



When someone dies in residential aged care: Grief and loss for families

June 2023

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This edition has been adapted for use by North Western Melbourne Primary Health Network.

To find out more about this project, visit the RePaDD website at flinders.edu.au/repadd.

palliAGED has funded a reprint to make this booklet more broadly available across Australia.

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Foreword

For families, the move into residential aged care can cause sadness and worry. Most residents will continue to live in the facility until their death. This project showed that bereavement, grief, and loss affected families and residents across the aged care journey, not just after death. Everyone felt that more information is needed.

Our booklet supports bereaved people by providing information on what is likely to happen over time from entry into aged care through to the end of life. It includes suggestions, practical resources, and supports for families. The content was shaped by evidence from Australian and international studies of residential aged care. We also listened to stories and feedback from South Australian families and from people working in aged care. The voices of the participants can be heard in the quotes.

We are getting older

Australia's population is getting older and we are living longer. Many older people will continue to live independently in their home with some support from friends and family. However, sometimes more formal care may be needed. An older person may become seriously ill and need extra supports. Changes in the person's ability to care for themselves, or a family member's ability to provide care, may mean that new arrangements are needed. Others may require more care in the last weeks and months of life. When an older person needs ongoing and substantial assistance, residential aged care may be required.

It was all very sudden, and I think luckily for us they already lived in the environment in a retirement village. I think if it hadn't been for that I would have found it really hard myself as to know what to do. I don't know where I would have turned really.

Family voice



Being prepared

Tip 1

Being prepared can help your family cope with the changes and the emotions you will experience.

Being organised may reduce some of the stress and anxiety associated with a move to residential aged care.

Talk to your GP about care needs and health concerns.

Visit the My Aged Care website to learn about residential aged care and the assessment process. It has information on how to find a residential aged care home, what to look for when making a choice, and costs and charges.
myagedcare.gov.au

Sort out practical matters including powers of attorney and guardianship, advance care planning, and wills.

What is residential aged care?

Residential aged care is provided by the Australian Government to older people who can no longer live in their own home. It provides accommodation and 24-hour support for daily activities and personal care, as well as access to nursing and general health care services. Entry into aged care follows an assessment of the person's needs.

Going into residential aged care is a major change for the person and there will be practical and financial matters to resolve. Families can find it difficult to make this decision. And for some people, this decision will be made in the context of a medical crisis and under time pressures.





Advance care planning

Many of us find it difficult to talk about death and dying. Advance care planning is about knowing and sharing what is important to a person at the end of their life. While all adults can prepare an advance care plan, making a plan becomes more important as you get older, if you have an early cognitive impairment, or if you learn that you have a serious illness.

Advance care planning generally covers three things:

- Thinking and talking about your healthcare values and preferences
- Appointing a substitute decision-maker or a person to speak on your behalf if you are not able to
- Completing a document such as an Advance Care Directive.





We actually talk about end of life wishes during the admission process not because we think they're going to die soon. But it's very important to include them in this end of life planning.

Staff voice

Useful resources

Advance Care Planning Australia has information on how to get started with advance care planning and access to the relevant state forms and documents. advancecareplanning.org.au

The Victorian Department of Health has an extensive collection of advance care directive forms and explanations. Find them at health.vic.gov.au/patient-care/advance-care-planning-forms

Living with dementia

Dementia describes an impaired ability to remember, think, or make decisions. This interferes with doing everyday activities. Alzheimer's disease is the most common type of dementia. Though dementia mostly affects older adults, it is not a part of normal ageing. Over time, the person's abilities will deteriorate, and care needs increase. Many people living with advanced dementia move into residential aged care to receive the support and care they need, including end of life care.

Often families have been involved in providing care and support for some time. It can be distressing to realise that you are no longer able to manage all the care needs, or to decide that you cannot continue to provide the amount of care required every day. Families can experience anticipatory and ongoing grief as they see changes to the person and the way they interact with the world.





Planning ahead is critical and changes are likely to be emotionally challenging for both the person and their family. Seeking support in decision making through your GP or the Dementia Australia Helpline on 1800 100 500 can be valuable.

Useful Resources

The Dementia Australia website has five help sheets dealing with residential aged care and dementia as well as a section on Planning Ahead. dementia.org.au


Entering residential aged care

Moving into residential aged care is a major life event. It will become the person's new home and, most likely, their last home. People entering aged care tend to be older, frailer, and often nearing the end of life. They may feel distressed and uncertain at the change or not fully understand what is going on.

It is a very emotional time for families. There are many practical things to do which can add to stress and tiredness. You may feel guilty that a move into residential aged care is necessary and see it as a failure on your part. You may also feel relief that the person is now somewhere safe.

Sometimes not everyone in the family agrees about the move. A family discussion can help sort out concerns and make sure that everyone is aware of the care needs. It is also important not to assume that others should be willing to provide care. Conversations with the older person are important in helping the transition work. Reassure each other that your relationship will continue. Make it clear that there will be time for visits, phone calls, and watching movies together.





Look, I guess it's very rare that you get a resident that is really happy to be there, especially if they're transitioning from home. They're confused, you can just see a grieving process as they see their home's getting sold, and there's a real stigma about going into a nursing home.

Staff voice

And the carer would say to me something like "Mum's happy, she's eating well, she's drinking well, she's talking to other people." But what I really wanted to know is, is she still angry with me for placing her there?

Family voice

Planning for entry

TIP 2

Take the chance to visit and become familiar with the facility. Spend some time getting to know the staff.

Find out about activities and how families can be involved in the residence.

Respite visits before entry can help the older person become familiar with the facility.

Talk to staff about how they will support your family member to settle in.

Help the older person select personal items to take into their new space.

Talk about how you are feeling with the older person. It is a big change for all of you. Accept that you may feel anxious about the future, worried about whether your family member will settle in, and sad that life is changing.

If you had been providing care to the older person, it might take some time for you to adjust.

Things will change

People living in residential aged care tend to be older, frailer, and have more care needs so health changes and deterioration should be expected. Some will be short term events, maybe needing a trip to hospital or medical treatment in the home. Others may signal that the person is declining and may be moving closer to dying. You may worry about changes and health problems. You may be unsure that your family member will recover.

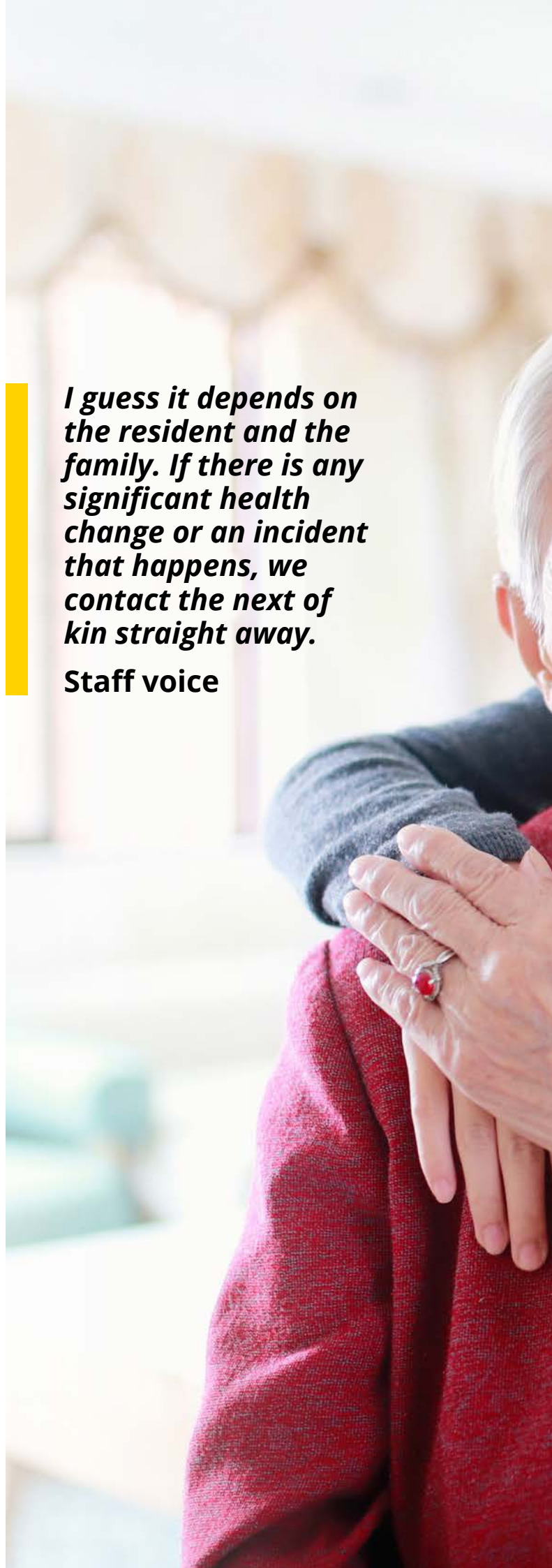
Communication is a major part of quality care - between care providers, between residents and staff, and between staff and family. Being able to share information is reassuring and also helps the facility to develop the best care plan.

The staff were fabulous. They were always there to support me and the other people in my family.

Family voice

I guess it depends on the resident and the family. If there is any significant health change or an incident that happens, we contact the next of kin straight away.

Staff voice





Good communication

Tip 3

Be clear about your preferences
“I want to know about any change, no matter how small”.
“You can ring me in the middle of the night”.

Try and organise one primary point of family contact for critical communications.

Sometimes a change in care needs will prompt a case conference or family meeting. This is a good opportunity to talk about care planning, including end of life care, if needed.

If there are language or cultural issues, think about an interpreter or a community advocate to help with important discussions.

Using the terms death, end of life, or dying can let the aged care facility know that you are willing to talk about this issue.

Don't be afraid to ask difficult questions even if they are hard for you to talk about. Remember that it is ok to be emotional.

This is particularly important if a resident cannot communicate their wishes and preferences. All of us have a part to play in good communication.

It is important to be able to talk about difficult things including death and dying. Some families can find this distressing as it makes it real that the resident will be approaching the end of their life. Or it may not be part of your culture or usual practices.

Discuss with the facility what you want to know and when. This can be very important if family members live interstate or overseas.

Helping the staff know who should be contacted is also critical. You may prefer that a specific person is contacted about things relating to the person's end of life.

You will get such a variation of their own processes whether it be from a cultural perspective or a family dynamic. It's very wide and varied how people will grieve and accept ageing and dying.

Staff voice

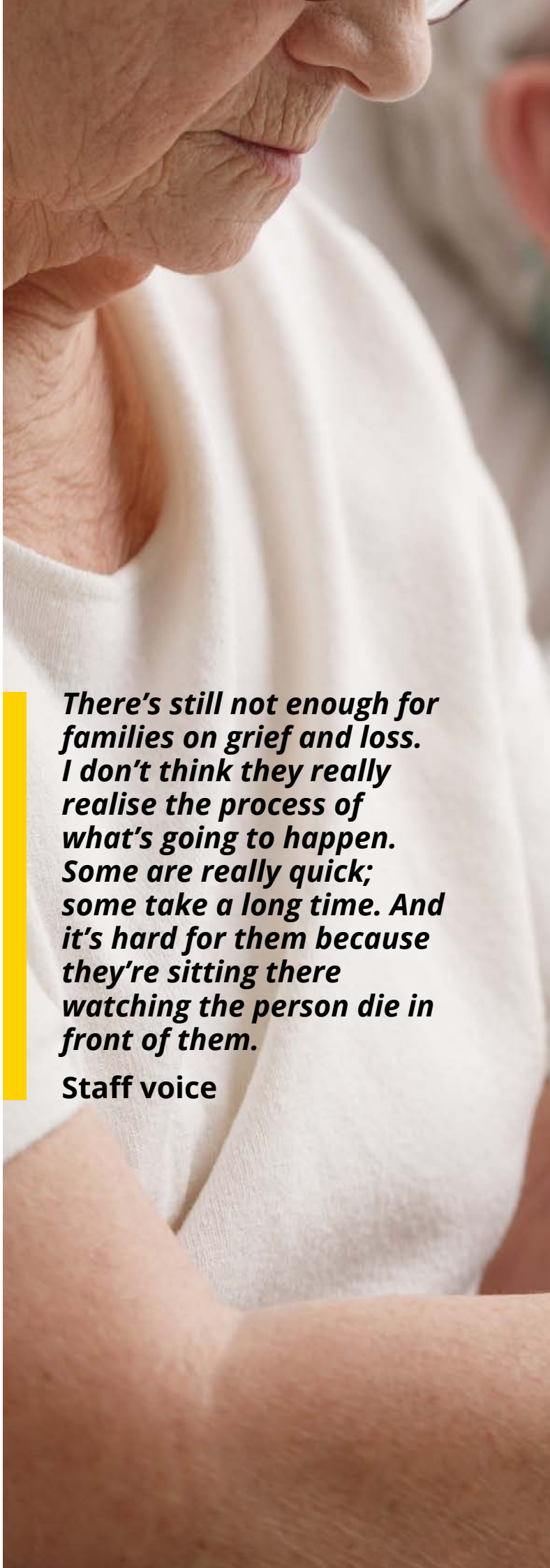


When someone dies

Depending on what you have previously discussed, one day a staff member is likely to contact you to let you know that it's possible your family member may die soon. This can be quite a shock, even though as a family you knew it would happen one day.

Many families will want to be with the person in the last days. If you need to contact other family members who may have to travel, ask how much time is left. If one of the family cannot come to the facility, being able to make phone calls or hold a video conference can help them to say their goodbyes.

Many people have not sat with someone who is dying. This can be a very special time. Talk to your family member or hold their hand. Offer them sips of water or moisten their lips. You could read a special book or play their favourite music. You are reassuring them that you are there and that you care about them. Remember each person is different and there is no timetable for dying. It is ok to take a break or to go home to sleep.



There's still not enough for families on grief and loss. I don't think they really realise the process of what's going to happen. Some are really quick; some take a long time. And it's hard for them because they're sitting there watching the person die in front of them.

Staff voice



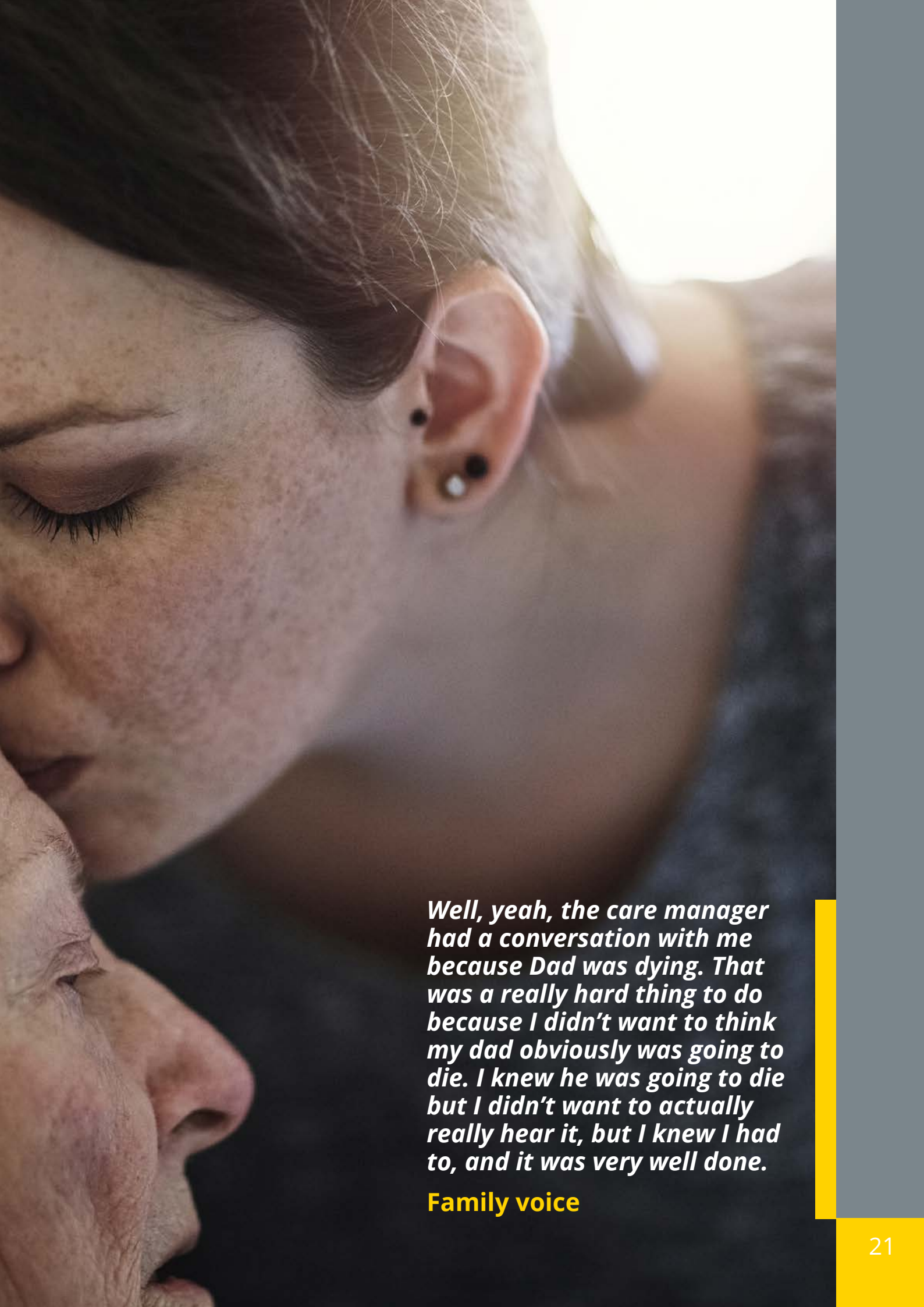
Signs of imminent dying

- Little interest in food or drinks
- Spends more time sleeping and may be difficult to rouse
- Increasing difficulty swallowing
- Very weak and tired
- May lose control of bowel and bladder
- May have rattling sounds in the chest
- Breathing patterns may be erratic
- Feet and hands may be cool and mottled

Remember that the staff will also be there providing care. Talk to the staff if you are worried that your family member is uncomfortable or in pain. Ask them to explain if you are not sure what is happening.

All deaths affect the family and friends as well as those who provide care. However, most people die peacefully. Knowing that there was good care and a chance for the family to say their goodbyes can help you create a positive way forward. Think about the good memories and share them when you remember the person.





Well, yeah, the care manager had a conversation with me because Dad was dying. That was a really hard thing to do because I didn't want to think my dad obviously was going to die. I knew he was going to die but I didn't want to actually really hear it, but I knew I had to, and it was very well done.

Family voice

After the death

If the death occurred in the aged care facility or if your family member died in a hospital, the staff will help you with practical matters. You will be able to spend time with your family member after death and say your last farewells.

The staff will help prepare the body and organise for a certificate of death to be made. This will enable a funeral director to pick up the body for funeral arrangements.

Many aged care facilities mark the death of residents with a ritual or ceremony. Some will form an Honour Guard as the body leaves while others will light a symbolic lamp or mark the resident's door with a special motif. This allows staff and residents to acknowledge the death of one of their community and to pay respects to the family for their loss.

The staff will also let you know how quickly you will need to move the resident's possessions from their room. As rooms need to be refurbished before a new resident moves in, the time can be quite short.

And the staff made a guard of honour which was just unforgettable. Family voice

If you've got someone going into aged care, it's really important, I think that you have a funeral director at least lined up because that would be really, really hard if they died in aged care and you didn't know who to contact.

Family voice

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And even in the last part leading up to her death, we were only able to see her once a week each, me and my brother, for a maximum of one hour. And in the last few weeks because of change restrictions we had to wear a face mask... And I think that was emotionally devastating too, and probably for her too, as well.

Family voice

Covid-19

Covid-19 had become a major impact on residential aged care during 2020 as the realities of potential spread and actual infections were seen in Australia. This dramatically influenced aged care and the implications of this are still being felt.

Not only was there fear about deaths in residential aged care, there were concerns about care practices and staff capabilities, as well as restrictions on visiting and public health orders around funeral numbers and social support. Families and residents may still feel sad and hurt about what has happened.

Grief and bereavement

People respond differently to bereavement at the beginning and over time. Being older and being in aged care does not lessen the loss that families feel. You may remain in shock in the weeks following the death of a loved one. You may feel overwhelming grief and sadness. Or you may feel guilt they weren't at home but also relief.

Support during dying and after the death from the staff is important. It reminds everyone that the resident was a person and connected to family and friends.

Coping with grief and loss often requires effort and it can be both emotionally and physically exhausting. You may find the grief is made worse by all the practical things that need to be done such as letting banks know or cancelling healthcare cards. You may also be sad that the relationship you had with the aged care facility is over, particularly if you have been a regular visitor for months or even years. You may also have formed new friendships and supports through the facility. It takes time to recover from a bereavement and there are services and supports if you need help.

Also, I've joined a group through another friend that I've made whose husband is in the dementia ward. All of them have either their husbands have died or they are about to go into care. That group has been fantastic, absolutely fantastic.

Family voice

And that was the hardest part to take really at the end, was having to part with him out of my care. Yeah. And I've never cried so much or so loudly in my life. I was a bit embarrassed afterwards I just broke down completely.

Family voice



Grief and Bereavement Resources

Victorian resources

- Grief Australia: Access specialised grief counselling and support services in your local area. Freecall: 1800 642 066; grief.org.au
- Precious Time: Resources, advice and information for people nearing end-of-life, their family friends and carers. For people in north, west and central Melbourne. Precioustime.org.au
- Births Deaths and Marriages Victoria: bdm.vic.gov.au/deaths

National resources

My Aged Care

- Residential aged care information
- Grief and trauma support for older Australians impacted by COVID-19
myagedcare.gov.au

Australian Grief and Bereavement Centre

- MyGrief: smartphone app
- Grief information sheets
grief.org.au

Death and bereavement: Services Australia

servicesaustralia.gov.au/individuals/subjects/death-and-bereavement

Australian Death Notification Service deathnotification.gov.au

CareSearch website: Patients, carers, families caresearch.com.au



Key messages

Loss and grief can be felt at different times across the aged care journey. It is not only felt after death.

Having a family member enter aged care is a significant life change for the person and for the family. It is an emotionally challenging time.

For most people entering residential aged care, this will be their last home. So, going to aged care acknowledges that death will be part of the future.

Building relationships with the aged care staff can help you and the resident settle in.

If you have been a carer for the person at home, the pattern of your life will change.

Being prepared and good communication can help reduce concerns and anxiety about the future.

Make sure you have explained what to do in emergencies or when things change.

Regardless of how prepared you feel, death is unexpected and can be a shock.

There is information and resources to help you make decisions and cope with change.

If you are struggling with grief, talk to your family and friends.

If you need help, there are services and supports available.

My Contacts List

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