

Sudden loss & the grief that follows

Information and support for families after a workplace death



icare would like to thank the many families who have shared their stories of losing a loved one. We have learned so much from you.

Thank you to Karen and Rod for their open letters about their experiences of loss and grief, and the years that follow. It is hoped that their courage might give you comfort when it is most needed.

Acknowledgement

Thank you to SafeWork NSW and the Australian Government Department of Health for providing information about supporting bereaved families.

Disclaimer

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This pack provides contact information for various external organisations and bodies. Please note that icare does not warrant or represent that information or advice provided by these organisations or bodies is correct or suitable for any particular purpose, or free from any bias.

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Foreword

Our thoughts are with you at this difficult time. I would like to express my sincere condolences to you and your family.

All of us deal with grief in different ways. We have gathered this information for you in the hope that it can provide you with relevant advice and assistance to help you navigate this difficult time. This pack contains insights into other people's experience of loss and grieving and where you can get support. This may be useful to you, your family and friends now and in the months to come. We have also collected some stories from people who were willing to share them with you, as they grieve for someone they lost.

We hope that you find this information helpful. More importantly we will do our best to help where and when we can – please just ask.

John Nagle, CEO



When someone you love passes away, the loss you feel is overwhelming, and for a time, you may feel that nothing will ever be right again. It can be hard/overwhelming to know what to do, and where to get help.

This pack has been developed to provide you with information about services within the community which may be helpful over the coming months. Two families who have experienced the loss of a loved one from a work-related dust disease have generously shared their stories with you.

The accompanying book 'Coping with Grief' offers insights about the different ways people respond to loss, and it provides practical advice about how you can help yourself, and support others affected by grief. We hope that it helps you through this difficult time.

Our thoughts are with you and those affected by the loss of your loved one

"Grief is not a disorder, a disease or sign of weakness. It is an emotional, physical and spiritual necessity, the price you pay for love. The only cure for grief is to grieve."

Earl Grollman



Grief: everyone's way is different (and that's ok)

Grief is a very personal journey, and your own experience and expression of grief will be different from anyone else's. You may seek company or need solitude in your sadness; you might express your feelings openly with others, or reflect on your feelings privately. You may do all of these things at different times as your needs change, and that's okay.

There is no right or wrong way to grieve, but there are emotional reactions which are common to most people when somebody dies. You may experience some or all of these feelings with varying intensity, in no particular order, and some feelings may return again and again, and for a time, feel overwhelming.

It might be helpful for you to recognise these to know that you are not going mad; you're grieving.

Shock

The loss of someone close to you is a tremendous shock. You may experience shock for days, weeks or, for some, months after the death.

Feeling numb

You may experience a period of feeling 'numb'; like living in a fog, you may think, "this can't really be happening", and that you will wake up from it. This numbness is our mind's way of protecting us for a short time from the loss. This is why some people are able to participate in the practical arrangements after the death, or may not cry at the funeral. However, once the shock wears off, the loss becomes real and the emotional pain emerges.

Disbelief & searching

It's natural to have difficulty believing what has happened is real; on one level you know that your loved one has died, but on another level it's impossible to accept. Moving between denial and realisation is a natural part of mourning and coming to terms with your loss. You may also find yourself unconsciously searching for your loved one – talking to their photographs, looking for them on the street and waiting for them to walk through the door. Confusion, panic and fear are common during this time.

Physical & emotional stress

Grief may be felt both physically and mentally. You may feel restless and exhausted at the same time, you may have disturbed dreams and find it difficult to concentrate or remember things. This intense emotional pain may feel like physical pain and you may experience dizziness, palpitations, shakiness, headaches, nausea and changes in appetite (under- or over-eating).

Anger

Feeling angry is a natural response to loss; intense feelings of rage often reflect a sense of helplessness at not being about to change what has happened. Anger may be directed at friends and others for carrying on with their lives as if nothing has happened. You may even feel anger towards the person who died. Anger is often felt most intensely shortly after the death but lessens over time.

Despair

Feelings of despair are common once you fully realise that your loved one is not coming back. Relationships with others are often affected because you feel drained and numb. You may feel that there is no purpose and feelings of suicide are not uncommon.

Fear

A significant loss can trigger different worries and fears. You may panic that this could happen to someone else in your family and become overly protective of them. You may also worry about the responsibilities you now face.

Grief & depression

Deep sadness and despair can feel a lot like depression, and people who have experienced a deep loss can be prone to depression for some years following the death. If your grief leads to a lasting depression however, additional help may be appropriate (you can find out more on page 23).

Some things you can do for yourself

- Spend time with people who know what you're going through and who allow you be open about your feelings.
- Find a space where you can be alone when you need to.
- If it's right for you, let others know that it's ok to say your loved one's name, to talk about them, to remember and share stories about them.
- Ask for help and let people help you. Others feel helpless by a death too – helping you lets them show that they care. Practical tasks such as cooking, picking up/dropping off kids, grocery shopping and lawn mowing are some examples.
- Cry when you need to. Crying releases endorphins which reduces stress and produces a calming effect.
- Little things might upset you that normally wouldn't.
 It's ok grief presents in many small ways
- Be patient with yourself and others you will have good days and bad days.
- Talk with others who have lost a loved one it may help you feel less alone. The contacts page has some counselling and support service contacts that may assist (see page 24).
- Try not to make any major decisions in the months that follow, such as moving house or changing routines; familiarity can be helpful during this time.
- Remind yourself that there is no time limit on grieving, and there is no 'right' way to grieve. Your way of grieving is the right way for you.

What others have shared

It can be helpful to know how others who have been through a loss have reacted, and to remember that there is no right or wrong way to respond to the loss of a loved one. Some families have said:

> "When a loved one passes away, it is not about just moving on and trying to forget, it is about letting yourself move forward."

"It is okay to still talk about your loved one or be reminded of them by things everyday." "Anniversaries are still big matters and they don't stop being important, however the meaning can change. Maybe it is no longer a sad reminder, instead it is a positive reminder to keep moving forward."

"Embrace finding what keeps you going, it is different for everyone but there will be something."

> "I still sign Christmas cards from my husband and I. After so many years of writing cards from both of us, it doesn't feel right to just put my name."

"For a long time I set his place at the dinner table. Nobody ever said anything about it; I don't do it anymore but it helped at the start."

"It's not always about putting on a brave face, it's about being comfortable to still have ups and downs, even years after the passing of a loved one."

"Give yourself the permission to move forward to laugh again, reminisce and cry."

A letter from...

You cannot describe to someone who hasn't been through it what it's like caring for someone who is terminal. It's not a journey that I would wish upon anyone but sadly it's affecting a lot of families.

My name is Karen, and I lost my husband Bernie to mesothelioma in November 2007.

Bernie was diagnosed with asbestosis early 1999. From that time on, our lives were forever changed. By February 2000, Bernie could no longer continue to work and in August 2007 he was diagnosed with mesothelioma. It was a very challenging journey for the both of us and it is distressing to see your loved one in such a bad condition. During my husband's last few weeks while he was in hospital, I was only getting one hour of sleep each day because I needed to be by his side.

After Bernie passed away, I felt a rollercoaster of emotions and each day was about putting one foot in front of the other. The feeling of loneliness was intense for me, even though I had a lot of people around me and I was trying to keep busy and it still felt like there was huge part of me missing. I also felt a sense of freedom and having time back to myself again. When Bernie was sick, I would hardly leave the house and if I did, I felt like I was always rushing to get home to be with him.



I feel that I'll never truly stop missing Bernie. Even after many years, it was not about moving on, it was about giving myself the permission to move forward with my life. For me, I channelled my emotions into a different mindset that let me just appreciate and celebrate the time that Bernie and I did have together. It was important for me to speak with other people who had lost a loved one to a dust disease and share our experiences. Being able to support others has helped to give me a purpose again. I've also taken up power walking and running, and I really enjoy getting outside and training.

There isn't a day that doesn't go by where I don't think or talk about Bernie and that is okay for me. I used think of the bad things, but now I just think of the good things and that is what keeps me going.

Karen

How men, women and children may grieve differently

Both social conditioning and biology influence the way we grieve. For many men, showing feelings may feel like a sign of weakness. Grieving men will often want to do things; sort out practical problems; take on physical tasks; actively seek answers. Providing practical support can provide men with the space to process their feelings, but it may appear to others like they are withdrawing or are in denial.

Women may be more likely to openly express their feelings and seek support from friends and family. Sharing their grief and talking about their loved one helps to make sense of their loss.

While these are very broad generalisations and do not reflect everyone's experience, it recognises that men often seek to distance themselves, where women seek closeness and support, which can put a significant strain on relationships. Grieving differently does not mean that one person loved the deceased more than the other; only that their expression of loss is different.

Some of you may have children or grandchildren who are grieving the loss of your loved one. It's normal to want to protect children from pain and grief, but it is important for children to learn that it's OK to talk about feelings of loss and sadness. Children experience the same feelings as adults, but might express them differently. They may even appear to be unaffected by the death, but this does not mean they are not grieving. If the child is still in school, advise the school of the death; talk with the teacher and the school counsellor about support. The behaviours below reflect some of the ways that children express grief. While these are normal reactions, if the behaviours continue, it may be helpful to seek professional advice.

Young children and grief (1–6 years)

Behaviours may include:

- Being 'clingy' and easily upset
- Playing out the loss with toys
- Anger towards friends, parents, toys
- Copying behaviours of the deceased
- Acting like a younger child or behaving more like an adult
- Not wanting to go to school, problems with school and school work
- Changed eating behaviours
- Disturbed sleep
- Physical symptoms such as stomach pains and headaches
- Asking the same questions repeatedly about the death or the absence of the loved one

Some things you can do to help your children with their grief include:

- Advise the school of the death; talk with the teacher and the school counsellor about support
- Practice with your child what they can say to people who might ask about what happened
- Maintain routines such as meal and bed times, after school activities and play time with friends. This provides a sense of consistency and security
- Include children in planning around special days such as birthdays or special occasions; they may want to make a card, write a letter or draw pictures for the person who has died
- Let them see your grief; it will help them to express their own grief in their own way

Older children and grief (6–12 years)

Children grieve differently at different ages. Some of the grief reactions that older children may experience include:

- Feeling guilty; that they may have done or said something that caused the death
- Creating stories to fill in gaps in understanding
- Being overly protective of self and others
- Anxiousness about being separated from family
- Attempting to 'parent' the parent and other family members
- Withdrawal and isolation including avoiding school and social activity
- Seeming 'spaced out', including difficulty concentrating at school
- Aggressive behaviour, emotional outbursts
- Regression (behaving like a younger child)
- Disturbed sleep and lethargy

Pre-adolescent, adolescents and grief (12–18 years)

Young adults may experience the same responses of younger children as well as:

- Depressed mood
- Rebellious behaviour including reckless risk-taking
- Excessive focus on physical or other activity
- Focus on revenge and punishment towards those who are perceived to have caused the incident, which may include the deceased

Everyone responds to grief differently, and these are just some of the behaviours that are described by families. If you are worried about changes in your child's or grandchild's behaviour, talk with your doctor or counsellor.

Some days are more difficult than others

Special dates, places, things

Significant dates such as birthdays, Christmas, Father's or Mother's Day and anniversaries, including the date that your loved one passed away can be very difficult. The 'first' of each of those events following the death can be especially painful and it may be helpful to plan ahead with your family or close friends about what to do. You may choose to celebrate or recognise the event in memory of your loved one, or you may choose to keep busy with activities until the day passes. There is no right or wrong way, and how you get through these days will change over time.

Why it can feel worse a few months after the death

After the funeral, there may have been a lot of visitors, calls and support, but after some weeks, people return to their lives and the activity dwindles. It is about this time, too, that the shock begins to wear off and the loss becomes painfully real. The intense feelings of loss may feel overwhelming and relentless. This is a normal grief response, and while it may seem impossible, the intensity of these feelings will lessen over time. Talk with caring friends or health professionals who can support you through this.

How long will I feel like this?

There is no timeline for grief and it may feel like it will never be ok again. These feelings are especially strong for the first 12 to 18 months. Many families describe a change in the intensity of their grief after about two years, and while the loss is still deeply felt, they have begun to learn how to accommodate their feelings into their lives, and are less often overcome by it. Over time, a new 'normal' emerges, one which provides space for your loss, alongside the necessary day to day tasks and routines.

> "The reality is you will grieve forever. You will not 'get over' the loss of a loved one; you will learn to live with it. You will heal and you will rebuild yourself around the loss you have suffered. You will be whole again, but you will never be the same again. Nor should you be the same nor should you want to."

Elizabeth Kubler-Ross



Getting help: when and where

It can be difficult to know when to get help in coming to terms with the death of your loved one. Some people will find that the support of family, friends, workmates and community is enough. For others though, when grief feels relentlessly overwhelming, getting professional help might be appropriate.

Talk with your doctor if you:

- Continue to feel numb and empty some months after the death
- Feel constantly overwhelmed by feelings brought about by the death guilt, anger, fear, abandonment
- Are not coping with the physical exhaustion, confusion, anxiety, panic or chronic tension that often accompanies grieving
- Work or exercise excessively to avoid thinking about your loss
- Feel like you have no-one to share your grief with
- Are drinking to excess or using drugs to cope
- Are thinking about suicide

Below are some options for accessing support for you and your family; you may have other supports within the community, such as a faith organisation or an interest group that you belong to.

Counselling and support

BEYONDBLUE

Information and support about mental health Grief and loss information: www.beyondblue.org.au/the-facts/grief-and-loss Phone: 1300 224 636 Hours: 24 hours | 7 days Online (via website): 3pm –12am Suicide call back service: 1300 659 467 **www.beyondblue.org.au**

GRIEFLINE FAMILY & COMMUNITY SERVICES

A dedicated loss and grief telephone counselling service for individuals, families and community groups.

Phone: (03) 9935 7400 or 1300 845 745 (National – Landline only) Hours: Midday to 3am | 7 days https://griefline.org.au

HEADSPACE

Free online and telephone support for people between 12 and 25 years. Phone: 1800 650 890 www.headspace.org.au







KIDS HELP LINE

Phone, WebChat and email counselling for kids or teens. Phone: 1800 55 1800

LIFELINE

24 hour crisis support and telephone counselling. Phone: 13 11 14 Hours: 24 hours | 7 days

www.lifeline.org.au

MENSLINE

Telephone and online counselling support for men. Phone: 1300 78 99 78 Hours: 24 hours | 7 days

www.mensline.org.au

NALAG (National Association for Loss & Grief) Telephone and face-to-face grief and loss support. Phone: (02) 9489 6644

www.nalag.org.au









THE BEREAVEMENT CARE CENTRE

Counselling for adults and children experiencing grief. Phone: 1300 654 556 www.bereavementcare.com.au

THE COMPASSIONATE FRIENDS NSW

A self-help organisation offering support to bereaved parents, siblings and grandparents after the death of a child (of any age). Group meetings (30 locations in NSW), peer support, telephone support, online information and resources. Phone: (02) 9290 2355 Toll free: 1800 671 621

www.thecompassionatefriendsnsw.org.au

Support groups enable people who have been affected by loss to come together to share support and companionship. They can provide understanding and coping strategies and it may help you to feel less isolated by your experience of loss.





Public and Legal Support

THE LAW SOCIETY OF NSW

Referral service to help to find a solicitor in your area (go to 'For the Community' section). Phone: (02) 9926 0300 or 1800 422 713 Hours: 9am-5pm | Mon-Fri **www.lawsociety.com.au**

SENIORS RIGHTS CENTRE

A community legal centre that protects the rights of older people, provides telephone advice, legal advice and educational services. Phone: 1800 424 079 Hours: 9am-5pm www.seniorsrightsservice.org.au LEGAL AID NSW

LEGAL AID NSW

Legal aid and advice. Phone: 1300 888 529

www.legalaid.nsw.gov.au

SERVICE NSW

For the registration and certification of deaths in NSW Phone: 13 77 88

www.service.nsw.gov.au

CENTRELINK

Provides assistance with age pension payments and other entitlements.

Their website includes useful information on what to do following the death of a loved one.

Phone: 13 77 88

www.humanservices.gov.au/customer/dhs/centrelink or www.humanservices.gov.au/customer/subjects/what-dofollowing-death

AUSTRALIAN FUNERAL DIRECTORS ASSOCIATION

To find a funeral director near you. Phone: 1800 613 913 www.fdansw.com.au

Support organisations

icare Dust Diseases Care is committed to assisting, and working with, a number of support organisations to provide you with the choice and information to access support groups, helplines and forums as you need them.

ASBESTOS DISEASES FOUNDATION OF AUSTRALIA (ADFA)

Phone: Toll free 1800 006 196 or (02) 9637 8759

adfa.org.au

Email: info@adfa.org.au

ASBESTOS DISEASES RESEARCH INSTITUTE (ADRI)

Phone: (02) 9767 9800 (Monday to Friday 9am-3pm)

www.adri.org.au

Email: info@adri.org.au

BERNIE BANTON FOUNDATION (BBF)

Phone: 1800 031 731; 0418 319 757 (within Australia) +61 418 319 757 (calling internationally)

www.berniebanton.com.au

Email angels@berniebanton.com.au

A letter from...

My name is Rod and I lost my wife Julie to mesothelioma in September 2011.

Julie was my life partner, and after 23 years together, her diagnosis of mesothelioma in July 2008 was devastating and our whole world changed.

I still remember exactly the time and where the phone rang when we were given Julie's diagnosis – we were told Julie had advanced terminal cancer and would live for a short time.

I called my best mate to tell him of Julie's diagnosis. It was during that phone call I accepted the gravity of diagnosis and started grieving.

After Julie had a major operation I had to move into another bedroom. It felt as though I had lost a party of my identity. I went from being a husband, partner, best friend and lover, to being a carer.

In the last six months of her life I looked after Julie at home 24 hours a day, seven days per week. Often I would not leave the confines of the house for weeks at a time. The feeling of loneliness was ever present.

When Julie passed away, I actually felt an immense sense of relief, as I knew her suffering had ended. I also had an enormous sense of guilt, as I personally felt a sense of freedom and for the first time in three years, a sense of control. To go from not having a moment of free time to myself, to being able to spend an hour drinking a cup of coffee, if I wanted, was strangely liberating. Over the years since, I have come to realise I am not alone in feelings of relief, or guilt.



Straight away I wanted to get rid of everything out of the house that reminded me of Julie's illness. Things like the hospital type air mattress and its pump. I had lived the mesothelioma journey for three years – I didn't want to live with physical reminders of it for a second longer than I had to. I wanted the house to be a home again, to be a peaceful place I could sit and remember Julie and our life before mesothelioma took control of it.

I still have fragile moments, after all, I am not a robot. And foremost, I am a man who has lost the love of his life, his best friend and life partner. I am a widower who will never replace his loved one, the time and future lost.

I am fortunate, I have no regrets regarding our journey, and importantly for me, I harbour no bitterness. I choose instead to focus my energy on helping others, who are sharing a similar path to the one I tread, to live life with no regrets, and for those who have lost, to move forward in life

Rod



There are a number of people and organisations you may need to notify about the death. It can be distressing to receive letters with your loved one's name on them, such as rates notices, membership renewals and appointment reminders.

Following is a list of some of the organisations that you might wish to notify. You may choose to contact the organisations yourself, or ask a friend to make contact on your behalf (note that some organisations might request confirmation of the death in writing).

Organisation	Phone number or email address	Date Notified
Accountant		
Australian Electoral Commission	13 23 26	
Australian Tax Office	13 28 61	
Bank/mortgage broker/ other financial		
Centrelink	13 23 00	
Child Support Agency	13 12 72	
Club/sporting association		
Dentist		
Doctor/other health providers		
Executor of Will		
Insurance companies (home/car/other)		
Medicare	13 20 11	
Optometrist		
Private health fund		
Property manager/landlord		
Schools		
Subscriptions (magazines etc)		
Solicitor		
Superannuation fund		
Vehicle registration/ licencing authority		
Utilities (gas/electricity/water)		
Phone service provider (home/mobile/computer)		
Others:		

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