feeling of pain you feel on behalf of the person you care for, as well as your own frustration and fears that arise. This double burden is a difficult one to carry – you are bearing the multiple pain and losses arising from your caring.

My son, Gerard, has an acquired brain injury as a result of being hit by a car. He started seeing Gail who initially befriended him. The friendship blossomed into a relationship. Gerard was in love with her and elated. After some time she walked away because she did not want to be committed to someone with a disability. He felt angry, depressed and frustrated at the situation. So was I.

Nanette, mother of son who was injured in his early adolescence

If you are caring for someone who has an addiction or a psychological problem then you may also feel reluctant to talk about your feelings with others out of fear they will be judgemental, and move further away from you, just when you need someone to listen.

2. Changes in the relationship with the care recipient

Grieving sometimes creates feelings that are hard to admit – even to ourselves. Sometimes feelings of resentment, of anger, even wishes that ‘all this would stop’ by the death of the person, leave carers feeling not only exhausted but also guilty.

As a carer you have found yourself with this task (for it is an added task, not an automatic part of the relationship you had with the person previously) sometimes with no warning at all.

In other cases the realisation comes slowly. Sometimes the relationship you had with this particular person may have been difficult before this situation arose, and the difficulty may be enhanced when the relationship changes through the caring arrangement. Just being a carer in itself makes it normal to feel overwhelmed. You are dealing with a difficult task and need, and deserve, all the help you can get.

When I became a carer of my wife I had to take on a new life. There wasn't much support and I had to let go of most of our social life and interests. Our relationship together was totally different and I really lost a sense that she was my wife. I worried about whether she was OK and how I would cope. One of the hardest things to bear was her unpredictable behaviour and moods. She couldn't follow conversations. I found it hard to deal with her unreasonableness, stubbornness and aggression. She was never like that. Much of the time I felt exhausted. When Barbara died I felt great sadness. But I was relieved she was gone. It was too hard for her. I'm also glad I did care for her.

Bob, who cared for his wife with Alzheimer's disease

Each 'category' of carer experiences varying types of losses.

If you are partner or spouse of the care recipient you may be keenly aware of:

- ★ Loss of sexual partner, intimacy, companionship
- ★ Loss of economic security
- ★ Loss of normal role in relationship
- ★ Loss of freedom to socialise, or to even leave the house to shop
- ★ Loss of shared dreams

If you are a young carer, say 16-24 years, you may know of fears of:

- ★ Loss of study/job possibilities
- ★ Loss of peer friendships
- ★ Loss of freedom

If you are the adult daughter or son of the care recipient you may experience:

- ★ Loss of time with your own family
- ★ Loss of ability to plan to pursue your own interests
- ★ Loss of identity
- ★ Loss of parent-child relationship, that is, finding it reversed

If you are a child who is a carer you may realise that your needs are ignored. This can happen because it is rare for children to be recognised as carers. An example of this would be where a parent with a terminal illness, addiction, disability or mental illness who is not prepared, for many reasons, to acknowledge their limitations and the child does the caring before and after school. Many children whose brother or sister have an illness or disability are also put under strain to help with the caring, change their play, or take on an added responsibility.

3. Different cultural and language groups

If you are a carer from another country there will already be issues for you even before you became a carer. Your culture, religion, language, rituals and ethnic background may already mean that much of what is offered in Australia to carers does not exactly 'fit' your needs. Because English is not your first language you may even find this booklet difficult to read and understand. Resources are limited to assist you, and our community needs to acknowledge that and address it.

I'm from Chile. I have cared for my Dad and mother-in-law for the past 17 years. I'm up two or three times a night and feel as if I have no independence. I don't have any plans, because there seems no point, I have a dream of doing things for the kids, but never get the chance. It can be very hard when Dad or my mother-in-law need medical support, because in Chile it is seen as a luxury, or associated with death. It's taken its toll. I feel like a train has run over me. But you get used to it.

Hortensia

The losses experienced by a carer from a non-English speaking background can be made worse if:

- ★ Their personal history includes being a refugee and leaving behind everything that is familiar
- ★ If they or the care recipient have been a victim of torture and so they experience fear of doctors and nurses – professionals whose services are often utilised in the torture situation
- ★ Their cultural background means there is some stigma around certain illnesses or disabilities
- ★ There are pressures from their family to keep the care recipient at home regardless of the carer's needs

4. Geographical location

If you are a carer in the country or otherwise isolated area, you are very aware of the difficulties of long-distance travel to reach services. You also know of the added expense of long-distance phone calls. Petrol costs money, and you often don't have financial security or an adequate income.

There's a myth that country people will get in and help you. They don't know how to cope, either.

Ann, who lives in the country and is a mother of a child with disabilities.

Ann's comment may or may not be your experience. The fact is that it does represent a real feeling of isolation and a sense that many people do not know how to support those in need.

5. Indigenous carers

Australian white history, until fairly recently, did not acknowledge the huge injustices against the original owners of the land we all call home. Indigenous carers have personal histories of being taken from their traditional land, their families, forced to speak another language and separated from all that was their culture.

If you are such a person, with such a history, the person you care for probably shares your history. So many losses. So much pain. And in addition to that experience you now, however willingly you became a carer, need to gain appropriate resources, information and support. Access to such support can be difficult to gain, and our community needs to acknowledge the layers of issues you are trying to deal with. Do not hesitate to contact the places listed in this booklet.

Sometimes the past is just too hard to look at ... my feelings throughout life of hurt, pain and rejection began as far back as I can remember.^{vii}

Chapter Four - What Carers Say They Need

As a carer you probably know how hard it is when others don't understand how difficult it is for you. Many carers have spoken about their needs and raised these issues:-

1. Good clinical support for the carer and care recipient

Professionals, who will acknowledge the significance of your expertise in knowing the person you care for, are crucial. You deserve to be heard and not overlooked. If you are not satisfied with their response look for another professional who will listen to your needs.

2. Community acknowledgement of the carer's work (in practical ways) Your local council, shopping centres, cinemas, local community, need to know if you are having difficulty with access. Ask whether entertainment venues are using carer and or companion cards for concession or for free entry for carers. Ask for professionals to back up your claims for access.

3. Information about standing up for themselves – sometimes called 'self advocacy' Find out the chain of command in organisations and always be ready to go higher if you are not happy with a response. Keep in mind the possibility of appealing to local senior council staff, counsellors/politicians, media and if these fail you can think about making a more formal complaint.

4. A sympathetic and helpful attitude as well as practical support Carers know the importance of the professional who relates to them as unique people and treats them personally. What is needed is professional warmth, respect and empathy. If people are judgemental, or hostile, then change professionals and be prepared to stand up for yourself.

When asking for support make sure you acknowledge how important it is to you, with all of the stresses you experience, to be received with a friendly and helpful manner.

5. Good and honest communication with professionals and others involved in the care situation A good professional will be open to you. You can be honest with them about your needs and feelings, eg your need to be heard, or recognised or your desire for personal space, or to be able to speak.

Family members, and friends, too, need to be open to how you are feeling about your situation. Being a carer does not mean you should be expected to be a ‘martyr’ and deal with it on your own.

6. An acknowledgement that your home has become a ‘public space’, because of those who visit the care recipient You are certainly entitled to feel frustration at losing your privacy. You may experience mixed feelings about this because you actually welcome the support that is offered by those who come to your home, but it can still feel as if there is no escape for you. It is at times like this that some form of respite care for you or for the care recipient can assist you in dealing with your sense of personal ‘invasion’.

These thoughts may be very obvious to you. However, it is important to state them, and to acknowledge that if any or all of those areas of concerns are addressed, then many of the losses, which are associated with being a carer, like you can be lessened.

Chapter Five – Caring for Yourself

Sometimes you may find yourself thinking that your caring work is your whole life, and your whole life is your caring work. Perhaps that is a good time to remind yourself that you also need to be cared for. Your whole life can be affected by your caring role, and perhaps the following list may be a reminder of some of the things worth considering. You will find a helpful list of people, places and contact numbers at the back of this booklet.

1. Information - Contact places like Carers Victoria, your local council, charitable organisations, the professional workers who assist you, and other carers. Find out what, and who, is available to support you. For instance there are specific groups such as the Alzheimer's Association.

2. Support groups - Sometimes meeting with others who have a similar role as yourself can be very helpful. Find out where these are when you are collecting information, and consider going along.

3. Listening voice - If you don't have anyone among friends and family who can listen to you in the way you want, don't hold in your feelings. That is bad for you. Ring somewhere like the CareLine or Lifeline or Care Ring. There you will find someone who will listen and not be judgemental. If you like, you don't even have to tell them your name. It will be private and confidential.

4. Assertiveness - Ask questions, say how you feel, tell people you need some support. No matter how much you love the person you care for, you have needs too. Search for someone who will assist you in some way.

5. 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.

6. 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 what you need for support. Look in the back of this booklet for some places to ring to arrange to see someone. Also some Community Health Centres offer free counselling.

7. Companionship - You need talk, fun and laughter. Try to have contact with other people to bring some of the good things into your life.

8. 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 the 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.

9. 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 that the people and places listed in this booklet (and many more!) are there to help you.

Chapter Six – Facing Difficult Times

Residential Care

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 the nursing home permanently.

‘More than a pat on the back’ – video

It is usually a turbulent time deciding on residential care. 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.

These and many more questions and thoughts may make the decision more difficult for you. They are normal feelings and it is good to discuss them, instead of them going around in your own head day and night.

When the person you are caring for is dying

This is a hard time with many emotions surfacing. If you are caring for the person at home it is very demanding. There is a huge amount to do and extra visitors, as well as dealing with your feelings. You may feel great sadness, relief that your work will come to an end, or guilt. You will have many feelings mixed together. This is normal. Seek out your own support.

There can be a lot of extra work too, such as:

- ★ Extra phone calls, extra house calls from friends and professionals
- ★ Extra washing and cleaning
- ★ Dealing with other people's advice as to what you 'should' be doing
- ★ Trying to support others who are also grieving
- ★ Coping with the feelings of the person you are caring for about their death
- ★ Coping with your own feelings about death: the care recipient's and also your own.

This time can be frightening as well as demanding. You may wish that the death would come quickly. However when the death does come there may be many different emotions you feel. This is normal and experienced by people who take on the work that you have.

When death finally comes

When the person you have been caring for dies, there are still many things to be done and arrangements to be made. Hopefully you know already that you will not have to deal with these alone. Even if you do not have any family or friends to give help, there are many places where you will find people and information about funerals and all the necessary paper work.

You may be asking yourself questions such as:

- ★ How do I arrange a funeral?
- ★ What will it cost, and can I receive financial assistance?
- ★ What do I do about any legal matters like the Will?
- ★ I feel unable to make decisions, who can I talk to?

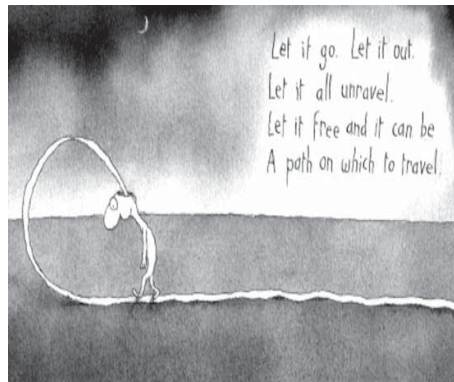
Your personal background will mean that you have your own questions. Perhaps you come from a religious background and you will receive support and information from your religious leader (priest, pastor, rabbi or sheikh for example).

If your particular ethnic or cultural background has particular ways of recognising death, then you will need to tell the doctor and funeral directors of those needs so they can be respected.

If you do not have a particular religious background, then the funeral company can assist you with any of your questions about who will conduct the funeral, where it can be held, etc. You may need to think about what you would like to have at the funeral eg speakers, music, readings. Most things are possible.

We live in a multi-cultural society in Australia, and are coming to realise more and more the importance of the different ways and rituals through which we recognise significant times in our life journey.

There are many questions, many needs at such a time. You can receive help from many people and places. Just remember to ask.



Chapter Seven - The Future

"I felt a tremendous sense of uselessness and emptiness after she died. I didn't know what to do with myself and I felt very lonely. I spent time crying and crying. Very slowly I started to look after myself and get out. But it took a long time to adjust to life without her."

*Melba, adult daughter of
mother with Alzheimer's disease*

Many people ask if there is an end to the intense grief that comes after death? In caring for someone you have already experienced grief. Grief has its own time of being completed and there are no rules as to when it is finished. You may hold a small amount of grief for the person who has died all your life. With time you will feel a sense of acceptance and that life can be good again and there can be new joys and new challenges.

Caring is hard work, and so is the grief that comes with it. We wish it wouldn't happen, but it does. Caring turns your whole life around, and so can grief.

Good and bad days come and go. You will experience the grief in your own way. There is no 'right' or 'wrong' way. It is a normal experience. If after a while you feel that you do not have the energy to do the things you'd really like to do, then this may be a sign that you need to talk with someone who is a counsellor or support person in the area of grief and loss. Contact can be made with such women and men through the National Association for Loss and Grief in your State or Territory (details in back of book.)

You will need to remind yourself that you did the best you could in the circumstances. Try not to be self-critical.

Even though it was hard, I am glad I did it, and I would do it all over again.

*Pat, who had looked
after her husband with lymphoma*

Carers need to acknowledge to themselves that caring for another person is an act of giving, of loving, that is very powerful, a candle of light in a harsh world.

You deserve all the support you can get ... so consider contacting people or organisations listed in this booklet.

You may find some interesting thoughts in the books recommended. Each loss has its own issues. There will be issues that this small booklet has not been able to cover. If that is so, do not feel disheartened. Information on other resources is readily available through Carers Victoria and the other organisations mentioned here.



Notes

- i Headaches, respiratory problems, digestion problems, and even in extreme cases strokes and heart-attacks have been documented as results of unexpressed grief and stress.
- ii There is no 'right' or 'wrong' way to grieve. The theories that have been developed have their value in offering guidelines as to what may be experienced.
- iii Clinical depression can often be overlooked as being just 'feeling down or stressed' during the time of caring with someone with high needs. Regular check-ups with a good general practitioner will help you in watching your own general health situation.
- iv Having feelings that are angry, even violent, in their nature is understandable when you are tired and stressed. However, these feelings are signals to you to seek assistance with the situation with which you are coping. Seek help immediately, and both you and the person you care for will benefit.
- v Ref *Disenfranchised Grief, Recognising Hidden Sorrow* Lexington Books New York (1989) K.Doka.
- vi An adaptation of Chapter 2 of *An Unrecognised Grief*, CAV, Melbourne, 1999
- vi 'Bringing Them Home' the report from the National Enquiry into Separation of Aboriginal and Torres Strait Islander Children and their Families. April 1997.
- vii Action Pack, CVic
- viii AFDA 700 High Street, Kew East, phone (03) 9859 9571 for information and advice

References:

- ★ Unrecognised Grief - Carers Victoria - 1999
- ★ Caring enough to be poor - Carers Association Australia - 1997

Recommended books for further reading:

- ★ Good grief: experiencing loss, Carol Lee. (London: Fourth Estate, 1994)
- ★ Living with loss and grief, Geoffrey Glasscock; Megan Gressor (Woollahra: Gore and Osment, 1992)
- ★ When the person you care for has died, Annie Jackson (London: Carers National Association, 1997)
- ★ Grief and Loss: the pain of caring, Iris Kotoukis (Melbourne: Carers Victoria 1995)
- ★ An Unrecognised Grief: loss and grief issues for carers, Maggie O'Shea (Melbourne: Carers Victoria, 1999)
- ★ A Grief Observed, C.S.Lewis (London: Faber and Faber, 1966)
- ★ Write through loss and grief: a guide to recovery through writing, Evie Hodge (Bairnsdale, Victoria: BW Publications, 1998)

Referral Information

Commonwealth Carer Resource Centre

Freecall 1800 242 636. Business hours, Monday - Friday
Free information, support and referral to appropriate services in your state.

National Carer Counselling Program

Freecall 1800 242 636. Business hours, Monday - Friday
Free or low-cost counselling, in person or by telephone. This service provides specialised counselling with a carer focus.

Carers Victoria

(03) 9396 9500. Business hours, Monday - Friday
Carers Victoria provides free workshops for carers throughout Victoria. Topics include: Loss and Grief, Looking After Yourself and Creative Survival Strategies for Carers.

