

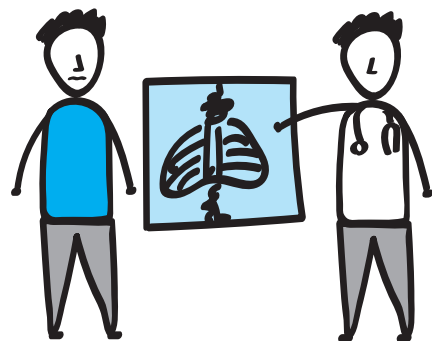
Prepared for
Digital Transformation Agency, July 2017

DTA User Research Studies

The death of a loved one



Contents



3 Executive Summary

4 Introduction

18 Prelude: 'good' deaths and 'bad deaths'

27 What's it like to lose a loved one?

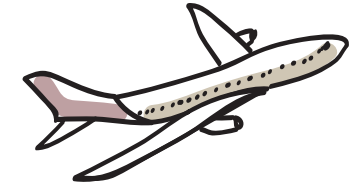
46 How does death effect the lives of carers?

59 Socially and culturally diverse perspectives

67 What's it like to be a death services provider?

75 Opportunity areas

78 Further research



Executive summary

Paper Giant was engaged by the Digital Transformation Agency to explore the experience of dealing with the death of a loved one and available services during the period leading up to, immediately after, and in the months beyond a loved one's death.

Death, dying and grief are difficult topics to discuss, so in order to prompt sensitive, open and honest conversations about death, PaperGiant designed and planned a set of research activities to help people share their experiences. In addition to narrative interviews, we invited participants to use a timeline to map the significant events in their experience and a proximity map to understand and document important relationships.

This report documents the findings of this research. The report begins by setting the broader context of death in Australia. Following this, we detail findings and outcomes from 33 interviews with 39 people who had lost a loved one between 6 and 18 months ago, and 9 service providers who work in death related industries.

We uncovered findings in five categories:

1. What makes a death 'good' or 'bad'?
2. What's it like to lose a loved one?
3. How does death affect the lives of carers?
4. Socially and culturally diverse perspectives.
5. What's it like to be a death service provider?

The outcomes of this research:

We identified key opportunity areas based on unmet or poorly met needs, that provide direction for future services.

- How might we help people better discuss, prepare, document and share for death?
- How might we help carers access benefits, respite and carers formal and informal supports?
- How might we help medical professionals communicate more effectively with each other and with carers?
- How might we help medical professionals perform their duties with greater sensitivity to carers?

Introduction

5 The death of a loved one in Australia

7 Research aims

8 The people in our research

13 Methodology



The death of a loved one in Australia

Death in Australia, is on the whole, 'managed' by expert professional support and knowledge. It is located within the domain of medical science.



The majority of deaths occur in a hospital and/or residential aged care facilities, despite the majority of people expressing a desire to die at home (Productivity Commission 2017). It is important to note that preferences for place of care and place of death are not always the same and can change over time.

The medicalisation of death and dying has changed people's experiences of death, influenced societal attitudes, the provision of end of life service support and care and helps shape what is legitimate/ appropriate as personal or societal responses to loss.

Social norms dictate that people are expected to be self-reliant concerning death. This view can serve to marginalise other voices and experiences of death.

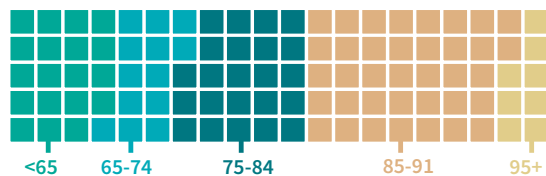
Community awareness and understandings of death have decreased and the broader impacts of dying and death are hidden away.

Productivity Commission 2017, *Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services, Draft Report*, Canberra.

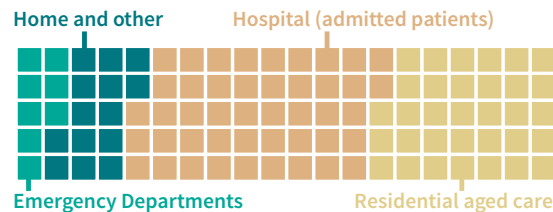
Introduction

Medicalised and silent approaches to dying, death, and bereavement shape professional practices, public understandings, and expectations of what is legitimate appropriate and societal responses to loss.

Age of death (Australia wide, 2015)



Place of death (Australia wide, 2015)



Number of people who die each year: approximately 160 000 people died in Australia in 2015 (ABS 2016), with about 80 000 and 140 000 people likely to require end-of-life care each year.

Cause of death: Coronary heart disease is the leading underlying cause of death in Australia, followed by dementia and Alzheimer disease, and cerebrovascular disease (including stroke). Lung cancer and chronic obstructive pulmonary disease (COPD) make up the top 5 leading underlying causes of death in Australia in 2014, for males and females of all ages combined (AIHW)

An ageing population: Demands for end-of-life care is growing, and will increase substantially in coming years. The annual number of deaths will double in Australia in the next 40 years, as a result of ageing populations, driven by large cohorts born during the post-World War II ‘baby boom’ into the older age groups (ABS 2013).

Main end of life services: hospitals, community-based palliative care services and residential aged care facilities, funeral industry, legal.

Productivity Commission 2017, *Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services, Draft Report*, Canberra.

AIHW National Mortality Database

ABS 2016, *Causes of Death, Australia, 2015*, Cat. no. 3303.0, September, Canberra

ABS 2013, *Population Projections, Australia, 2012 (base) to 2101*, Cat. no. 3222.0, November, Canberra

Research aims

The aims of this research are to understand;

1. What it is like to deal with the death of a loved one, from socially, culturally and economically diverse perspectives.
2. Available government and non government services during the period of time leading up to, immediately after, and in the months beyond a loved one's death.
3. Opportunities to improve services and resources during this emotionally distressing time.

The people in our research

We conducted 31 interviews with 37 people, throughout Victoria, New South Wales, Queensland and the Northern Territory, who had experienced the death of a loved one between 6 – 20 months ago.

Participants were (at least in part) responsible for organising the deceased person's affairs before or after their death. We interviewed 26 people in their own homes, 1 in an office space and 4 were conducted over the phone.

We also conducted 9 face to face interviews with service providers in Victoria and the Northern Territory.



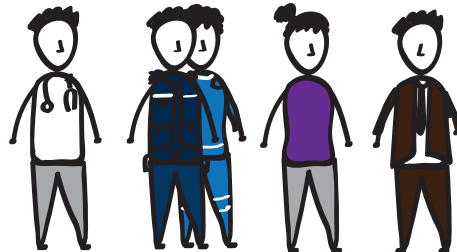
Carers

The primary participants of our research; people who were in part responsible for managing the affairs of someone who had died.



Loved Ones

The topic of our conversations with carers; the recently deceased.

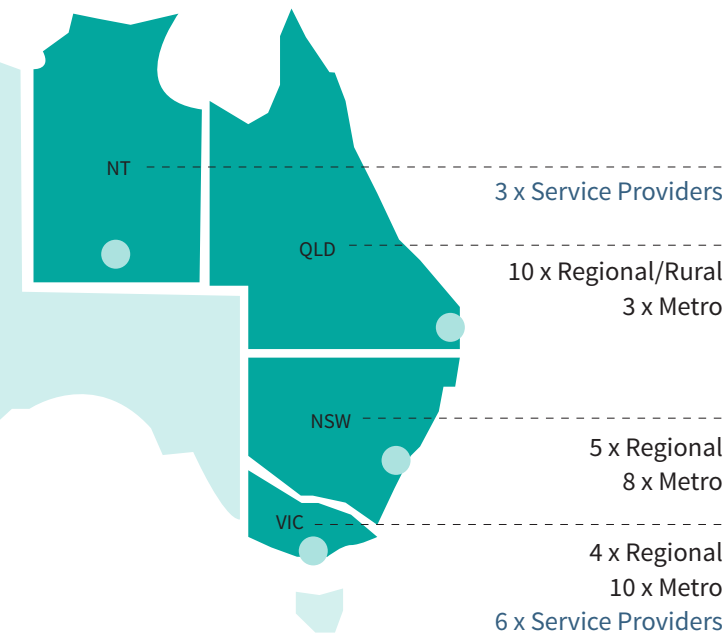


Service Providers

People that provide professional services along the journey; medical staff, lawyers, counsellors, and funeral directors.

Metro, regional and remote

We interviewed people who lived across Victoria, New South Wales, Queensland and the Northern Territory – in cities, regional centres and rural locations.



Participants

The people we spoke with had different kinds of relationships to the deceased, including;



- Immediate family members – parents, children, siblings, other close relatives.



- Spouses/long term partners.



- Others closely involved in the deceased person's life (friends).

Religious background

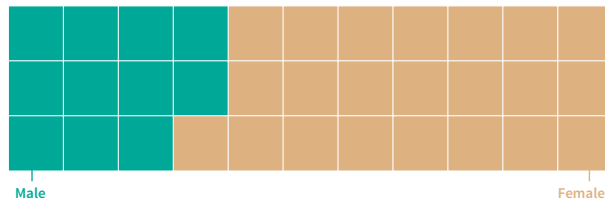
Participants came from different social backgrounds, ethnic groups and religions: Australian Aboriginal, Buddhist, Catholic, Agnostic, Anglican, Greek Orthodox, Lutheran and Muslim.

Service Providers

To help us better contextualise the experiences of carers, we spoke to service providers in death related industries, including;

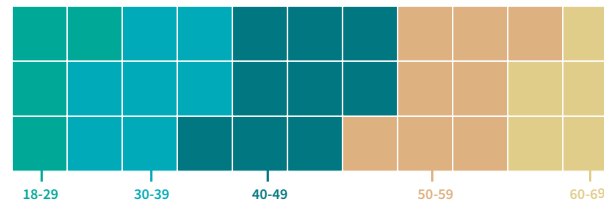
Social workers (x 2)
Funeral director
Lawyer
Aged care nurse
Registered nurse and manager of care facility
Palliative care nurse & ward manager
District nurse
Financial coach
Clinical psychologist

Our participants



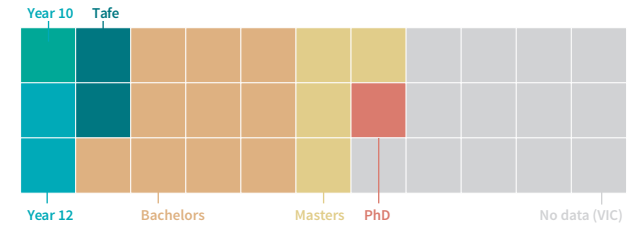
Sex

There was a clear bias towards female participants in our sample. This may reflect who is performing end of life care, as this care is often gender determined. In addition, women may be more inclined to share their experience in such a study.



Age

Our participants were evenly distributed across age groups. Approaches to death and the level of disruption a death brings to everyday life are in large part determined by the life stage of participants.



Education

We spoke to people across a range of education levels. Education level did not translate into making the process of managing the loved one's affair any easier. However, education level could be said to increase confidence in advocating for loved ones and getting second opinions around diagnosis and care.

Our participants



Place of birth

The majority of our participants were born in Australia. The 8 participants born elsewhere were born in Ukraine, China, Oman, Italy, Serbia, Greece, UK, and America.

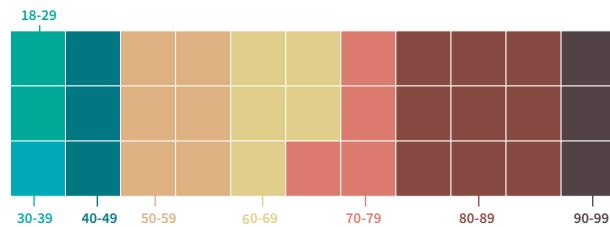
Working status

Working status greatly impacted carers availability and existing life demands. In reality, bereavement leave does not cater for the impact that death has on work life, including the sometimes long lead up and ongoing strain.

Income

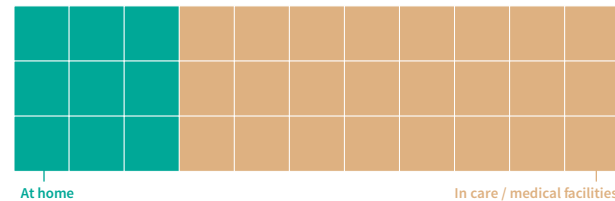
Participants income suggest how different financial circumstances impact on carers. For low to middle income earners, just finding the money for end of life care and funeral expenses can be a great stress. The assets of the dying are also of great significance.

The deceased (loved ones)



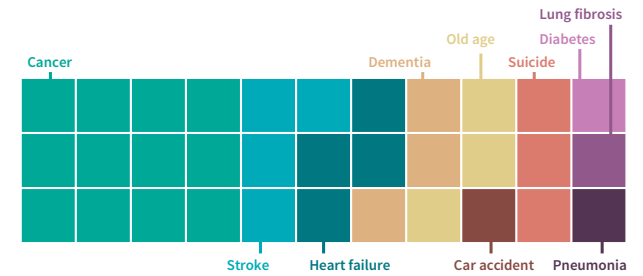
Age at death

Even though death is commonly framed as something that happens in old age, people die at all ages. Despite some participants describing the death of their elderly loved one as ‘unexpected’ there is at least a level of knowledge that their life will end. For those who died at a young age, the trauma was distinctly different. their life will end.



Place of death

It is a common wish to die at home. In reality, slow deterioration and the need for intensive palliative care regularly drive people to facilities at the end of life. Here, experiences are shaped powerfully by interactions with care/medical facility staff. The experiences of death at home in this study resulted mostly from unexpected deaths (accidents, heart failure or suicide).



Cause of Death

We discussed a range of causes of death (represented as nominated by the participant). While cancer is grouped together, there were specific types of cancer included that were more or less aggressive. The cause of death impacts upon the preparation time, treatment experiences, duration of decline and ability to get affairs in order.

The cause of death impacts the emotional distress experienced, especially in the case of medical negligence, and sudden unexpected deaths, including suicide. Certain causes of death are more taboo than others, impacting on how the participant seeks support. Life care and funeral expenses can be a great stress. The assets of the dying are also of great significance.

Methodology

We conducted qualitative research to uncover deep insights into people's experiences of the death of a loved one.

Narrative interviews were conducted in the privacy of people's homes, and some regional narrative interviews were conducted via the phone.

Using a discussion guide developed in consultation with the DTA, we asked participants to share their experiences of the period leading up to, during and after the death of their loved one.

We used a series of activities to further engage participants:

- A timeline to map the significant events in their experience;
- A proximity map (support circle) to understand and document important relationships and their roles; and
- Icons to define the services/supports around them.

Our fieldwork methods and reflections, a detailed profile of each participant, including interview transcript, and our findings were documented weekly on our project blog.





Narrative interviews: Tell us your story

Semi-structured interviews were used to encourage and stimulate people to tell their experiences in dealing with the death of a loved one.

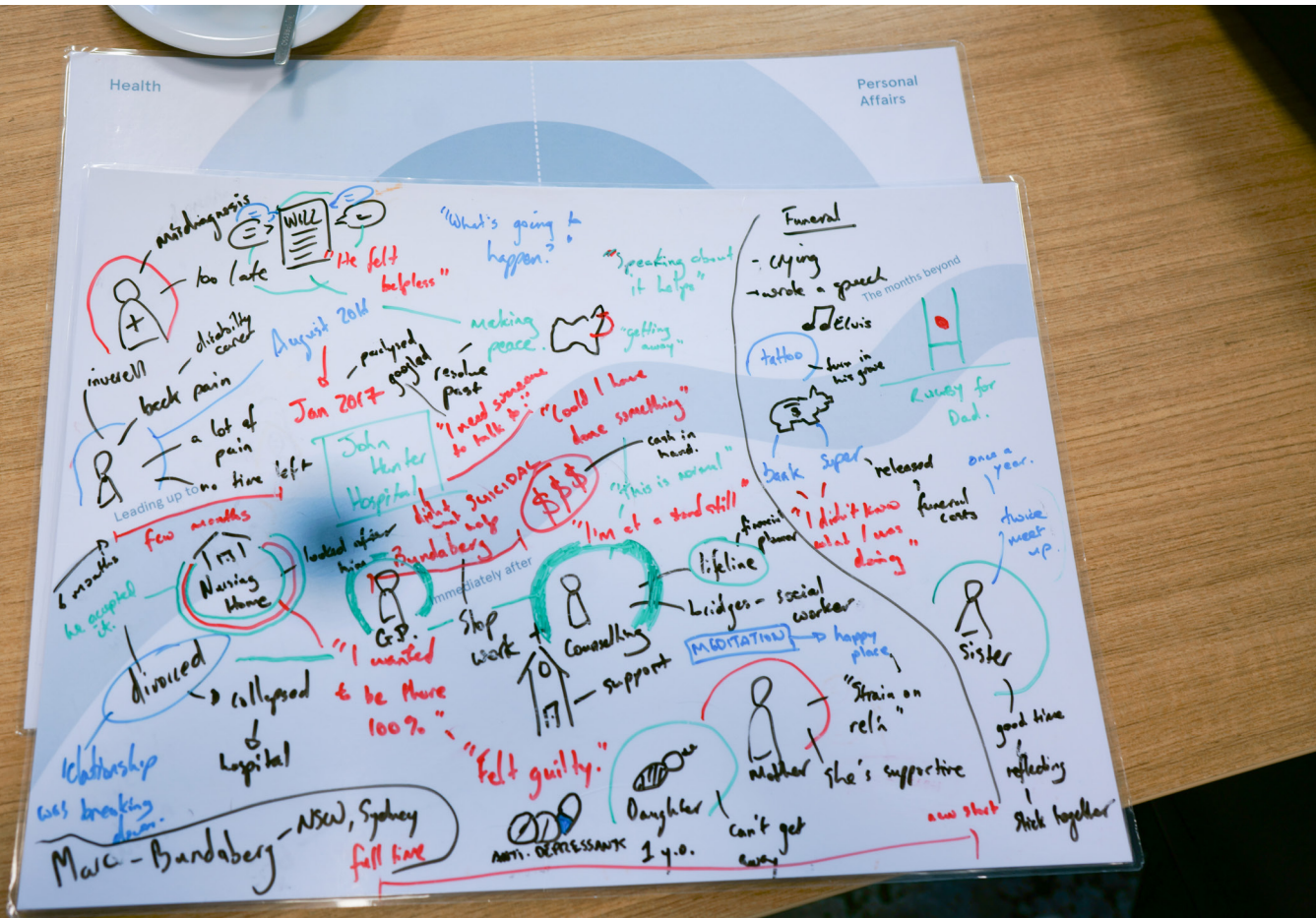
The interviews enabled us to engage with participants and to understand their experiences from their own perspective. It gave participants an opportunity to tell us what they wanted us to hear and what they thought was important to tell as part of their experience.

With participant's permission, the interviews were audio and video recorded. All interviews were transcribed verbatim in order for us to conduct thematic analysis of descriptive themes.

Following the narrative interview we conducted activities to further engage participants. Sometimes, though, participants were comfortable just telling their story and we did not need to use any of these further activities.

The death of a loved one

Methodology



Timeline

We designed a timeline template to chart and document key moments and events narrated by the participant.

The timeline was a useful note taking and checking device, and was a playful way for researchers and participants to build out an understand of their experiences together. It allowed the researchers to clarify with participants key events in order to confirm what we had heard and to identify any gaps in their narration of their experiences.

The death of a loved one

Methodology



“Okay there’s me. That’s my mum! She hasn’t got a walking frame or anything, but she is in her 70s. My mum, definitely.”

– **Melanie**



Support circle

A proximity map (support circle) was designed to chart and document significant relationships and the role they played in supporting the participant. The circle was divided into 4 support categories - health, financial, personal affairs and emotional.

Using figurines, participants were able to identify who provided them support in the different categories at different points in their journey. The proximity map allowed us to understand who provided the most enduring and consistent support.

The figurines made people smile and the choice of which figure represented their support people provided relief for them and more understanding of their relationships for us.

It was also a good way for us to ask further questions about people who had only been mentioned briefly (for example ‘you mentioned that you have a brother. What role did he play in this, if any?’)

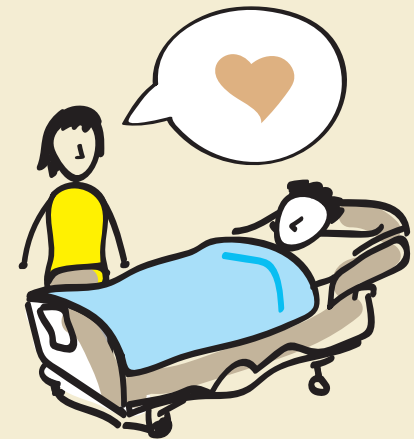


Prelude: 'good' deaths and 'bad' deaths

19 What makes a death 'good' or 'bad'?

21 Expected and unexpected deaths

22 What else shapes the experience?



What makes a death 'good' or 'bad'?

Death is a uniquely personal and subjective experience, but the ways people cope and contextualise a death are shaped by three key variables;

1. Whether carers felt **relief** or **shock** after a death.
2. Whether the death was considered **expected** or **unexpected**.
3. Whether the death was considered **fast** or **slow**.

Rather than thinking of these variables in purely quantitative terms (as regular time measurements, like weeks or years), participants interpreted fastness and slowness, expectedness and unexpectedness in largely subjective, qualitative ways.

It was how people felt that was most important, not whether a measureable, standardised timeframe had passed. Deaths involving the same circumstances and time periods were interpreted differently by different people.

It is the combination of these three variables that largely predicted whether people considered a death 'good' or 'bad'.

Relief

Shock



Was the death a welcome event, from the loved one's and their family and friend's perspective? Or did it feel as if a life was ended prematurely?

Slow

Fast



Was the death considered slow or fast? Either on their own are not necessarily negative. More importantly: was the death considered *too* slow, or *too* fast?

Expected

Unexpected

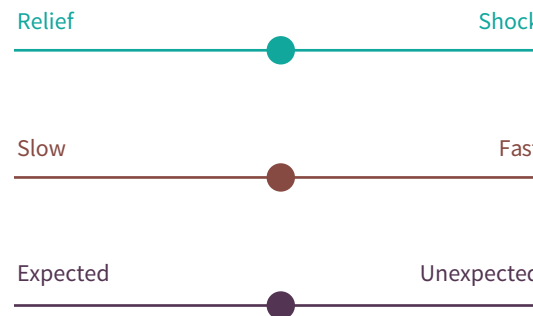


Were people expecting the death to happen soon? Or did it feel like it came out of the blue? Even in the case of terminal illnesses, the division between expected and unexpected is not so clear.

Prelude: 'good' deaths and 'bad' deaths

Interpretations of a death were complex, however it was possible for our participants to frame the death as either 'good' or 'bad'.

A good death: 'goldilocks' zones



In a 'good' death there was a balance between relief and shock (the loved one was not in pain), and people were relatively prepared for the death (they knew it was coming, just not exactly when). They felt they had enough time to say goodbye and make preparations (death was not drawn out or sudden).

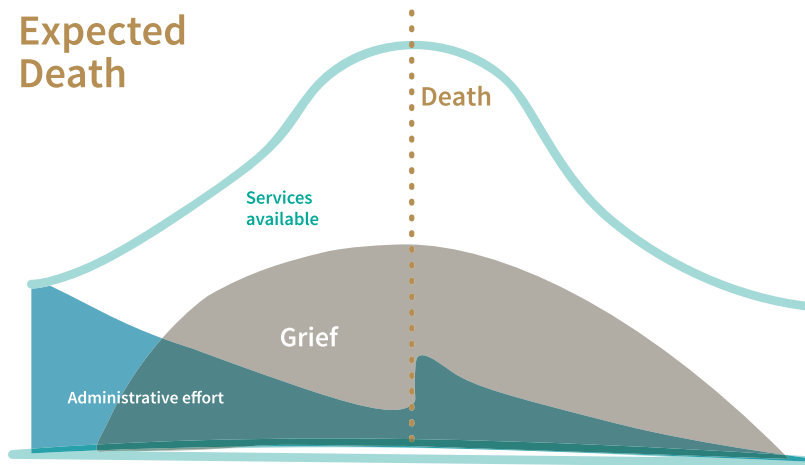
A bad death: extremes



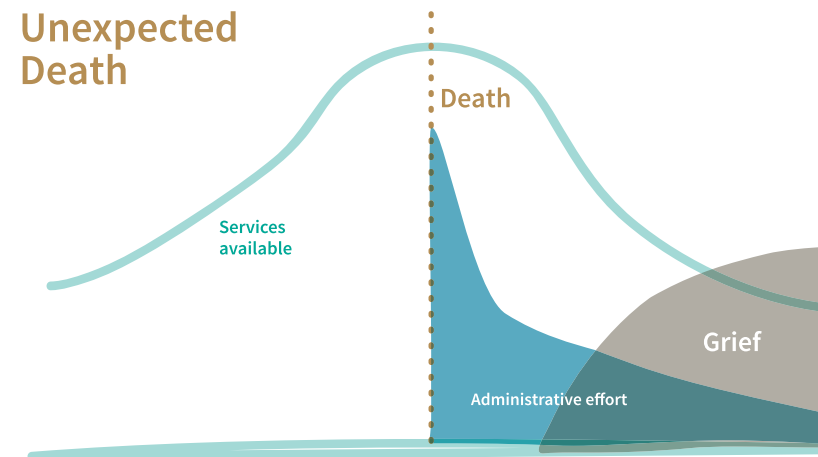
In 'bad' deaths there were extremes in any interpretation of the variables. Relief often meant long periods of pain or dementia in the lead up; likewise an unexpected death, or one considered either too fast or too slow was considered a 'bad' death.

Expected and unexpected deaths

Administrative effort and periods of grief differed in expected and unexpected deaths.



With an expected death, people are able to commence the administrative side of estate management while the person is still alive. People begin to grieve earlier, and there are readily available supports and services that help people prepare and plan. The death itself brings more administration, but formalised supports drop off after the funeral.



An unexpected death brings with it large amounts of administration. Grief is present but the process of grieving is often delayed until administrative burdens ease. Supports and services are focused around the management of the body, and less on supporting carers through the process of estate management or emotional recovery.

What else shapes the experience?

In addition to the three variables introduced here, there are many other smaller factors we found that contributed to people's understanding of whether a death was 'good' or 'bad'.

Having wishes respected: If the wishes of a loved one were respected and acted upon through the dying process and in the months beyond, a death was considered 'good'.

Adequate preparation: Being prepared for death often led to better outcomes for loved ones and carers. Preparation activities include advanced health directive, enduring power of attorney, statement of choice, will and funeral arrangements.

Amount of pain: Absence and/or adequate management of pain in the lead up to a death was considered important. This was not only for loved ones, but for their family and friends, who would often feel traumatised after the death by their memories of pain.

A sense of closure: Feeling as though a life had reached closure in the lead up to death was important. Having opportunities to say goodbye, feeling that life was well lived contributed to this closure. Unexpected or traumatic deaths, such as suicides or accidents, are strong counterpoints to this.

Choice in treatments: This is related to choice around prolonging life, a belief that all available treatments were used and a sense of control over treatment choices. Euthanasia and/or physician-assisted suicide was also discussed in relation to terminal illnesses and chronic pain.

Experiencing dignity in the process: This consists of being respected as an individual and maintaining independence. Elderly loved ones, and those experiencing dementia, in particular had varying experiences in relation to dignity.

Lucidity: Preservation of consciousness and personality was vital for family and friends of loved ones. It was traumatic when people were always asleep (from pain medication), or their personalities were altered (as in dementia).

Quality of life: It was better for loved ones and their families if loved ones remained relatively independent and at home during a lengthy illness.

Prelude: 'good' deaths and 'bad' deaths

Location of death: It is common to want to die at home, but most often that's not possible. A good death was one where loved ones were able to stay at home longer.

Family presence and perspective: Knowing how other family felt was important. Family support, acceptance around the death, and whether family could 'be there' all contributed to a positive experience.

Relationships with healthcare and service providers: Having access to medical care on the foundation of good, trusting relationships was vital in the experience of death. Those that had ad hoc or

actively negatively relationships with service providers suffered.

Documented and discussed wishes: Having wishes documented legally was important, but so was having discussed those wishes openly with people likely to have a claim on the estate.



“He wanted to be at home with his wife, his dog, his friends and family, where he was comfortable. He said to me ‘I’m not dying in bloody hospital’, he said ‘I want to die in my own home.’ I just held his hand and went, I understand. He said ‘everyone is trying to tell me I have to go [to hospital]’ and I went ‘no bugger that’...I think there is a long way to go to making people feel that it’s still okay to have your needs met in death.”

– Ally



Case Study

A celebration of life

Amanda talked to us about her mother Susan's death, which she said was 'a really good experience'. Susan lived a rich and full life and, after an extended terminal illness, and organised her own living wake and funeral. Due to Susan's initiative, Amanda said she 'felt there was nothing for us to do' in terms of the many administrative tasks that other participants felt needed to be organised.

“My mum planned her own funeral. She had her own wake before she died. She interviewed her funeral directors. We had to watch these people squirm in their seats...it was hilarious. We had the best wake ever before she died and she was there. She organised the whole thing.”



The death of a loved one

Prelude: 'good' deaths and 'bad' deaths

Case Study

Slow and painful death

Nicole (daughter) and Maria (mother) were responsible for looking after Milena (grandmother) through her slow decline from dementia. Over the many years of her deterioration, they were worn out and did not feel like they did enough to reduce her suffering. They felt despair over the suffering she experienced during her death and how long it took.

“Then she really went downhill but it took her 5 whole years to die. Poor thing she was in so much pain, suffering so much and diabetes too. Poor darling. She really didn't deserve that death. Nobody does. It's the cruellest death I have ever seen. I work in a nursing home and see people die, but not like that under your eye just shrinking and shrinking. With all the morphine she was still crying with pain. It was so cruel. I've never seen anyone die such a cruel slow death.”

ARTICWTAH T



What's it like to lose a loved one?

28 Death is foreign

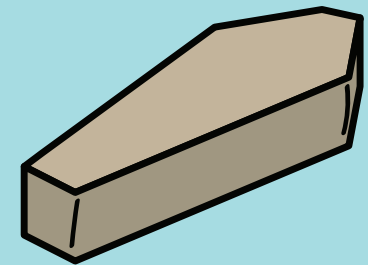
31 Planning for death is hard

33 Death is medicalised

37 It's hard to know what to do

39 It's hard to contextualise

43 Death is uniquely personal



Death is foreign

In countries like Australia, death has become less familiar, more taboo, and harder to talk about.

Death is a taboo topic, and something most people work hard to actively avoid discussing or considering. As a result, death has become absent from our lives. This avoidance and absence makes death hard to discuss, and leads to increased trauma and grief once a death occurs.

Death is hidden: being exposed to death and dying is rare until someone close to us dies. It is easy to ignore in our everyday lives.

We are not familiar with the reality of death: often we are left to figure out the process of dying and grieving for ourselves, relying on medical staff and funeral directors to tell us what to do once we are faced with death.

We do not know what to say, do, how to cope or how to grieve: in both personal and professional lives, many people experience discomfort when it comes to personal and collective processes around loss and grief.

Past experiences of the death of a loved one: may make people more inclined to be open about death and dying, or reluctant because of a previous traumatic experience. Experience doesn't necessarily translate well.

“We’re shocking nobody wants to talk about it. I’m happy to chat about it, it’s my job. I’m very comfortable talking about death and dying.”
– Nicole, Funeral Director

What's it like to lose a loved one?

People with no experience with dying: may be uncertain and fearful of what may occur so keep silent.

Existing family dynamics: influence whether conversations that need to happen prior to, and during the dying process, take place.

Talking about death may upset our loved ones: typically we do not want to see those closest to us upset so avoid discussions taking place.

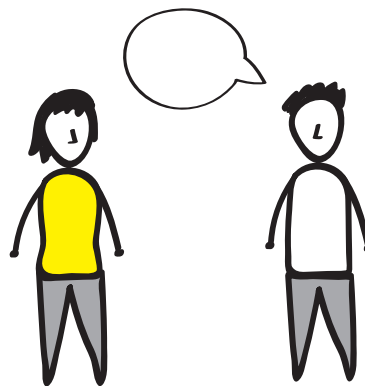
Talking about death may lead to a family dispute: discussing end-of-life planning, funeral wishes, inheritance matters may cause conflict in families with a history of fractured dynamics.

Conversations around medical care can be challenging: often these conversations do not take place. People do not know what to ask, or can feel uncomfortable discussing the matter. Medical staff may never broach the subject.

Conversations with a loved one at the end of their life: sometimes the opportunity to have a conversation with a loved one at the time of death is not possible. This leads to further confusion about death and what it's like to experience.

“I had plenty of opportunities to drop in on my way home but I never did.
What would I say?”

– Dean





The death of a loved one

What's it like to lose a loved one?

Case Study

A conversation about death

Dean was partially responsible for his father Thomas's affairs while he died. Dean is a realist when it comes to death, but felt that conversations about death were silenced. He wants to see more conversations about death so that both the dying and their support networks are better prepared.

“ We're all going to die, and it's something in Western civilisation we really don't talk about. We cling to the formalities and protocols of having a funeral and having a wake and all those sorts of things – it's like they're life buoys that keep you afloat. It's almost like when someone dies it's a terrible shock. We treat the whole thing about death like – if we don't talk about it or if we pretend it doesn't actually exist.”

Planning for death is hard

For those left behind, the most important aspect of a death is the planning around it. Death is difficult to think about, and so is planning for it.

Given death is foreign and taboo, knowing what to plan for is difficult; what to think about, how to document and who to tell are all key questions people have in the lead up to a death. Knowing how to help others plan is even more challenging.

It is unsettling to think about death: the finality and uncertainty that surrounds death can be frightening.

Preparing for death is confronting: Thinking about, discussing and documenting wishes around death can be challenging for many people.

Many people are unprepared: maybe there is debt, lack of savings, or people are anxious about how their family would manage financially if they died. These uncertainties can keep people from preparing for death.

Talking about wishes can difficult: This conversation is often only triggered by professionals, or major changes in life circumstances – a death of a loved one, the onset of an illness, retirement, birth of a baby.

Documenting wishes: wills were common in our research, but they are relatively flimsy legal documents. In contested estates, things like time-frame and thoroughness matter. Wills that haven't been openly discussed cause problems for those left behind.

Familiarity with death: being exposed to death and dying is rare until someone close to us dies. It is easy to ignore in our everyday lives.

Past experiences of the death of a loved one: may make people more inclined to be open about death and dying, or reluctant because of a previous traumatic experience.

People with no experience with dying: may be uncertain and fearful of what may occur so keep silent.

What's it like to lose a loved one?

Planning is triggered by professionals: in most cases, people only plan for death when prompted to do so by medical professionals, financial planners or lawyers. People that have regular and easy access to these professions were more likely to have prepared for death better.

Help seeking varies: whilst information and services exist to help people plan for death, people are typically unlikely to seek out support until their relationship to death is changed. This change is triggered by prompts from service providers, a confronting medical diagnosis, or a direct personal experience with death.



Death is medicalised

Medicine has become the dominant framework for understanding death, dying, and how to act when death approaches.

The medicalisation of death dictates how people respond and associate to it. Rather than being part of life, it is considered something to manage, like any other illness. This can lead to people's wishes being overridden, and carers can feel a loss of agency.

Medical professionals assume responsibility of the care of people at the end of life: they influence how that care is understood, delivered and communicated.

Medical professionals define the dying process: they are in charge of medication and life support. They become the gatekeepers of the dying transition.

Institutional protocols and legal requirements: can dominate the experience of death and dismiss social, cultural and emotional needs of friends, family and their loved one.

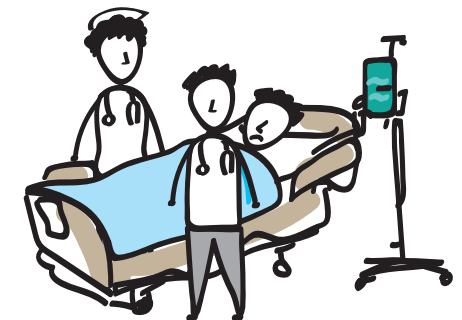
Dying in a way people would not choose: forced medical intervention can leave carer's feeling distressed, guilty, and uncertain.

The care and death people experience: not reflecting their values, goals, or informed choices.

Clear communication: from medical professionals about what happened, when, how and why, is required for people to trust and understand in the process and to make sense of the death of their loved one.

Uncertain wishes of a loved one: with regards to medical decisions like life support, organ donation, and decisions around quality of life can cause immense stress for the medical power of attorney.

Strong advocacy: is needed for those who have wishes outside of a medicalised death, such as denying treatment, refusing resuscitation and staying at home.





The death of a loved one

What's it like to lose a loved one?

Case Study

Heavy sedation not explained

During a small routine operation, Kathleen's mother June's lungs collapsed and she died three days later under heavy sedation. No family members voiced their concerns about June's sedation, but Kathleen thinks that the option to communicate with her would have made a big difference to her experience of June's death.

“There was so much unsaid in our family and it ended up being another unsaid chapter. Maybe a lot of meaningful things would've been said. But as it was, it was all silent.. It wasn't managed really well at all. It would've been nice for mum to be not so sedated so she could speak to us before she died... I just assumed that that's the way it happens. The Doctors, the nurses, they'd obviously done it a million times before and that's the formula they had and did it the same way every time presumably. There was no option. It was a real mess.”



The death of a loved one

What's it like to lose a loved one?

Case Study

Poor communication from medical professionals

Jennifer and Dianne were extremely hurt and angry at the hospital experience around their mother Colleen's death. There was a lack of communication throughout their mother's stay. Jennifer found out it was nearing the end from another patient, who said 'they're talking a lot about your mother in the hallway here these Doctors and they said she is so sick she won't be here on Thursday'.

“I said to the head nurse, my mother is dying isn't she and she wouldn't answer me. I said don't you dare stand there and tell me she is not because I have seen this before. Dianne asked the Doctor and she said no. I gave her the filthiest look and Dianne said please don't lie to me, tell me the truth, and she said yes she is I'm sorry.”



The death of a loved one

What's it like to lose a loved one?

Case Study

They don't want to know about it

Nicole spoke to us about her father Peter who passed away 18 months ago from suicide. Nicole wanted to know the details of her father's death. Given the cause of death, Nicole found it difficult to find people close to her who would talk to her about her experience.

“ I don't really talk to my actual friends about what happened. I guess they seem to not want to know about it is what I've come down to. That goes for friends as well as all of my family – my husband, his brothers and sisters and their partners, his parents, even they don't seem to want to know about it.”

“ I wanted to know some of the practicalities of what would've happened to him – whether he would've experienced any pain and how long and that sort of thing. She [counsellor at Coroner's office] was able to answer all those questions that I couldn't have asked anyone else. ”

It's hard to know what to do

The death of a loved one is extremely challenging, requiring many decisions to be made under considerable emotional distress.

At the time of death, carers are often emotionally distraught. As people responsible for the affairs of their loved one, they also take on greater responsibility, and that responsibility begins as soon as someone has died, and when carers are at their most vulnerable.

Whether a death is expected or unexpected:

there are many administrative tasks that need to be addressed and organised.

Knowing what to do: immediately after and in the days and weeks following the death of their loved one many people found it difficult to know what to do for their loved one or themselves.

Emotional distress: the immediate aftermath of a death of a loved one is emotionally challenging, impacting people's ability and capacity to deal with the needed administrative tasks.

Previous experience/familiarity: when people had previous experience with the death of a loved one, they were more readily able to deal with the administrative tasks - for example, using the same funeral director.

“Even if the perfect thing had of been there and had flashing neon lights attached to it I don't even know if I would've noticed it such was my confusion about everything. The world seemed turned upside down. It would have to be something pretty exceptionally well-advertised for me to even notice it let alone say oh yes, that might be useful for me.”

– Dean

What's it like to lose a loved one?

Availability and access to information/services:

those living in regional areas found that services were not well advertised, or readily and easily accessible.

“It’s emotional - well we were all pretty much in shock. It was just – I remember my head felt like, I don’t know. Everything looked very fuzzy the whole time. I felt like I was in a dream or something. It was really hard to concentrate.”

– Kathleen

Google searches: people conducted internet searches to understand what they needed to do at the different stages, but many people expressed a preference for recommendations based on ‘face to face’ contact and close community ties.

Social connections: some people were able to rely on family, close friends or acquaintances to seek advice, get recommendations of services to use, and been be in the position where friends provided them professional services.

Social support: some people described having a friend or family member guide them during the process, particularly in the time immediately after death. Others wished they had someone to ‘take their hand and guide them.’

“It’s a little bit overwhelming to figure out what you have to do or what happens next. I did a lot of website looking and stuff to find out okay what the hell am I supposed to do.”

– Ella



It's hard to contextualise

Some people struggle to make sense of things following the death of a loved one.

The death of a loved one is a transformative event, and it can be difficult for carers to understand the impacts it has on them until much later. Those that coped well were ones that could contextualise the event and memorialise their loved one effectively.

People's lives can fundamentally change: following the death of a loved one.

People rely on different meaning making processes: and coping strategies to adjust to the death of a loved one.

Finding meaning in death is emotionally labour intensive: as it can challenge people's worldview and rupture their sense of control over life events. The meanings people attach to death can have important implications with people's ability to endure the emotional distress caused by their loss.

Acceptance/denial: This depends on the circumstances of the death. A traumatic and sudden loss is difficult to accept and people struggle with issues surrounding responsibility and guilt.

Rituals surrounding death: these give meaning to that which cannot be explained; they are the tools that enable us to honour and cope with death. Obvious examples include funeral/cremation and/or a memorial service, wakes, and spreading ashes.

Making sense of emotions: people talked about finding ways to process their emotional distress. Strategies included talking to family, friends and seeking professional support, religious and spiritual understanding, writing, and making art.

Ways of finding meaning: people mentioned reflecting on what could have been different, discussing their loved one's legacy, educating others about the experience of loss, and in comforting others.

Death literacy: being involved in caring for a person who is dying can extend their knowledge, skills and personal resources. People may incorporate these skills into their lives use in new ways, including volunteering at a cancer centre and hospice, doing advocacy work with emergency services about suicide.

What's it like to lose a loved one?

Life transformations: Losing a loved one changed the way some people viewed their world. People spoke of changes in their approach to life, such as shifting work-life balances and prioritising their loved ones.

Memorialising their loved one: this was done in some form of private or public tribute, ritual or action, examples we heard included; telling stories about their loved one, having imagined conversations with the deceased, celebrating their birthdays and anniversaries, and reviewing artifacts that represent or once belonged to them, and donating in their memory.

Preparing for own or other loved one's death:

Reflection upon their experience of the death of their loved one made some people want to reevaluate and think about, discuss and document their wishes concerning their own deaths and the deaths of other loved ones.



“Look, I like to say that he died of heartache for his mum. It was a long time for me to deal with her death and it made me really angry. ”

– Anthony



The death of a loved one

What's it like to lose a loved one?

Case Study

Making meaning through faith

Elizabeth's husband and son died within two years of one another, only months after Elizabeth and her husband had moved from America to Australia. While she was still experiencing emotional distress, her religious beliefs enabled her to focus on positive aspects of her life.

“He passed October 21st 2013 and my son passed October 21st 2015. So I have an appointment with God to say what the hell were you thinking...I thank God up above, really to put me in on that street with those wonderful people...I say thank God I had him. How many women get what I had in a lifetime - all of us are guaranteed to die. We are. I got that figured out really strong in my head now. ”



The death of a loved one

What's it like to lose a loved one?

Case Study

Using the experience of death to prepare for the future

Marina's father left his entire estate to her as documented in his will. He didn't tell his long-term girlfriend his wishes, and when he died, she contested the will. Resulting legal proceedings and probate processes compounded stress for Marina. As "insurance" against family squabbles in the future, Marina organised to video her mother in the presence of a lawyer.

"I decided to video my mum because I don't want to go through the legals and probate again, when the time comes."

Death is uniquely personal

The death of a loved one is an emotionally distressing and a uniquely personal experience.

It is difficult to predict how someone will react to a death. People themselves are surprised at the extremes of emotion they feel, and at how much support they need. There is rarely a consistent, repeatable experience.

Everybody, and every loss, is different: the death of a loved one is difficult and brings up a raft of emotions and experiences that can be confusing, unexpected and contradictory.

Accepting death can be difficult: emotional distress is part of all loss. While emotions can be extreme, scary and uncomfortable, they are an important and inevitable part of the loss of a loved one.

Emotional distress is determined by: the diverse circumstances of individuals and their communities; relationships with their loved ones, their family and friends; the cause of death; the life stage of themselves or loved ones; culture; religion; gender, and what the loss means to them in their everyday lives.

People express emotions in different ways: these are influenced by personal character, social norms, expectations and conditioning influence how emotions are felt and expressed. Public or private, spoken or silenced.

Permission to grieve: it is vital for carer's to feel respected in their own experience of loss, to feel the emotions as they arise, and to honor the relationship with their loved one.

Cumulative stresses: death happens in people's everyday lives, and additional stressful life events or multiple losses can radically enhance the emotional distress of loss.

The '6 month struggle': many people referred to the 6 months after a death as a period of intense emotions and activity, like a 'limbo'. It's not the end of the emotional distress, but the 'six month struggle' of getting through grief is something common amongst our participants

Putting on a brave face: is something we heard from many individuals as either a pressure they felt themselves, an approach to 'coping' or a socially assumed response. Presumed or imposed resilience often acted as barrier to people seeking professional support.



The death of a loved one

What's it like to lose a loved one?

Case Study

Extreme emotions

Anthony experienced two deaths close together: the first was his aunty Michelle from cancer, and second was his cousin Connor from suicide. The losses brought up extreme emotions, past personal traumas of abandonment, suicidal ideation and self harm. The two deaths compounded their effect on each other, and Anthony was not sure how he could get through his grief.

“ When Michelle died I was kind of fucked up, it was lack of support, lack of understanding because some people don't [participant crying]. Some people don't want to cry every day. I cried for a long enough time. It hurt me for the longest period of my life. It was a long time for me to deal with her death and it made me really angry... I actually didn't cope with either and I started drinking... I actually sliced through my own leg. I found it very hard. ”



How does death effect the lives of carers?

47 Individual circumstances matter

50 Caring is a job

53 Supports are sought from many places

54 It can be hard to access formal services and supports

56 Informal Supports are vital



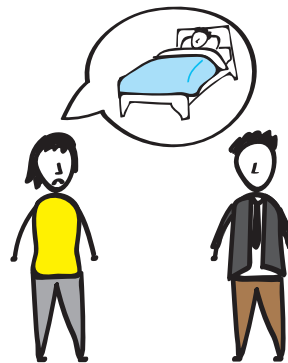
Individual circumstances matter

People's everyday lives shape and influence the experience of losing a loved one.

The experience of losing a loved one is mediated by many individual life factors.

Death is embedded in people's everyday life circumstances and is influenced by socio-economic factors, previous experiences of trauma and of death, a slow decline, emotional resilience and the quality of people's support and social networks.

The emotional and practical demands of death can be compounded by other life circumstances such as caring for other family members who may be sick, looking after disabled relatives, doing several jobs to make ends met.



“I think it's probably got to do with my upbringing. From the age of eight split from Italy to here, not having a mum having a stepmother. You do what you've got to do. Somebody else probably wouldn't be able to handle it. I know friends of mine and even their kids they haven't been handling it.”

– Stella

How does death effect the lives of carers?

Socio-economic factors: shape people's access to financial support. There are many financial demands associated with caring for and the death of a loved one. For some, accessing necessary funds was problematic and stressful. A slow decline impacts the financial stability of the carer. In several instances the care was pensioned, or on a disability payment, working part time or not at all.

Life histories: Past experiences of death, loss and trauma can return and culminate in increased emotional distress.

Existing family relationships/dynamics: end of life is a time when families may have to work together through emotional and logistical struggles and can be torn apart or brought together.

Emotional resilience: whether people are able to adapt to the adversity of death and loss without lasting difficulties impacts how the death of a loved one will be experienced.

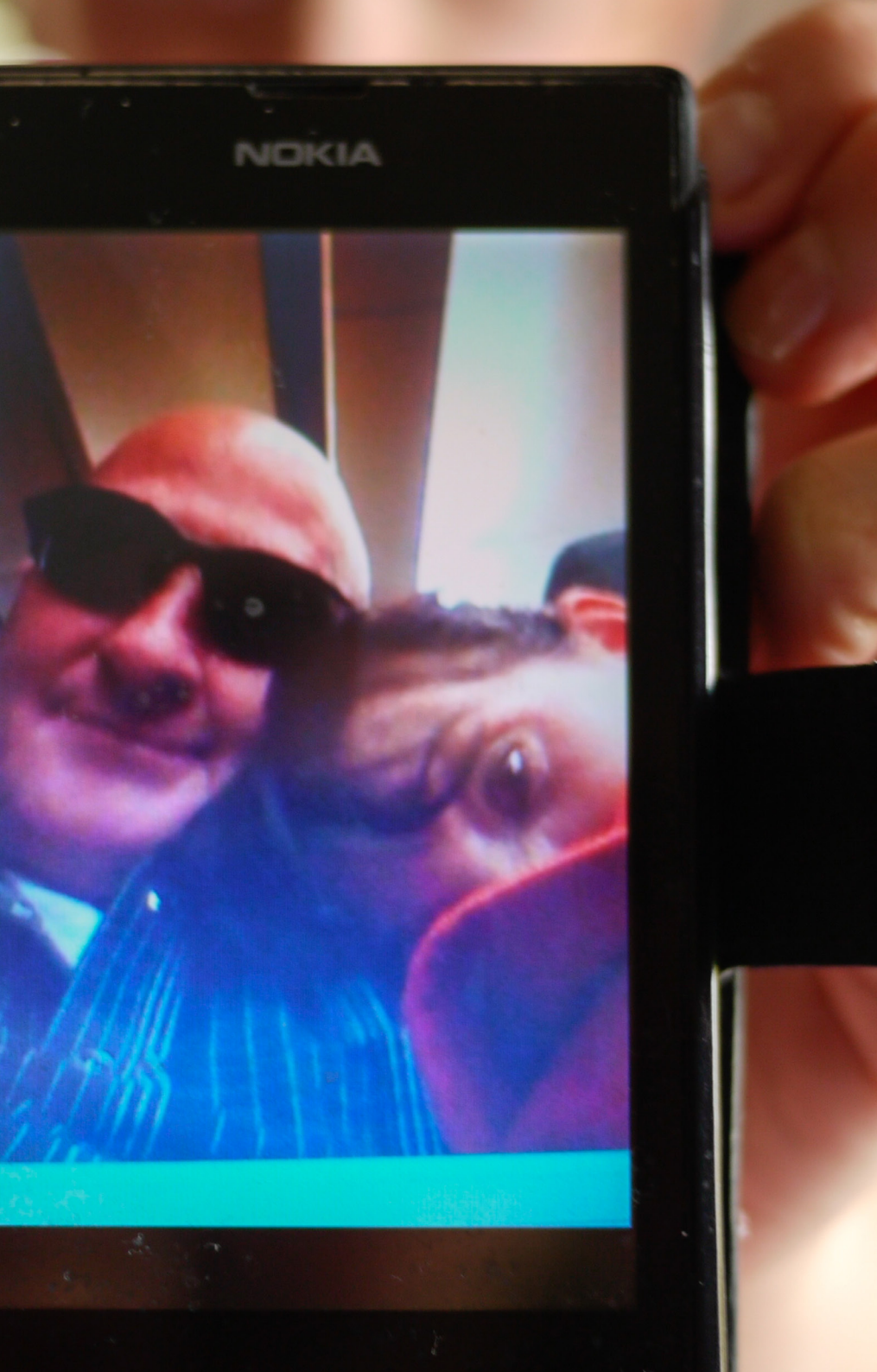
Compounding life stressors: People's emotional resilience is also impacted by other life stressors, such as family dynamics, pressures from work, own health and well being.

Social networks: Support from social networks is a key factor in enabling people to be emotionally resilient during the death of a loved one. People were able to draw support from family and friends, work colleagues, and people in their local communities.

Isolation: Social isolation, loneliness and living alone can have negative implications for people dealing with the death of a loved one. A sense of being loved, appreciated and cared for can lessen the impact of emotionally distressing events.

“He had a lot of financial issues because he had to take a lot of days off, probably at least four months of that year he took off [to look after his wife]. Most of that was without pay. My siblings weren't working. At the time I was working and giving him a little bit just to help out. It was tough.”

– Melissa



The death of a loved one

How does death effect the lives of carers?

Case Study

Ongoing financial stress

Sharon described in detail the struggles of helping her friend Peter through treatment for cancer and end of life planning. This was happening on top of Peter's substance abuse, violence, police involvement and emotional blackmail towards Sharon, financial stress, and disagreements with his estranged family which caused ongoing stress and trauma for Sharon.

“Normal Peter without drinking was fantastic. Drinking Peter was shocking. But I could see the goodness in him...Peter didn't have any money, no one to help. I couldn't help him because I'm on a disability pension. He went and got a Centrelink loan. You can get a Centrelink loan of \$1,000.00 and he actually used that Centrelink loan to pay for his own funeral...I learnt good people die and not so good people die and families are shocking when someone dies.”

Caring is a job

Carer's shoulder substantial responsibilities leading up to, immediately after, and in the months beyond their loved one's death.

Many people perform significant unpaid caring roles for family members and /or friends. The care provided is diverse and can be extensive done in conjunction with formal care arrangements (residential care facilities, hospitals, funeral homes), shared with other carers, or as a sole carer.

Carers make a significant contribution to supporting their loved ones during their decline, nearing the end of their life and during the administration of their affairs following their death.

Forms of labour: The physical, emotional and practical labour associated with the preparation, treatment, care, decline and administration of death are hugely demanding on carers.

The labour can be divided unevenly in families: Often assumptions existed from both males and females about who was expected to play a particular role and pick up the pieces where others would/could not.

The labour is gendered: The labour related to before, during and after death was often distributed differently to men and women. Often, women were more commonly responsible for emotional labour, long term support and care work.

Decision making: Many decisions have to be made by the carer in conjunction with others (the loved one, family members, and service providers) associated with the preparation, treatment, care, decline and administration of death. Carers can feel distressed when they have to make decisions alone

“Mum looked after him [Melanie's father] at home for eight and a half years. She did extremely well. The last 12 months of the time that she looked after him he wasn't to be left alone even while she went to the toilet because he went head first through the front window.”

– Melanie

How does death effect the lives of carers?

or rapidly under pressure. Some carers felt that they could not question the medical decisions being made on behalf of their loved one.

Care gaps: Many people spoke about their role in filling the gap between formal supports and their loved one's personalised needs, especially when their loved one was in an aged care facility.

Managing existing family relationships: End of life is a time when families may have to work together through emotional and logistical struggles. Grief and inheritance can both galvanise and fracture family relations.

Support for carers: caring can provide personal rewards as well as burdens and strong support networks for carers are critical.

Social death: If the loved one has experienced a long decline, the impact on daily life can take years, often with the carer sacrificing aspects of their own lives in order to provide care.

Continuity of employment/education: Maintaining employment, care and other household responsibilities can be a burden. Some had to give up their full time jobs and or education in order to care for their loved one, others had to juggle part time work with caring role and other responsibilities.

Costs associated with caregiving: often the extra costs associated with caregiving, transportation, time off work, delivering groceries etc were absorbed by the carers themselves. The Centrelink carers payment and/or carers allowance was not enough to cover the additional costs.



The death of a loved one

How does death effect the lives of carers?

Case Study

Slow death, carer's fatigue

Melanie's father had dementia over a period of nine years. Melanie's mother cared for him at home for much of that time, however the demands of care got too much. She could not leave him alone, even to go to the toilet; he was changing in character and getting abusive; it was physically demanding work.

Respite beds were unavailable or not able to be booked in advance. The struggle to find available respite care when the family needed a break was a cause of serious stress.

“You had to go knock on doors yourself. There was nowhere you could ring to find that (respite availability) out. Apparently there was a lady you could contact about respite, sometimes it was two or three days before you got a phone call back. When you call for respite you need it now.”

Supports are sought from many places

Some people found it difficult to access various advice, support, and guidance throughout the process of dealing with a loved one's death.

Formal Supports: Many participants recognised a need for formal support in helping them cope. However, they assumed it was expensive or difficult to get support particular to their needs, and this factored in to access issues.

Finding informal supports: When people think of support, it can be easy to focus on formalised, paid support. Many carers find comfort in community groups and specific support networks (i.e. Survivors of suicide.) These are often harder to find than more formalised support services.

Social support network: family are important support mechanisms, where family ties are non-existent or tenuous, friendship and neighbourhood links form a critical part of a person's informal support network.

Help seeking tendencies: Existing social norms tend to make people inclined to 'cope' with adverse situations. This is especially the case concerning emotional health. If people do not think they should be seeking help, then they won't. Upon reflection, many people thought that accessing some kind of grief support would have helped them.

It can be hard to access formal services and supports

People experienced different opportunities and barriers to accessing services.

“Grief support is not easily accessible and affordable. Not everybody can go and spend \$90.00 for an hour.”
– Nicole, Funeral Director

Knowledge of services: Accessing services is dependent on knowing what services exist, often services are not advertised.

Access to services: This is dependent on life circumstances (employment, family commitments) and financial resources.

Financial burden: Gap payments (for mental health plans) are affordable for some, but not others. Access to quality services is often dependent on socioeconomic factors.

Specialised services: Specialised services (psychologists and psychiatrists) are often not available, which may mean long distances are travelled.

Services in regional areas: People have limited access to, and choice about, the services they receive, as often services are limited locally.

Equity of services: In addition to service access difficulties, many people end up with little real choice over the kinds of care they receive in the available services.

Accepting support from external sources: In some cases, carer's preferred to provide the care themselves rather than relying on external supports. Some people did not like having strangers in their house, and thought that community nurses provided limited and often inadequate support and care.

“There is not much out there for carers. We're the people that care. We don't ask for anything. We just want understanding. That's the whole thing I think is the understanding. We're trying to do a job.”
– Dianne



The death of a loved one

How does death effect the lives of carers?

Case Study

Making peace

Angela talked to us about the death of her father Constantine, and making peace with him after many years of estrangement. Both of Angela's siblings worked full time so she took on the majority of the responsibility for Constantine. It was the 'one and only' time in his life that he said to me 'I love you'. This experience had a dramatic impact on Angela's understanding of her past and her identity.

“Mum and dad had been divorced for about 25 years and my siblings and I had been estranged from my father for about 15 to 20 years...he was an extremely abusive man... Then about 12 months prior to my father passing away we received a call to say that my father had been found in a car sort of semi-conscious, he had suffered some strokes. We just decided to settle the past aside, forget about it, and we went to his aid.”

Informal supports are vital

Informal support networks, or supports that were not professional or paid services, were essential to many of our participants in coping and recovering after a death.

Family: despite sometimes being fraught, close family relationships were a lifeline for people experiencing the death of their loved one. Parent - child and sibling - sibling relationships featured often.

Friends: support from friends is significant as it can, in some cases, focus solely on the carer's wellbeing. Having someone to check in, have a coffee or get outside of the situation for a while offers great respite.

Workplace: in some cases, an understanding boss or a colleague who just offers an ear is a great support. Having a flexible and understanding workplace alleviates much stress.

Neighbours/local community: small gestures and helpful acts like food drops at the door, an invitation for a cup of tea, collecting mail and minding children all offer great support, particularly when offered without having to be asked.

Innocent bystanders: in the case of an unexpected death, sometimes a kind-hearted passer by offers great support.

“Every night one of those people on that street came to my house at 11 o'clock at night. They made my tea and they stayed with me and staying the whole night if I needed them.”

– Elizabeth



The death of a loved one

How does death effect the lives of carers?

Case Study

Help from a stranger

Joanna's mother Michele had been told she had a mass on her lungs, but it had not yet been identified as cancerous. On her birthday, she went to the bathroom feeling sick. The mass on her lungs had ruptured and she died at home in Joanna's arms. Joanna was alone, waiting for an ambulance and didn't know what to do.

“I was screaming for help and this girl was walking past to catch the bus and she came in and I was covered in blood and this dead woman was there... She was so nice. She sat with me and cleaned the blood off my hands and face, waited till family and things arrived. She stayed with us the whole week and went to the funeral. She was like an angel.”

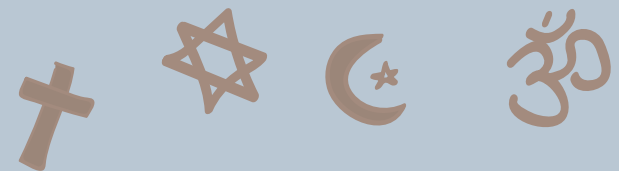


The death of a loved one

Socially and culturally diverse perspectives

60 Australian Aboriginal and Torres Straight Islanders

63 Migrant and Refugee backgrounds



Australian Aboriginal and Torres Strait Islanders

Grief, loss and death are central in Australian Aboriginal and Torres Strait Islander lives.

Much of Australian Aboriginal and Torres Strait Islander life is focused around various scales of grief and loss. In order to represent the diverse perspectives of First Australians, we spoke to indigenous service providers in Alice Springs, NT, over 3 days. Before reporting our findings from the fieldwork, it's worth noting some important statistics regarding death in Aboriginal & Torres Strait Islander communities.

Various sources point out that:

- Aboriginal & Torres Strait Islander Australians life expectancy is about ten years less than that of non-Aboriginal Australians (AIHW 2014).
- Aboriginal & Torres Strait Islander Australians die at younger ages and at higher rates than non-Indigenous Australians (AIHW 2014).
- The high mortality rate, coupled with more regular, traumatic and justice-system based deaths have created an ongoing accumulation of shock, grief, trauma, loss and sorry time for the individuals and community involved.
- Communities have unique and different ceremonies after death, and each community places significant importance in dying on traditional lands. The time before and following death are subject to a number of customary practices.

Death and Communities

No such thing as a 'natural death': In communities, blame for a death is always attributed to a primary carer, based on kinship systems. Even deaths due to old age require assigned blame and payback.

Payback: With blame attributes, communities need to exact payback on the person considered responsible for the death. This payback can often be violent (particularly in the case of sudden death of an important person), and may lead to further death.

Sorry business: When a community member dies, the entire community enters 'sorry business'. This is both a period of time and a psychological location. Camps are set up outside communities to perform funeral rites. Sorry time is considered an extremely significant time, with no set finish time. People drop everything to attend - children are taken out of school, and people apply to get out of jail to attend.

'Domestic' death: If a death occurs in the home, most of the belongings in the deceased house are burned and the house smoked. Remaining family members almost always need to relocate, resulting in periods of homelessness.

Changing names: Community members with the same name as the deceased are required to take on a new name. It is not uncommon for a death to trigger identity changes, and over the years it is not uncommon for community members to have had 5 or 6 different names.

Multiple identities: Changes in names and residential addresses make it extremely difficult to trace estates and superannuation for a deceased person. It can often take many months to trace specific identities and accounts.

Service Providers in Communities

Mentioning the dead: It is not taboo to mention the dead, but service providers who do so need to be prepared for dramatic displays of grief in response. Grief is demonstrative and performative in these cultures, which makes it difficult to understand the true feelings of those involved.

Lack of cultural knowledge: Western service providers often appear in communities in response to traumatic deaths (i.e. to prevent copycat suicides). They are regularly ineffective as they lack the specific, localised knowledge needed to navigate sorry business, and are not allowed to be present in the ways they want to be.

Mental health and cultural guilt: Rather than helping people through grief and trauma about the death itself, most mental health support in the aftermath of a death is related to cultural guilt around avoidance or administration of payback. Avoiding payback due to you often means long periods of estrangement from communities, and ostracisation from peer and family groups.

Community based supports are seen as service navigators: Most service providers in communities (teachers, medical staff) spend as many as 20 unpaid hours a week helping community members navigate centrelink and other government requirements so that they may continue to access benefits. This sometimes prevents them from doing their paid roles effectively.

Migrant and Refugee backgrounds

The loss of a loved one comes with particular challenges for people from migrant and refugee backgrounds.

We spoke to people from migrant and refugee backgrounds as part of our research. We think it is worth highlighting the broader factors impacting upon the experience of death, especially where there are marked linguistic, cultural, material and economic differences between migrant and host communities (Vasey and Manderson 2010).

Experiences of death can be compounded by:

- poor command of language, dependence on welfare support or lower positions in the employment sector.
- isolation from the mainstream society and the absence of local ethnic communities, and a diminished social circle of friends and family.
- stresses that impact their well being, including the loss of cultural norms, religious customs, and social support systems, adjustment to a new culture and changes in identity and concept of self.
- barriers to accessing the health service system and other services in general, including limited access to transport, finances, limited interpreting services, low health literacy, religious and social taboos, lack of trust in services.
- Socially constructed understandings of dying and death, grief expressions, and interpretation of the meaning of loss.

“She says in our culture (Sudanese) we don’t discuss death, we don’t talk about death, that’s why he was angry. She said to me how dare you mention death to him.”

– **Marguerite, manager
multicultural community service**

Vasey, K., & Manderson, L. (2010) The social and cultural context of immigration and stress. In Sher, L. and A.Vilens, eds. Immigration and Suicide, Stress, Psychiatric Disorders and Suicidal Behavior Among Immigrants and Refugees, New York: Nova Science Publishers, pp. 295–311.

Socially and culturally diverse perspectives

Death conversations are taboo: as with the broader Australian society, talking about death is a difficult topic, and in some cultures there is an understanding that you ‘should not think about death when you are not dead’.

Knowledge and access of services: access and engagement barriers are often greater for migrant and refugee populations due to language and financial barriers.

Cross-cultural understandings of mental health services: in many resource poor countries mental health services are often non-existent. As a result, seeking formal support for emotional distress is not accepted. In addition, a few people were skeptical about how counsellors could understand what they are going through.

Reliance of community based organisations: Often migrant and refugee groups are dependant on local multicultural/ethnic community groups for support with such things as employment, finding housing, understanding the health and legal system.

Cross-country administrative burdens: some migrants had the added complication of organising the affairs of their loved one between two countries. This can add additional emotional distress, financial strain and interruption to daily life. Tasks may involve:

- travelling to their homeland at short notice;
- organising the transportation of a body or ashes;
- planning a funeral or cremation;
- assisting with the administration of their loved one’s affairs.

Lack of social support and social connectedness: migrant’s families are often based elsewhere, and it is common to have felt a loss of community based on history, language and culture in the process of migration.

Language barriers: In addition to organising their loved one’s affairs across countries, they may have difficulties with understanding language, documents and protocols related to the process of registering the death and may need assistance with administrative tasks.

Cultural expectations around funerals: Cultures with significantly different funeral practices (such as some African communities) find it difficult to find appropriate services in Australia, or struggle to find information regarding cultural and societal norms in their adoptive country. It is difficult for them to understand what is expected of them, and what is different to their own countries.



Case Study

Adhering to cultural practices

Qi's mother Jing died unexpectedly from lung fibrosis whilst on holiday from China. Qi experienced her death without extended family support, and had to navigate laws and customs from both countries. In order to conform to their cultural practices, Jing was cremated with many items of clothing and personal effects, her ashes were transported by an Uber rather than the family car, and kept overnight in a hotel. Her ashes were quickly flown back to China for burial, which required thorough documentation.

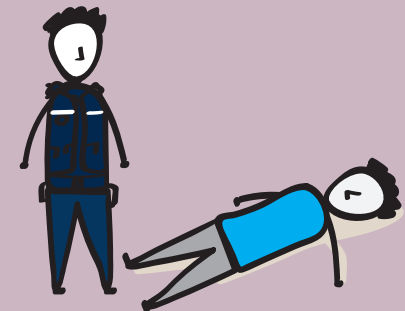
“It's terrible. When the Doctor come to me we have to pass your mum's body to the coroner office and they have to do the autopsy I said 'why because she already passed away.' They explained that is the law. I felt like we did something really wrong....I feel bad. In our tradition we want the body together.”

What is it like to be a death related service provider?

68 Even as a professional, death can be hard to talk about

71 It's difficult to work with other service providers

73 Caring about the wellbeing of death professionals



Even as a professional, death can be hard to talk about

People depend on professionals to initiate conversations about death, but professionals are inadequately trained for holding such conversations.

Professionals start conversations: but themselves find these conversations can be challenging, draining and emotional.

Professionals understand: that it is highly emotional time for people involved and make allowances for that even if it involves being abused by family or being blamed for the death.

Death literacy: professional training is rarely provided on how to sensitively deal with death during the different periods leading up to, immediately after, and in the months beyond a loved one's death. This is true even for medical professions that are the primary providers of care throughout the journey.

Professional experience: learning how to deal with and communicate sensitively about 'death' was considered something 'intuitive' and learnt on the job, through experience.

Approaching death sensitively: despite a lack of training on how to deal with death, approaching and communicating sensitively about 'death' was an important consideration for the nurses we spoke to.

“I think you do learn to deal with it on the job. Also I think part of it is inherent – it's either you know how to deal with it or you don't.”

– Andrew, lawyer

What is it like to be a death related service provider?

Case Study

Learning on the job

Even in caring and medical professions, learning to deal with death is considered an 'on the job' skill that is learned through experience. There is rarely formal training, even for end-of-life carers.

“It’s been thousands and thousands of people I have nursed to death and what I take away from that is the people that are there in the room, the family members, it’s one of those times that stays with them, everything that happened. It’s like when you give birth to a child everyone that comes and makes contact with them is imprinted on their brain forever. If we can ease people out nicely it’s so much nicer for family members and they remember it as a graceful dignified death. We do that more often than not.”

– **Gaye, Registered Nurse**

“There was a patient that died years ago and one of the staff were in Echuca and they saw the wife in the street and started talking. Her image of her husband was that I shaved him and that was beautiful to her. That was the image she kept, how this male nurse shaved her husband and had him looking really nice when she came in before he died. So we’re very mindful of what you say and how you approach people.”

– **Paul, Registered Nurse**

What did we hear about particular services?



Hospitals at the end of life

We heard about uncertainty of prognosis, delayed recognition of dying, misdiagnosis and poor communication with patients, families and community care providers.



Residential care facilities

These were hard to access and the quality varied considerably. Often they lack specialists (such as gerontologists, and mental health professionals). GP's are rarely present at clinics, which leads to delays in assessment, medication access and signing of death certificates. Staff are underpaid, undertrained and overworked.



Hospices and community-based palliative care services

The supply is limited, and only a small proportion of those who die have access to palliative care services. Hospice respite care was also in limited supply; often carers were unable to have a break from their caring.



Mental health and pastoral care

People have received support from hospital social workers, a priest, Beyond blue, counsellors (psychologist, specialist counsellors). Availability of these services is inconsistent and dependent on other issues around access.



Emergency services

Emergency services were critical in cases of unexpected deaths and were often the first point of call. Police, ambulance and medical staff can be insensitive, especially in circumstances where death has occurred at home or by accident. Their remit often means they cannot be supportive (e.g. police in a suicide that may seem suspicious).



Financial support

Where required and available, financial support was accessed from government and non government sources. Centrelink often caused people distress, and carer's payments were often considered inadequate.



Professional advice

Some participants employed private professional guidance to help them, such as financial advisors, care-home liaisons, solicitors, and real-estate agents. These can be expensive and as a consequence not available to everyone.



End of Life services

Participants liaised with funeral homes, crematorium and cemetery staff, funeral directors and celebrants. The majority of participants spoke highly of their experiences with these services.

It's difficult to work with other service providers

The service system is fragmented. Service providers find it hard to navigate the system.

Service provider silos: service providers expressed the desire to work with other services, but care is fragmented and there is a lack of integration between health and social services.

Holistic care: due to the of lack of integrated coordination of services offered by different agencies, there is less emphasis on providing holistic, end-of-life care and 'dying in place.'

Referral to other services: the service providers we talked to did not know where to refer people after they had left 'their service.'

Referral to bereavement counselling: the service providers did not know about any bereavement counselling they could refer family members to, especially for more complex family situations, such as assisting younger children of parents who are dying. Several mentioned developing information on bereavement support, but it was ad hoc.

“I know how to refer for meals on wheels but not for family members about loss.”

– **Melanie, Community Nurse**

“I think there should be some counselling out there for families. But I'm not sure what's out there. It's almost like once that patient's left my ward I'm looking at the next person to come in and their issues.”

– **Paul, Palliative Nurse**

Case Study

Sensitivity: a nurses' perspectives

Paul, a palliative nurse, described looking after a patient, who needed a catheter inserted. Together with an experienced nurse they turned the patient who subsequently had a huge convulsion and died.

The family blamed Paul for the death, and he had to decided to just 'cop it' rather than explain what he had witnessed and give that image of the death to the daughter.

“They said ‘we killed him, we murdered him. ‘ Why did you put that in, he was comfortable, why did you have to do that, why did you turn him, why did you touch him’. Very aggressive. I’m thinking to myself, I could be really blunt and tell you what I’ve just seen, but do I give that image to that daughter who is going ballistic and a grandson who is really aggressive to walk away with or do I just cop it sweet for 10 minutes. Do they want to know what I saw, him having a major convulsion and dying right in front of me?”

– Paul, Palliative Nurse

Caring about the wellbeing of death professionals

Healthy carers understand better, make more informed decisions and offer the best chance of good care and good death.

Professionals absorb people's emotional distress:

dealing with trauma and suffering on a regular basis can have a deep impact on people working in death related industries.

Emotional supports: generally providers do not access external supports (professional counselling) to deal with their 'everyday' experiences of death. They debrief with colleagues, a partner or friend and having a 'meltdown' every 6 months.' Others said 'you just move on, because the next person has got issues.'

Professionals make mistakes: due to the emotionally charged environment they are often working in, professionals can experience undue abuse from patients and family members when mistakes are made.

Professional's well-being: we tend to consider certain people or professional roles as resilient. If we want professionals to perform at their best, we need to consider their well being



The death of a loved one

What is it like to be a death related service provider?

Case Study

Professionals honouring the dead

Amanda spoke to us about the death of her mother, and her experience working as a midwife attending the death of newborn babies. There are about 2 deaths a week at Amanda's hospital and Amanda attends most of them. She prefers being there for the women, rather than giving the job to a young midwife who lacks the experience to deal with 'this awful stuff'. Amanda honours the babies who died and encourages other midwives to do the same. These rituals help them process their feelings about dealing with dying and death.

“I come home and I hug my kids a lot harder after a baby at the hospital dies. By the front door, there is a little chain of bells and I add a bell to the chain every time I look after a dead baby. I hear those ringing all the time. They're my angel bells. I encourage the midwives to buy a bead and make a bead necklace every time they look after one of these little angels or plant a tree. One midwife at work has little gems she buries under a tree every time she looks after a dead baby.”

The death of a loved one

Opportunity Areas



How might we...

Help people better plan for death?

Adequate planning was the single biggest determining factor in the experience of those responsible for managing the affairs of a loved one. Documentation of wishes was one thing, but the sharing of those wishes before a death was equally important.

Help people better navigate benefits?

For carer's helping someone through a lengthy illness, it was difficult to access and assess their eligibility for various benefits and payments.

Provide better respite and carer's supports?

Caring is a job, and carer's get fatigued and need breaks. They need respite, but they also need help keeping track of medical histories and documents. Providing better resources and information for the carer's support networks and employers is also important.

Help carers find, trial and maintain support services that are appropriate for them?

Finding the right supports and establishing the right routines for a loved one is important and difficult, and is a process that needs continuous updating and adjustment.

Help carers and medical staff articulate their needs and expectations together?

Differences in expectations and communication between medical staff and family and friends can lead to tension, stress and trauma as people near the end of their life.

Help emergency services perform their duties with greater sensitivity to carers?

Police, paramedics and home nurses struggle to have supportive conversations with family and friends of a loved one whilst balancing their duties. Our service provider participants wished they knew how to talk about death better.

How might we...

Help people document what they need to tell?

It is difficult for people to document and share their stories, and the details of a death, with service providers, friends and family.

Help people get faster financial support?

Many participants fell into short term financial hardship in relation to funeral costs and unplanned travel.

Help informal supports to know how to help?

Many people don't know what to say or do in the lead up to, or after the death of a loved one.

Help medical staff, the coroner, and Births, Deaths & Marriages communicate more effectively?

The burden of sharing of documents is currently on those suffering the bereavement. Inefficiencies in communication between hospitals, the coroner, and Births, Deaths and Marriages regarding medical certificates often lead to lengthy, stressful and traumatising delays in administration that hinder or delay the grieving process.

The death of a loved one

Future research



Next steps

We suggest that the next steps toward service improvement should include research into the following topics:

- Research with those suffering a terminal illness, to understand the process by which people approaching the end of life prepare.
- Research into the Aged Care industry, including its relationship to palliative care, to understand the type, amount and quality of end-of-life care Australians receive.
- Research with more targeted population groups, including Aboriginal and Torres Strait islanders, and CALD groups.
- A deep dive into the processes, systems and people involved in the issuing and handling of death certificates.
- Research with services, such as banks, into their end-of-life processes and procedures.

Project team

Chris Marmo, Project Lead

Reuben Stanton, Design Lead

Katie Vasey, Senior Design Researcher

Lilian Pearce, Design Researcher

Leah Baxter, Design Support

Special thanks to Leisa Reichelt and Gillian Bowan
at the Digital Transformation Agency.

Acknowledgement and special thanks are extended
to all people who generously shared their stories
with us.



