

End of Life Care & Bereavement Guide



*“More than a
hospital”*



Rochester & Elmore
District Health Service

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Caring For Your Loved One

Caring for your loved one in their final months, weeks or days may be a new experience for you.

This booklet was put together in partnership with Rochester and Elmore District Health Service to try and prepare you for the rewarding but challenging role of the carer. Hopefully, by being prepared and more informed, you and your family may feel less anxious and overwhelmed about caring for your loved one.



Looking After Yourself

Sometimes your loved one may become irritable and frustrated due to being sick and slowly losing functioning and independence. Try not to take this personally as they don't mean to take out their frustrations on you.

It is important to accept offers of help from family and friends as their support can make a big difference in your ability to cope. You may initially find it difficult to say yes to offers of assistance but it will not only help you but it gives others the opportunity to feel helpful.

It is good to talk to someone you trust about how you are feeling. Caring for someone who is dying can be overwhelming. Speak to your doctor if you are starting to feel particularly low or having trouble sleeping. Also let the care team know how you are feeling and they can offer advice as well. You might like to attend a support group, as it can be helpful to speak to others who are in the same situation as you.

Rochester and Elmore District Health Service have social work and counselling services available. Ask one of your care team to connect you to the service or call 5484 4465.

It is a good idea to rest when your loved one rests. Carers often don't get the sleep they need at night, because they are always listening in case their loved one needs something. Speak to the care team if you would like some respite, which can occur either in the home or outside the home.

Advance Care Planning

Advance care planning is a process of planning for future health and personal care needs whereby the person's values, beliefs and preferences guide decision-making when that person cannot make or communicate his or her decisions for themselves.

Having an *Advance Care Plan* can help families, carers and your healthcare team understand and respect your wishes for end of life care with dignity. You can also document your views regarding unacceptable outcomes. Often families are unaware of their loved one's views about what they would want done when too ill to speak for themselves. Families can feel burdened by the concern that they will make a wrong choice. Rochester and Elmore District Health Service have trained staff to assist with the development of an *Advance Care Plan*.

The Dying Process

Many different changes can occur when someone is moving through the final stages of living. Dying affects the whole person; physically, mentally, emotionally and spiritually. These effects will vary as each person is unique. However, there are some general changes that often take place:

Withdrawing: your loved one may start to withdraw from the world and become more preoccupied with their own thoughts. They may also start to withdraw from their loved ones, which can be upsetting, but it is a natural part of the process of leaving this world.

Overwhelmed by groups: visitor numbers may need to be monitored to allow your loved one to rest. Patients often become overwhelmed by larger numbers of people. Although, in some cultures, large numbers of visitors can be the norm. It can be useful to put a sign on the door saying 'we are resting now, thank you for calling in, and please leave us a message on the notepad beside the door'. It can also be good to utilise an answering machine, so that you and your loved one can get adequate rest.

Fatigue: everyday tasks take more time, both emotionally and physically to achieve. Carers may need extra patience, to allow their loved one to undertake tasks at their

own pace. You may need to manage the energy they do have and think about what activities and invitations should be declined. They might like you to read to them, when reading themselves becomes too tiring.

Anxiety and agitation: there are a number of reasons why your loved one may start to show signs of agitation or anxiety. You may be able to have a conversation with your loved one about what is concerning them. Some people can become confused and disorientated. The palliative care team will be able to assist with dealing with this issue.

Sleepiness: as the body's functions start to deteriorate, your loved one will wish to spend more and more time dozing or sleeping. Just talking and spending time with others will become exhausting. It is important that your loved one sleeps when they wish to as they feel extremely tired.

Eating and drinking: do not worry when your loved one wants to eat and drink less over time. Their body is slowly shutting down and they no longer require so much nutrition. The body is no longer able to effectively digest food as well as it did and therefore they do not feel as hungry. As carers we can often find it difficult to let go of the task of feeding our loved one. You can offer small sips and small snacks, depending on what your loved one feels like eating. Cracked lips can be soothed with lip balm and things like ice chips and icy poles.



The Final Days and Hours

Skin colour changes: as the body's circulation starts to slow down, the face, hands and feet become cooler and sometimes more sensitive when touched. They may start to feel cool and take on a bluish tinge. The person's back may look mottled as blood moves away from non-vital areas. Temperature may fluctuate between being too cold and too hot.

Incontinence: some people who are dying lose control of their bladder and bowel because their muscles are no longer able to function normally. The palliative care team will be able to manage this issue with advice, aids and personal products.

Breathing patterns: breathing patterns change as death approaches. Breathing may become rapid at times or irregular with pauses between breaths. These pauses grow in length, until the final breath is taken. There may be moaning

noises or wet breathing noises which can be upsetting for the family but it does not cause distress to the person dying.

Consciousness: your loved one may start to drift in and out of consciousness and gradually they will be unable to respond. Your loved one may be able to still hear what is being said to them, so your words of comfort and reassurance will be important at this time. If your loved one is showing signs of pain or agitation, this can be effectively dealt with by the administration of medications. Speak to the nursing staff, district nurses or the palliative care team if you have any concerns at all in this area. If needed, palliative care staff will provide you with clear instructions on how to give your loved one medication, to ensure they are comfortable.

Eventually, your loved one will stop breathing altogether. There may be a few muscle twitches but that will cease and their face will relax. In a small number of cases the body may expel fluids from the rectum, bladder or mouth. It can be a good idea to have some dark towels close by.

"I was honoured to be appointed as executor of my mum's estate, but I did not know what was involved or where to start."

For a free copy of our executor checklist which sets out your duties as an executor, go to:

www.statetrustees.com.au/executor-checklist

While being the appointed executor of someone's will can feel like an honour, it can also be a huge responsibility - one that often comes at a time when you are grieving a personal loss. The prospect of carrying out your executor duties including applying for a grant of representation, preparing a tax return and resolving family conflict may also be overwhelming at an already difficult time.

The right help and advice can make all the difference.

Talk to us

If you have any questions, please call us on 03 9667 6444 or 1300 138 672 from outside Melbourne.





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When Your Loved One Dies at Home

You will need to contact your preferred funeral director, but there is no hurry to have your loved one's body removed from the home. If the weather is warm, keep the room as cool as possible. The muscles will not start to stiffen straight away and some families like to use this time to bathe and dress their loved one and arrange them in a straighter position. If you do not wish to do this, that is fine; the funeral director can do this later.

Family, friends and children may wish to spend some time with their loved one. They may wish to talk to them, stroke their hand or simply just be with them for a while.

When your loved one dies, the doctor must sign a certificate (Doctor's

Certificate of Cause of Death) which confirms the death.

It is best to speak to your doctor prior to your loved one's death and confirm that they are available to do this. The doctor can do this at home or the funeral home. The funeral director will pick up your loved one from the place of death, whether that is at home, hospital or residential aged care facility. Because your loved ones' death was expected, you do not need to phone an ambulance or the police.

Funeral directors can come to your home, if you wish, to discuss your loved ones wishes in regards to their funeral. The funeral director will collect all of the information needed for registering the death and send it to the relevant authority. They will also ask you to pick out some clothes for your loved one to be buried or cremated in.



Information Required by Funeral Homes

- The full name and time of death (including maiden name and any other names)
- Loved one's date of birth and place of birth
- Religion (if any)
- Last address
- Occupation
- Date of marriage(s)
- Surviving spouse information (name, date of birth)
- Benefits the person was receiving
- Does your loved one have a pace maker (funeral home will need to remove it for cremation)

Burial or Cremation

People have a choice of either cremation or burial and also place of burial. Ultimately, this decision is a matter of personal choice. It can be a good idea to have a conversation with your loved one, when they still have the energy to do so, as to their preferences and write this down. Sometimes this preference is recorded in the Will.

Cremation is increasing in popularity. Generally, a cremation will cost less than a burial, depending on the location of

burial. Some choose to keep the ashes and not have them interred. Some families may already have a license/lease for a grave, which has allowed provision for further interments, in which case reopening and digging fees would apply.

The Funeral Service

Your funeral director will give you a number of choices in funeral services, for example, church service or civil celebrant service. Other arrangements may include; who will be the pallbearers, notices for the newspaper, flowers, donation to a charity, hymn and reading choices, music selection, presentation of photos, order of service booklets and refreshment arrangements. You will need to consider how many people are likely to attend the funeral. You will also need to choose a coffin, which differ greatly in appearance and cost.

How Much Does a Funeral Cost?

The cost of a funeral varies. As an approximate guide, funerals can range from \$7000 to \$10,000, depending on the options you choose. The funeral director will be able to show you and your family the options available to you, depending

on your budget. Some people pay for their funeral in advance. Funeral plans often involve paying in advance for an agreed funeral service. Funeral bonds represent money the person has put aside to cover their funeral costs. Others may have funeral insurance. It would be best to contact your insurance company before making funeral arrangements, so that you know exactly what you are covered for.

It would not be unreasonable to organise more than one quote for your loved one's funeral, although this may be more emotionally taxing.

Viewing Your Loved One

A viewing gives people the opportunity to see and spend time with their loved one prior to the funeral. In some cultures it may also occur during the funeral. There is no obligation to have a viewing and it is a matter of personal choice and requires sensitivity in approach.

Provided explanations are given to children in words that they can understand, there is no reason why they should not have the opportunity to be involved; however, it may be best to allow them to decide.

The Ashes

After the cremation the ashes are gathered and placed into a container. Each funeral home/crematorium will have a different process in how they provide the ashes to the family. Ashes are generally available a few days after cremation. You can then decide, perhaps at a later date, if you wish to keep the ashes with you or spread them in a meaningful place. Your loved one may have previously disclosed where they wish this to be.

Organisations to Contact

There is no rush to contact these organisations. It is just something to consider when you have the time and emotional energy.

- Executor of the Will
- Financial planner / accountant / solicitor
- Centrelink
- Medicare / health fund
- Veteran's Affairs
- Bank
- Superannuation fund
- Nursing services
- Insurers
- Electoral office
- Motor vehicle registry
- Utilities



Coping With Loss and Grief

Grief is our normal reaction to the loss of our loved one. Grief is a very individual experience that can sometimes feel quite overwhelming. Grief can affect how we think, how we feel, our physical health and our relationships with other people.

Many people experience strong emotions, such as shock, sadness, anger, anxiety and guilt. Confusion, tiredness, sleeping problems and eating changes can also occur.

When grieving it is common to have good days and bad days, after the initial shock of the loss starts to wear off. There is no one right way to grieve.

Looking After Yourself When Grieving

- Talk to someone you feel comfortable with
- Be patient with yourself, grief has no set pattern or time frame
- Let others know how you are doing and what you need
- Accept sometimes you will feel the pain of loss and know it will ease
- Look after yourself; make a point of eating well and exercising
- Delay big decisions until you feel you are thinking more clearly
- Consider attending a bereavement support group
- Listen to your favourite music
- Go for a walk; somehow everything seems better in the fresh air

- Ask a friend to help sort out your loved one's possessions, if it's too overwhelming to do alone
- Write down your feelings in a journal
- Don't be afraid to ask for help
- Talk to your doctor

Some People May Need Some Help

Some people experience a more complicated grief journey. You may benefit from more professional assistance, if you:

- Can focus on little else but your loved one's death
- Have persistent feelings of longing for your loved one that don't go away

- Have thoughts of guilt or self-blame
- Believe you did something wrong or could have prevented the death
- Have lost your sense of purpose in life
- Feel as if life isn't worth living
- Think you may be depressed
- Have suicidal thoughts

Grief Counselling

Grief and bereavement counsellors are trained and experienced in helping people cope with grief. They listen and help you understand and express your individual grief experience. They can provide you with support, information and new strategies to help you deal with your grief.

If you need assistance finding a counsellor, please contact the care team.



Useful Contacts

Australian Centre for Grief and Bereavement Providing information on grief and bereavement resources. www.grief.org.au	9265 2100
Australian Funeral Directors Association Promoting professional funeral standards. www.afda.org.au	9859 9966
beyondblue Support Service <i>beyondblue</i> is an independent, not-for-profit organisation working to reduce the impact of anxiety, depression and suicide in Australia. www.beyondblue.org.au	1300 224 636
Funeral Information Australia Funeral information resource for Australian residents. www.funeral-info.com.au	
Kids Help Line Counselling service specifically for young people. www.kidshelpline.com.au	1800 551 800
Lifeline (24 Hr Counselling) Crisis support and suicide prevention. www.lifeline.org.au	131 114
MensLine Australia Help, support and counselling services for men. www.mensline.org.au	1300 789 978
REDHS Social Work Service	5484 4465
SANDS Australia (24 Hrs) Miscarriage, stillbirth and newborn death support. www.sands.org.au	1300 072 637
Sids and Kids (24 Hrs) Bereavement support services assist families who have experienced the sudden and unexpected death of a baby or child, during birth, pregnancy or infancy. www.sidsandkids.org	1300 308 307
State Trustees Helping Victorians with legal wills, estate planning, probate, power of attorney and trustee services. www.statetrustees.com.au	9667 6444 or 1300 138 672 (outside Melbourne)
The Compassionate Friends Victoria Support group for families after a child dies. www.compassionatefriendsvictoria.org.au	9888 4944
Talk to your GP about a referral to a Psychologist	

*Do not stand at my grave and weep,
I am not there; I do not sleep.
I am a thousand winds that blow,
I am the diamond glints on snow,
I am the sun on ripened grain,
I am the gentle autumn rain.
When you awaken in the morning's hush
I am the swift uplifting rush
Of quiet birds in circling flight.
I am the soft starlight at night.
Do not stand at my grave and cry,
I am not there; I did not die.*

- Mary Elizabeth Frye



**Rochester & Elmore
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