

Private Thoughts

Bringing our inner selves into the open

Edition 3: End of Life

April 2023

Introduction

Private Thoughts

Private thoughts are ours alone, kept safely to ourselves. As social animals, we learn early to fear judgement, criticism or rejection from sharing these private thoughts. However, this means on sensitive topics we are like islands in the sea, disconnected from each other, wondering whether our inner thoughts, feelings and experiences are the same as others we know. This can undermine our understanding of and empathy with others and even ourselves.

Private Thoughts is an initiative to create a way to share inner thoughts on sensitive topics that are traditionally difficult to research. This is possible by using the latest in Conversational AI technology to engage with a large group of people about sensitive topics. By talking with a non-judgmental and inquisitive chatbot people can openly and safely discuss their private thoughts, without fear of judgement or repercussion.

This edition

Our first edition of Private Thoughts addressed the highly sensitive topic of sex. Many people are uncomfortable expressing their views about sex, their sexual preferences and behaviour to others, including their partners.

We then moved on to the topic of Gut Health, a study undertaken in conjunction with The Gut Foundation and The brand agency.

In this edition, we have explored one of the most avoided and difficult topics of all – death and end of life.

In this and all future editions, we analyse and report our study findings without judgement. Our goal is to report the facts as they are and to remain objective in doing so.

About the research

For this latest study on death and end of life, we undertook a 15-minute national online survey of males and females aged 18+. Our sample partner was Pureprofile, a specialist research panel.

We explored:

- Experiences with death for self and others
- The impact of death experiences on living life
- How people experience death and dying
- The level of support available and the experience of support resources

The study was undertaken in November 2023 and n=1,025 people responded.



Introducing EVE™ and Conversational AI

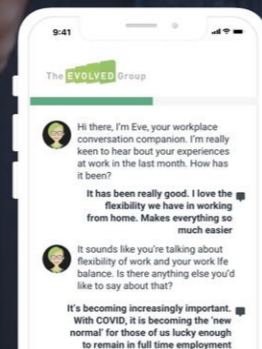
Conversational AI is the use of technology (artificial intelligence) to simulate a conversation between a human or humans and a machine. The application of Conversational AI for research is relatively new and requires quite different capabilities. Whilst Digital Assistants provide answers to user questions, the goal of Conversational AI in market research is to elicit knowledge and insights about people including their needs, motivations, attitudes and opinions.

The Evolved Group has developed Conversational AI technology specifically for application in market research, called EVE (Evolved Verbatim Engine). EVE is a system to create a guided conversation on a topic. This includes defining subject matter, guiding on where to probe or prompt and the opportunity to dynamically explore subject matter that is unexpected or new. The different parameters that guide the conversation, including seeding of subject matter of interest, is controlled through an online portal. The system includes a tool to create the conversation and it also categorises responses.

The application of conversational AI on this study means we can explore attitudes and experiences about a sensitive subject matter without fear of judgement from a human that would inhibit truthful and revealing responses into what is *really* happening.

Drawing on over 1,000 individual EVE powered conversations and advanced text analytics we've uncovered a rich data set that is often difficult to read but also fascinating and a window into the reality of how we experience death and dying.

Introducing EVE, AI powered conversations; enabling meaningful engagement with humans at scale



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"Your feedback feels more meaningful and listened to with this approach...with AI interaction providing interesting questions."

Contents

1

Experiences with death & dying

2

Working with death

3

Coping – those left behind

4

Our thoughts about death

The questions we asked

SELF DEATH EXPERIENCES

Thinking back over the last 2 years (24 months), which of the following apply to your personal experiences with death and dying

OTHER DEATH EXPERIENCES

Now thinking about significant others in your life, friends, family and colleagues, please indicate if in the last 2 years (24 months), someone close to you has...

CLOSENESS OF SIGNIFICANT OTHER DEATH EXPERIENCES

Thinking now only about your most recent experience with death and dying of a significant other. Relative to all your other relationships, how close did you feel to the person dying or who died?

IMPACT OF THEIR DYING/DEATH

Thinking about this significant other who died, how much did your shared experience of their death impact you and your life?

TYPE OF DEATH

Was the death of that significant other person preceded by an illness, diagnosis, condition or age that allowed you time to think about their death before it happened??

ACCEPTANCE

Before your significant other died, during the period where you knew they would die, did you reach a point where you felt acceptance of their death? That is emotionally and mentally you had come to terms with what would happen allowing you to make plans and prepare?

PERIOD REACHED ACCEPTANCE

How long before that person died, did you reach the point of feeling acceptance of their death?

DEATH OUTCOMES - SELF PERSONAL

Please think about your own personal experience with death or dying (IFA1A=3 "that is, not thinking about your experiences of death and dying when it comes to others"), Which of the following applies?

DEATH OUTCOMES - OTHER

You said you have experienced death or dying in relation to a significant other. Which of the following occurred because of that experience?

KEY DEATH OUTCOMES - WORK

You said that you work in an occupation where you are exposed to death and dying. Which of the following has occurred because of this?

KEY DEATH ATTITUDES

How strongly you agree or disagree with each statement about death and dying.

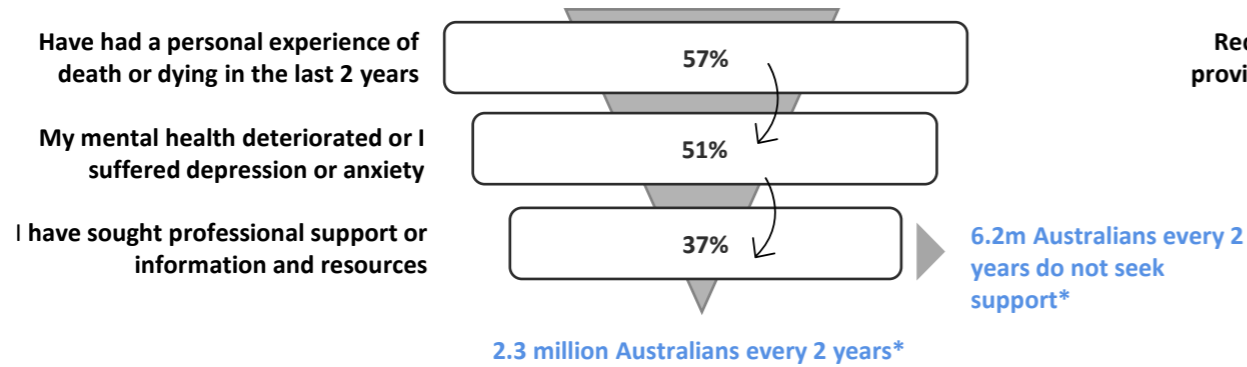
EVE TALKS ABOUT THE END OF LIFE

How I'm really keen to hear about your experiences with death and dying including the period leading up to death? Specifically, I would like to understand how your experiences with death and dying over the last 2 years has affected your emotional wellbeing. Can you please tell me your story and experiences and how they have affected you?

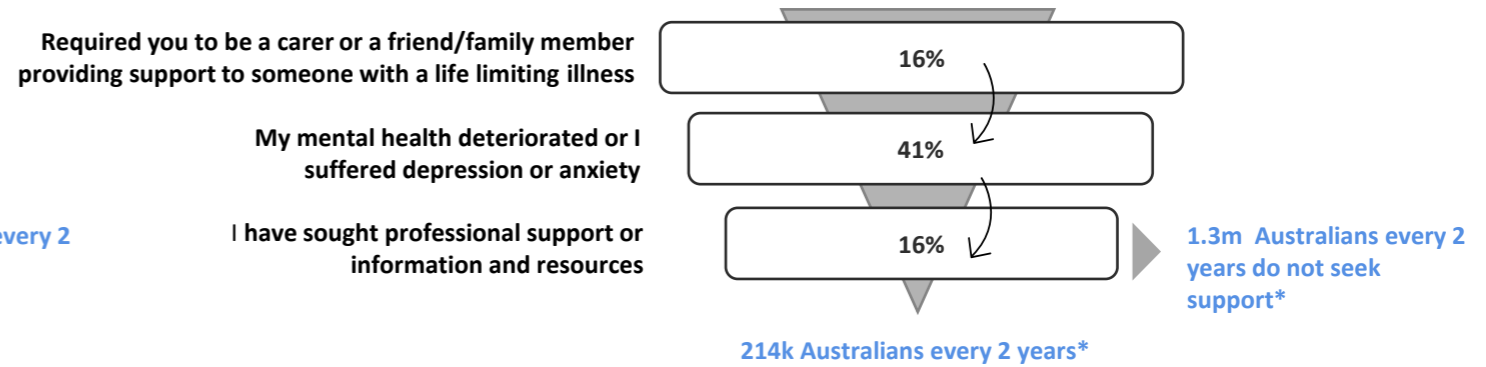
Why the findings of this report matter

This report identifies a significant problem in the way we fail to support people when it comes to death and dying. Each year, literally millions of Australians are impacted but do not seek support despite suffering serious mental health issues.

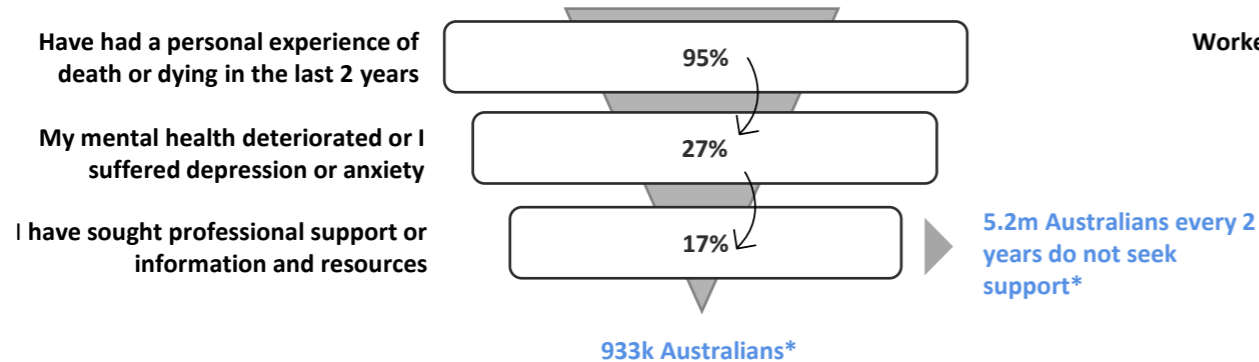
Impact of one's own experience of death or dying



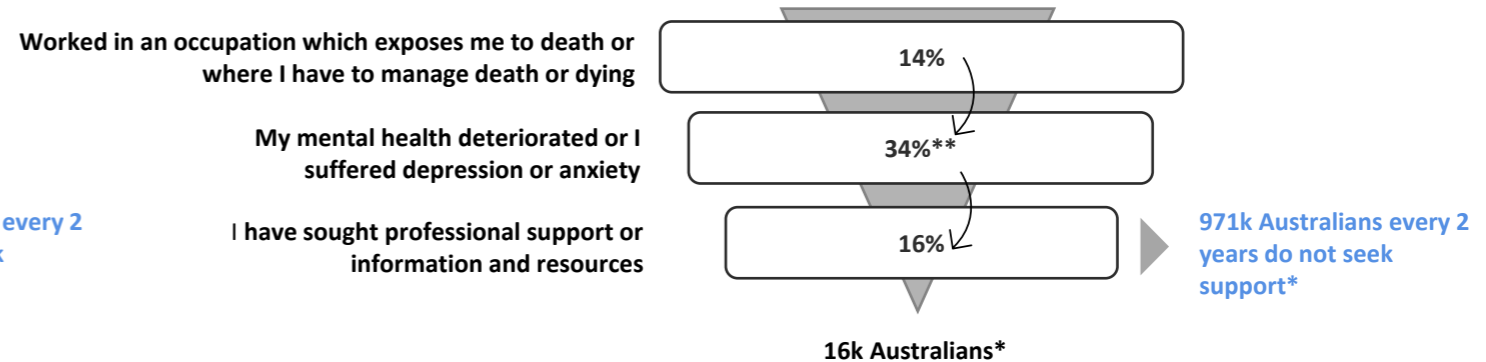
Being a carer for someone with a life limiting illness



Impact of experience of significant others death or dying



Impact of working in an occupation dealing with death or dying



** 35% also took time off work and 51% said it impacted on their personal life and wellbeing

Using Conversational AI, 1,000 Australians had shared their experiences of death and dying

So it isn't just the numbers, in this report, we have also considered the human impact by allowing people to spend a few minutes sharing their stories anonymously with a non-judgmental but inquisitive chat bot. Here are some 3 examples from the 1,000 stories we have reviewed to write this report



My mother and three remaining grandparents passed away due to health and age related issues. I felt powerless to prevent their suffering, but gave all possible support that I could.

Can you tell me what you found the most emotionally difficult aspect of this experience? How did this impact you?

Their suffering, and a feeling of loss, caused me to feel sad and scared. My own feelings were not especially important to me at the time, but have become difficult to manage since then, as I have not yet dealt with the grief.

Thank you so much for sharing. Before we finish, please tell me about a memorable experience you have had with support resources for death and dying, and how you feel about how much support is available.

There are minimal support services available for people who are grieving, they take time and financial resources to obtain.

My husband was diagnosed with an aortic aneurysm and had to have open heart surgery. It was a very stressful emotional experience and going through that during Covid where he could have no visitors or anyone to hold his hand while he was in preparation for a huge operation was something that I will never forgive the government for

Can you tell me what you found the most emotionally difficult aspect of this experience? How did this impact you?

The most emotionally difficult thing was knowing how scared he was and not being able to be with him

Thank you so much for sharing. Before we finish, please tell me about a memorable experience you have had with support resources for death and dying, and how you feel about how much support is available.

We had no support in fact he was discharged from the private hospital 5 days after his operation only to be so sick he ended up back in hospital 2 days later

My brother-in-law was diagnosed with blood cancer. It was a slow lengthy period of treatment and we could cope with the thought that he might pass away but hoped it would not be soon. We thought life would go on while he was being treated and we would be able to plan holidays together with him. Suddenly the diagnosis was terminal with days to live. We were all in denial. How could someone so strong and active be going so quickly. The suddenness of his death has left us unable to cope / understand/accept that he has really gone.

It sounds like you're talking about a sense or level of denial. Can you please tell me more about that?

He was very active and strong. How could someone so healthy develop cancer and die so suddenly. He died 10 days after his final diagnosis so we had little time to actually understand / comprehend / accept that he would no longer be here. Our families did everything together and now he wouldn't be there.

Thank you so much for sharing. Before we finish, please tell me about a memorable experience you have had with support resources for death and dying, and how you feel about how much support is available.

Palliative care did everything possible but at times due to rule, regulations or accepted guidelines they could not act fast enough. We needed an immediate assessment done due to his imminent death but had to wait our turn. In our case support was not available when we needed it.



Part 1:

Experiences with death & Dying

Experiences of Death and dying affect all Australians

01

Over a two year period, most Australians will need to cope with an experience of death. Whether it based on a personal experience (53%) or that of a significant other (95%) death is truly the one constant in life.

Death and dying are triggers for multiple negative emotional, physical and financial outcomes

02

Of even greater concern is that breadth and extent of the impact of death and dying is not matched by people's awareness or willingness to engage support. For example, over a third of us indicated that death has caused their mental health to deteriorate, yet only around a third (37%) of that group sought support. Clearly, this national issue is not getting the focus it needs.

Those who deal with death in their professional life, are particularly impacted and unsupported

03

41% of people who are exposed to death and dying in their professional role indicated it has impacted on their professional life and wellbeing. Yet only 15% said they had sought professional help, information or support.

The impact of death on our wellbeing can be reduced by preparation and planning

04

When a person is prepared and accepts the expected death, the proportion indicating it had a negative impact on them decreases from 78% to 56%. This strongly highlights the opportunity for proactive support rather than reactive support.

There is also an underlying need to help all Australians understand death and dying and reduce anxiety about it

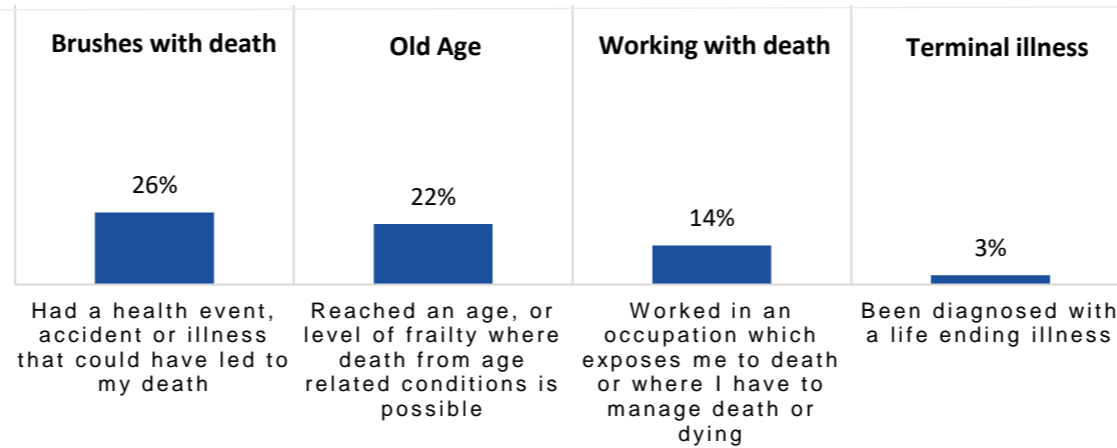
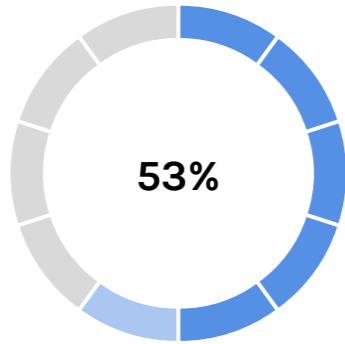
05

Almost half (46%) of Australians agree they are fearful of death. Even more concerning is that (34% agreed that they have struggled with grief and have been unable to fully return to life after the death of someone close to me. Only 45% agreed that there is sufficient support for people to help with the emotional impact of death or dying.

More than half of Australians have had a personal experience or mortality in the last 2 years...almost all of us have experienced loss or impending loss of a loved one over the same period.

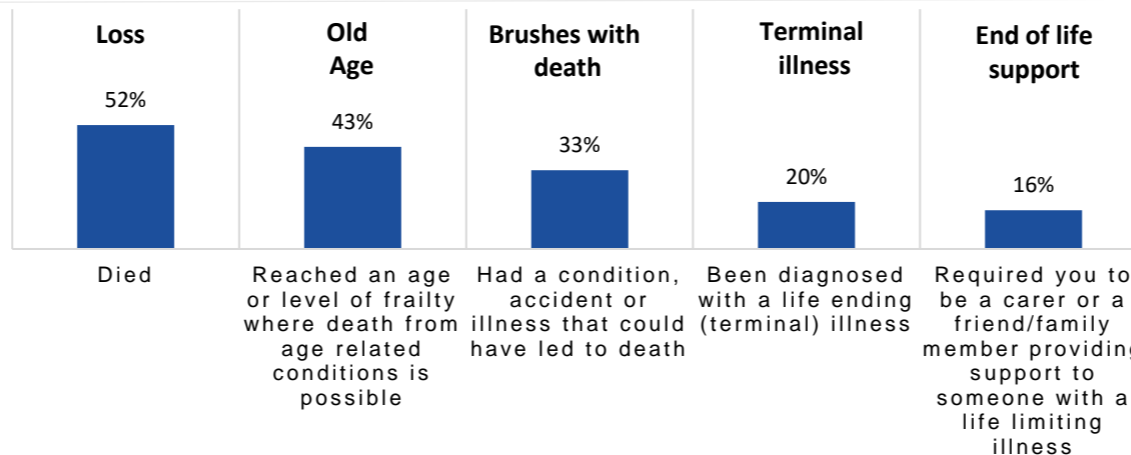
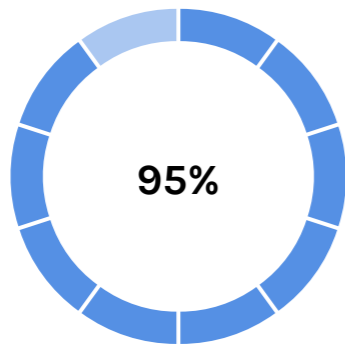
Experience with Death and Dying - Personal

Base: All (n=1,025)
Thinking back over the last 2 years (24 months), which of the following apply to your personal experiences with death and dying. I have...



Experience with Death and Dying - Significant Others

Base: All (n=1,025)
Now thinking about significant others in your life, friends, family and colleagues, please indicate if in the last 2 years (24 months), someone close to you has...



Insight

Death and dying is omnipresent. It is all around us all the time. In Australia, just within the last two years:

- 53% had a personal experience with their own potential or impending death
- 95% of the entire population experienced the potential, impending or actual death of someone close to them.

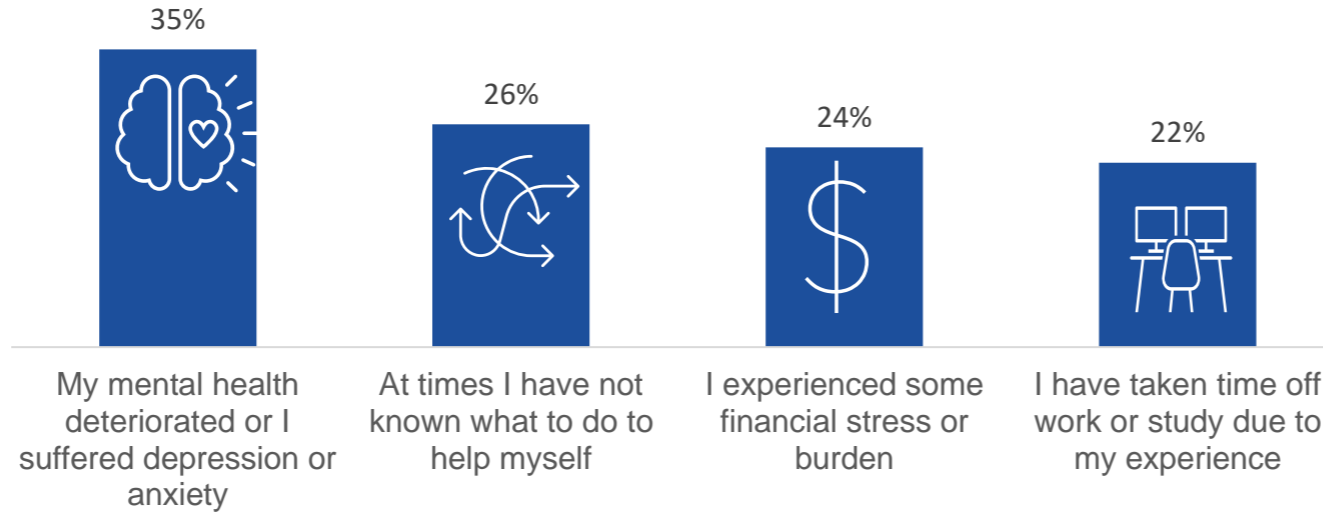
These figures highlight the pervasive impact of mortality on our lives and the importance of preparing for end-of-life situations.

It also begs the question, when death is so pervasive, why are we not talking about it more in public discourse?



The impact of a personal experience with death is varied but potentially profound – particularly for mental health - yet few people are seeking support or talking to significant others about it

Impacts from personal experience of death



Spoken to significant others about death or dying	32%	38%	31%	30%
Sought professional support, information or resources	37%	34%	43%	36%



Insight

The impact of a PERSONAL experience with death or dying can result in a deterioration of one's mental health, some financial burden and having to take time off work or study.

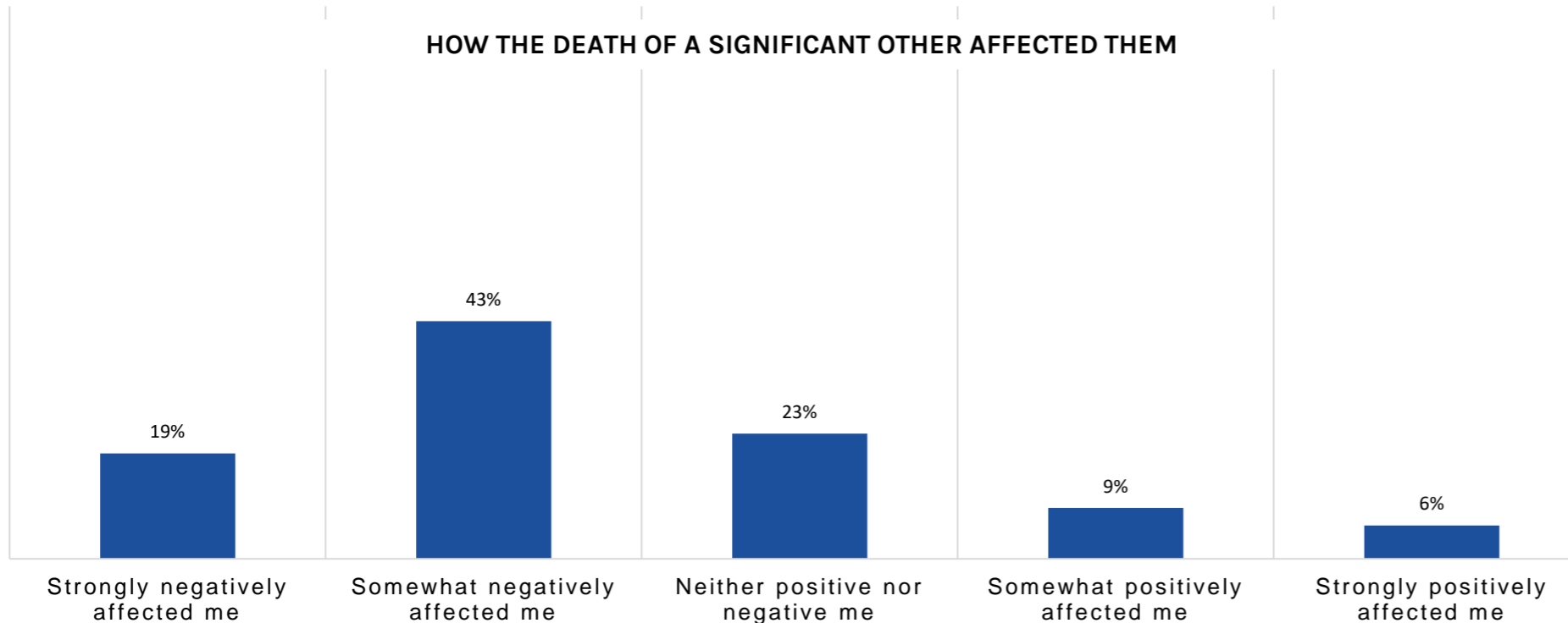
Yet...

- A quarter (26%) of people did not know what to do to help themselves
- Only one in three people (35%) are speaking to significant others about their death and dying
- And, only one in five people (20%) have sought professional help



The emotional experience of the death of a significant other is strongly negative

Nearly two thirds of Australians (62%) said they were negatively affected, with almost one in five (19%) saying they were strongly negatively affected. Death was actually a positive experience for 15% of people.



Insight

The proportion of people who said the death strongly negatively affected them almost doubled if the death was unexpected (26% versus 15% if it was expected)

Being unprepared adds to the shock and grief. There is less or no time to come to terms with it ... or say last goodbyes.



PRIVATE
THOUGHTS

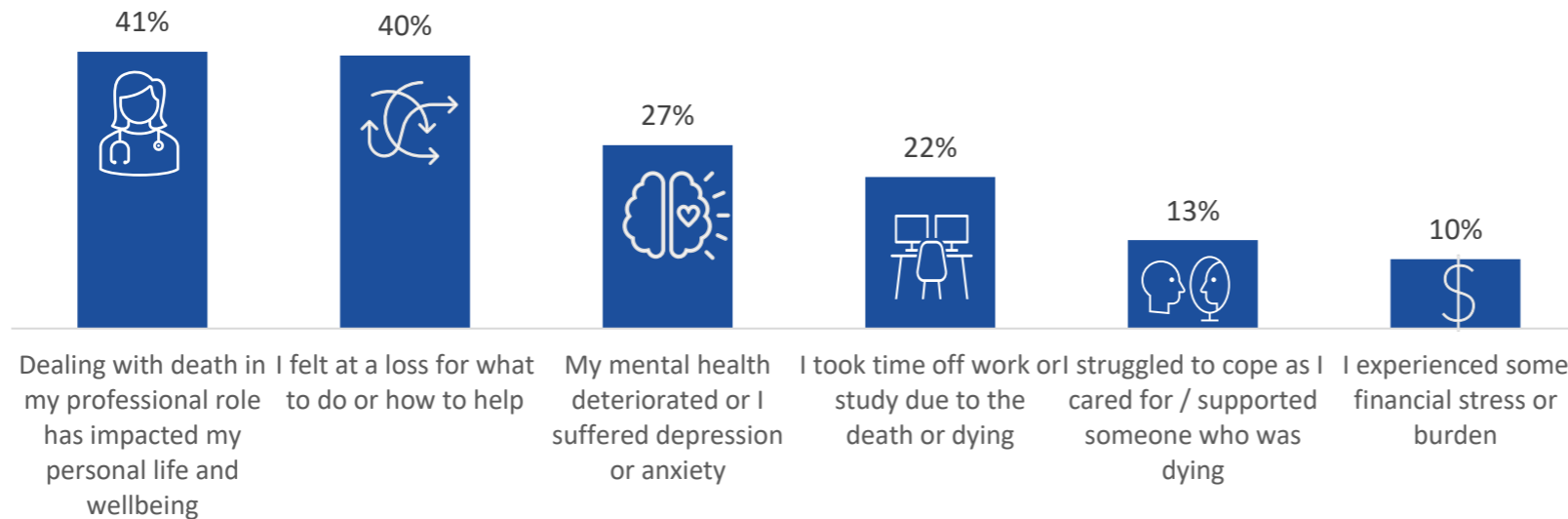
Base: (who had someone close to them die in the last two years n=530). Text colour indicates significantly higher / lower results at p<.05 versus the average.

Thinking about this significant other who died, how much did your shared experience of their death impact you and your life?

The death of significant others has an even stronger negative impact than when we have a personal experience with our own mortality – yet we are less likely to seek help or speak to the person affected

Over three quarters of people said they had one or other negative impact – most notably an impact on their wellbeing, not knowing how to help and mental health deterioration.

Impacts from significant other death experience



Spoken to significant others about death or dying	25%	24%	23%	23%	34%	30%
Sought professional support, information or resources	15%	8%	17%	17%	20%	23%



Insight

A group that is particularly negatively affected are those who care for others who are dying.

Amongst this group, which is 16% of Australians (more than 3 million people)...

- 56% said that it impacted on personal life and wellbeing
- 41% said their mental health had deteriorated
- 39% struggled to cope
- 21% experienced financial stress or burden

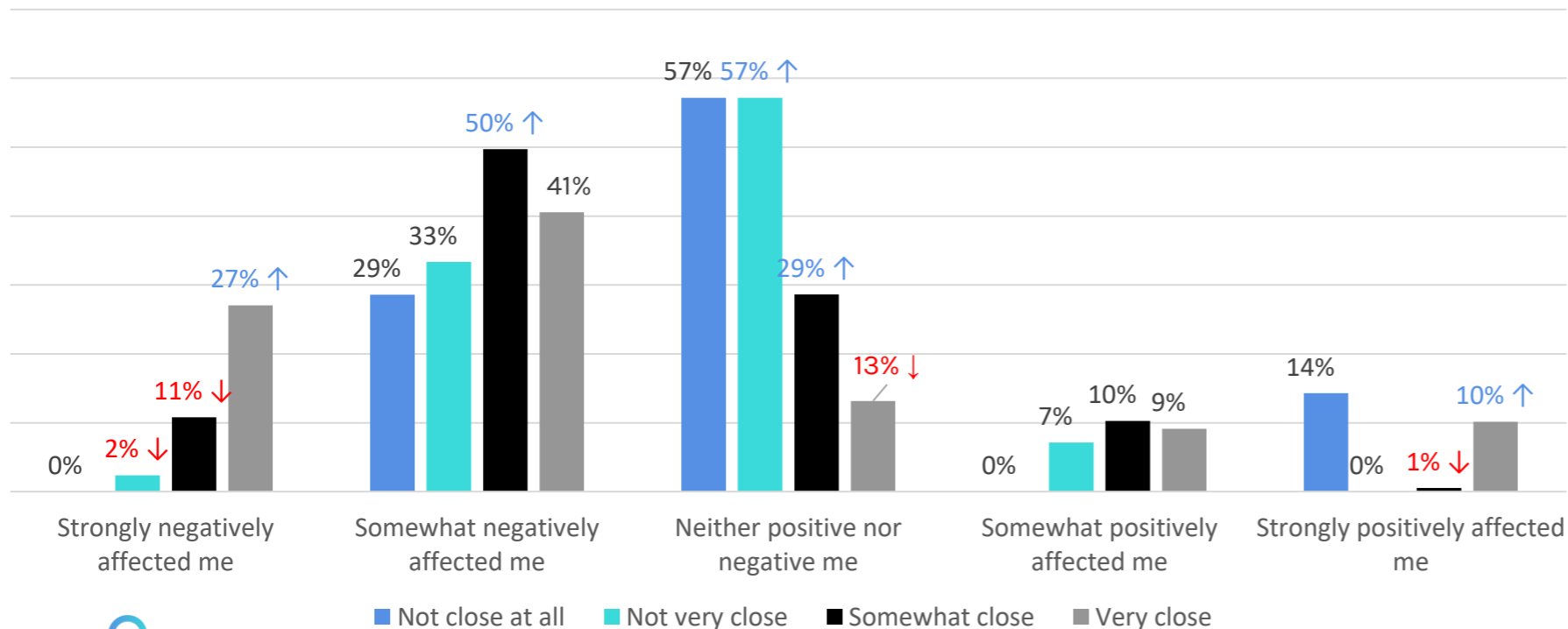
For all Australians who experienced the death of a significant other, 40% were at a loss for what to do or how to help and only 9% sought professional help.



As would be expected, the death of someone close to us is a profoundly negative life experience

Although, we do not need to feel particularly close to the deceased to be negatively affected – the death of anyone we know can have a significantly negative impact

HOW THE DEATH OF A SIGNIFICANT OTHER AFFECTED THEM



Insight

Even if not close, the death of someone we know can be traumatic. Particularly if it is witnessed or the details were particularly harrowing. The EVE conversations tell us that the outcome of experiencing the death of a significant other is that it also makes us think about our own mortality, and for some, a trigger to fear our own death or those we love.

Dying or losing someone is one of life's most challenging experiences

When the deceased was ill and in pain, death was seen as a relief from suffering. If they were old and frail, death was not totally unexpected and part of the cycle of life – death can be a celebration of their lives

“

Losing a close family member was **distressing, heart breaking and draining**. I had the chance to speak to the loved one before her death and felt while this helped me it also **traumatised me**. The weeks and months afterwards trying to cope with the immense loss. This made me **exhausted, feel down and seek support from those around me experiencing the same situation**. It took a while to get through it. I felt like I coped as well as I could during this traumatic time. I coped as well as I could on my own and sought support from others when I needed it. (Married, 45-54, Female)



I have been **stressed** trying to cope with this issue and at times **felt alone**. My husband wasn't sure how to support me and I felt totally drained and exhausted. My sleep patterns weren't good either and had difficulty with eating too. Coping with being there emotionally to support my father and dealing with all medical staff involved in this situation I was in. **I felt alone and mentally it took a toll on me because everyone else in my life are busy working or coping with their own families**. Support is there and plenty of helpful brochures. People particularly social workers are caring individuals who showed compassion and empathy towards me. (Married, 65-75, Female)

I have seen my close friend dying in a road accident recently. It was shocking and I could not believe that he is no more. **It has a really bad impact on me and my mental health. I never expected things to turn the way they have**. Life without your friend is impossible. **When you lose someone who is so close to you, it makes your life unexpectable**. I was in touch with the support services and they really help me in understanding about the life and how should I cope up with the loss. (Married, 35-44, Male)

“

I think it made me realise that life is very short and fragile and I feel that my happiness was affected as I constantly do something with an end in mind. For example, I will be on a vacation and I will think that I have only XXX number of days left. **I don't fully immerse myself with things I want to do because I keep thinking about the end in mind**. It is not a bad thing but there are times I wish I could let loose and have fun.

Nobody in the family talked about it. The person who passed was my grandfather and my mother and grandmother were very affected. As the only daughter, I felt obliged to support them emotionally and be there to comfort them on my down days. **There are days that I don't want to deal with it too but I feel that I had to be there for them**

Sometimes I will watch a touching movie or do something that reminds me of my grandfather and I find myself very distracted. I cannot focus or I will shed a quick tear and it makes me very drained emotionally. Other times I just become really numb to the world and nothing shakes me or affects my emotions. I think **my emotional wellbeing just slowly declined**. Somedays I find myself feeling tired and low though I did not do anything strenuous. **Sometimes I just don't want to socialize**.

I did not actually seek resources available. Somehow I just pushed the thought aside. The funeral and cremation was so quick and no one really processed emotions, **would have been good to have someone to talk to at that point in time**. (Single, 18-24, Female)

The one question that I kept asking myself is **why me?** I have not done anything bad all my life but yet I am dying from cancer. So why me? Others had done wrong yet they are rich and healthy and live way past 100... **It is not fair...**

I have considered killing myself many times already and the only thing that is holding me back is my family. No one can help me right now. Not even god can help me. **So I am just dragging my dying body day after day and see how long I can keep dragging it along**. (Married, 45-54, Female)



When losing someone can be a positive experience

When the deceased was ill and in pain, death was seen as a relief from suffering. If they were old and frail, death was not totally unexpected and part of the cycle of life – death can be a celebration of their lives

“

My father who was 87 and **illness had taken its toll** on him, passed away. He had **come to terms** with it and as he has always said, the only certainty in life is that one day we will take our last breath, we just don't know when that will be, **so enjoy 😊 life and make the most of it**. It may sound harsh, but **relief** comes to mind, as **dad wasn't in pain** anymore. I'm now 59 and was diagnosed with a cancer 2 years ago which has been treated and no longer an issue. So as dad said, the day will come so make the most of today 😊👍. Dads farewell was a **celebration of his life well lived**. Worked hard, provided for his family and left us in good stead for the future. A very good support network of family and friends to help during the difficult times. (Married, 55-64, Male, Perth)



It hasn't really affected me other than some sadness at the time and a period of missing the person after their death. The person involved was frail and elderly so it was somewhat of a **relief her suffering was over**. Some sadness, particularly at her funeral, but it is **the way of life and a natural part of life experience**. She **went quickly, no pain and it was expected due to her frailty and age**. No support used. The funeral parlour did a good service. (Married, 55-64, Male, Melbourne)

I am **very accepting of knowing that we all have to die one day**. A close friend and I hope that we will die in our sleep. The recent death was a very good friend of mine but when she went into **hospital I knew she did not have long and I had accepted that**. I have never used support services. I know the people I love who have died will be with God and that sustains me. I also feel that God helps me to cope. (Single, 65-75, Female, Melbourne)

My experience confirms that death is part of living. This helps me deal with my inevitable death in an accepting way. Being **able to support someone as they passed proved invaluable for my emotional well-being**. (Single, 55-64, Male)

“

My wife and **I had an amazing experience with her dying father**, I gave him permission to leave us which he apparently accepted & he died within a hour - I felt **elated that I had psychologically helped him to accept his fate**. (Married, 75+, Male, Sydney)

My sister died within the last two years. While I knew it was a distinct possibility, it still came as a **shock** when it happened. She was 82, **had COPD, breast cancer and a certain amount of dementia**. I still miss her terribly, and it is hard to come to terms with losing her. I still think of phoning her before realising that she is no longer just a phone call away. **There is a great sense of loss. I accept the fact that death is inevitable** (I am also at an age where I could quite possibly die from health problems). Having lost friends and family over the course of my life, **I accept that it is part of the cycle, and that no-one can live forever, and who would want to?** I think younger people have a tougher time accepting death. Friends and family are the best support when you lose someone you love - particularly people who also knew the person who has died. People who will share memories of them and let you talk about them. (Single, 75+, Female, NSW)

A friend who I had known for 70 years recently died and although I am sorry, it hasn't affected me in any way. It was **not difficult to accept. He was 81**. I felt sorry for his wife but she has accepted his death as part of life. You **should accept it as part of your own mental health**. Some people carry on like its the end of the world but it **has to be accepted and move on**. (Married, 75+, Male, Sydney)

Nothing has been emotionally difficult, it's been a calm experience. Everyone dies, it's the last part of living and I've accepted that. I've accepted that **I'm going to die soon and I think that it will be a blessing**. I nearly died in recovery after an operation and the medical staff kept me alive. (Married, 65-75, Male)



When people expecting the death accept it before the event, it reduces the negative impact

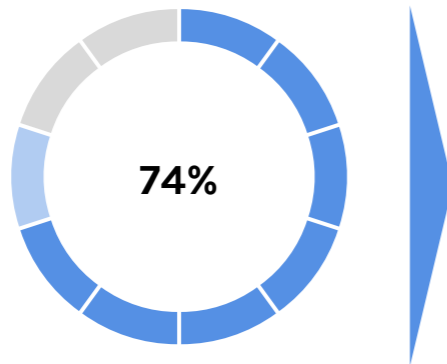
This highlights the importance of counselling and support services and the impact on millions of Australians who are unable to come to terms with the impending death of their loved one.

Acceptance of Death?

Base: All (n=348)

A1e. Before your significant other died, during the period where you knew they would die, did you reach a point where you felt acceptance of their death?

That is emotionally and mentally you had come to terms with what would happen allowing you to make plans and prepare?



74% said they had accepted the death of a significant other when they had time to think about it before it happened

Versus how the death affected them....

Column %	Yes	No
Strongly negatively affected me	11%	27%
Somewhat negatively affected me	45%	51%
Neither positive nor negative me	28%	14%
Somewhat positively affected me	11%	1%
Strongly positively affected me	5%	7%
NET POSITIVE	16%	8%
NET NEGATIVE	56%	78%



Insight

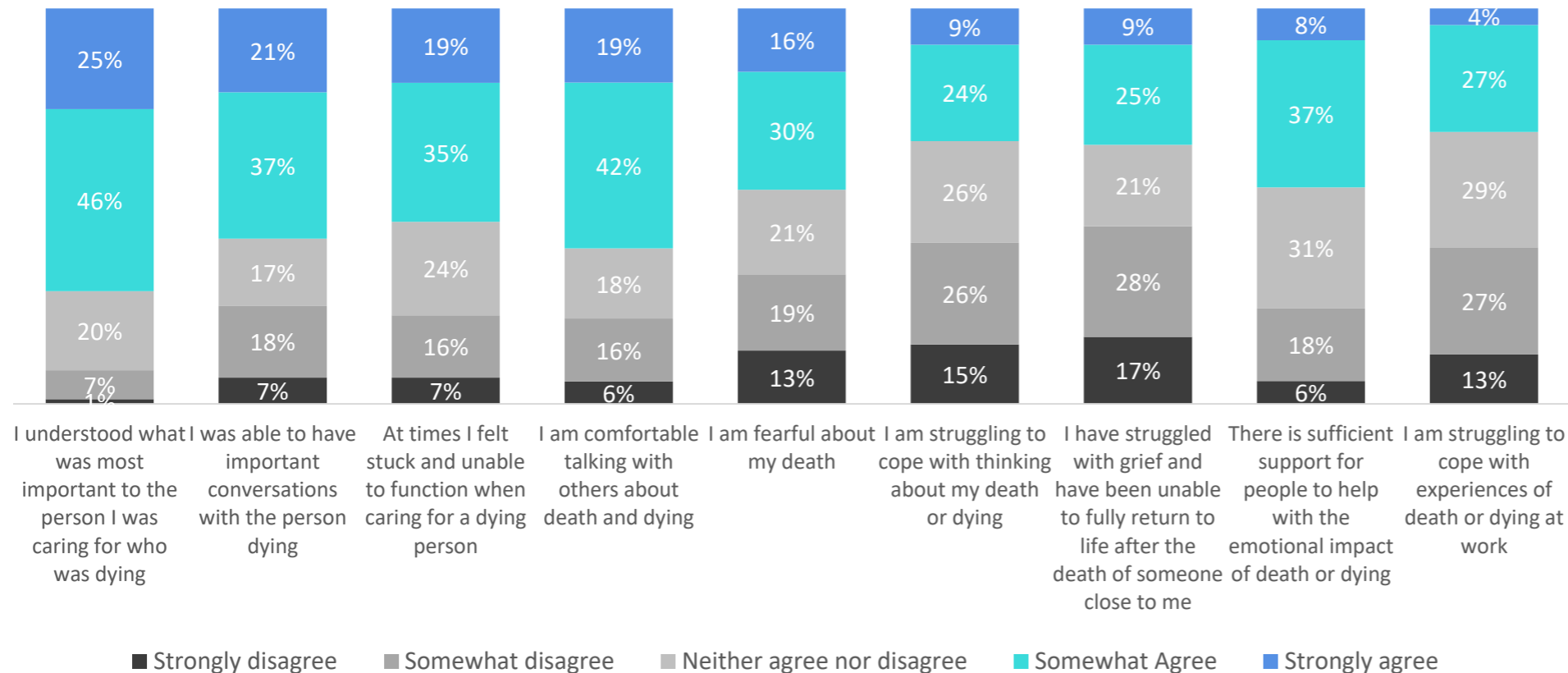
Having time to come to terms with the fact that a close one is going to die makes it easier to reach acceptance. The grieving process begins before the person actually dies.

The EVE conversations help us understand why this is the case. People talked about:

- When death is known to be coming, one has the time to talk with the dying person. The mood can be shifted with meaningful reminiscing and reflection. They are able to discuss the dying person's feelings, hopes and wishes. Knowing about an impending death allows us to say goodbye and reach some sense of closure.
- Often, death is preceded by a painful illness which helps us see death as freedom from suffering. It can be a relief.



One in 3 Australians will struggle with death and dying in some way and almost half of us are fearful about our own deaths



Insight

More than half (56%) of people aged 18 to 24 agreed that they had struggled with grief and unable to fully return to life after the death of someone close.

One third of all Australians overall are struggling with their grief, coping with their own mortality and the experiences of death and dying at work.

Almost half of the population are fearful about their own death.

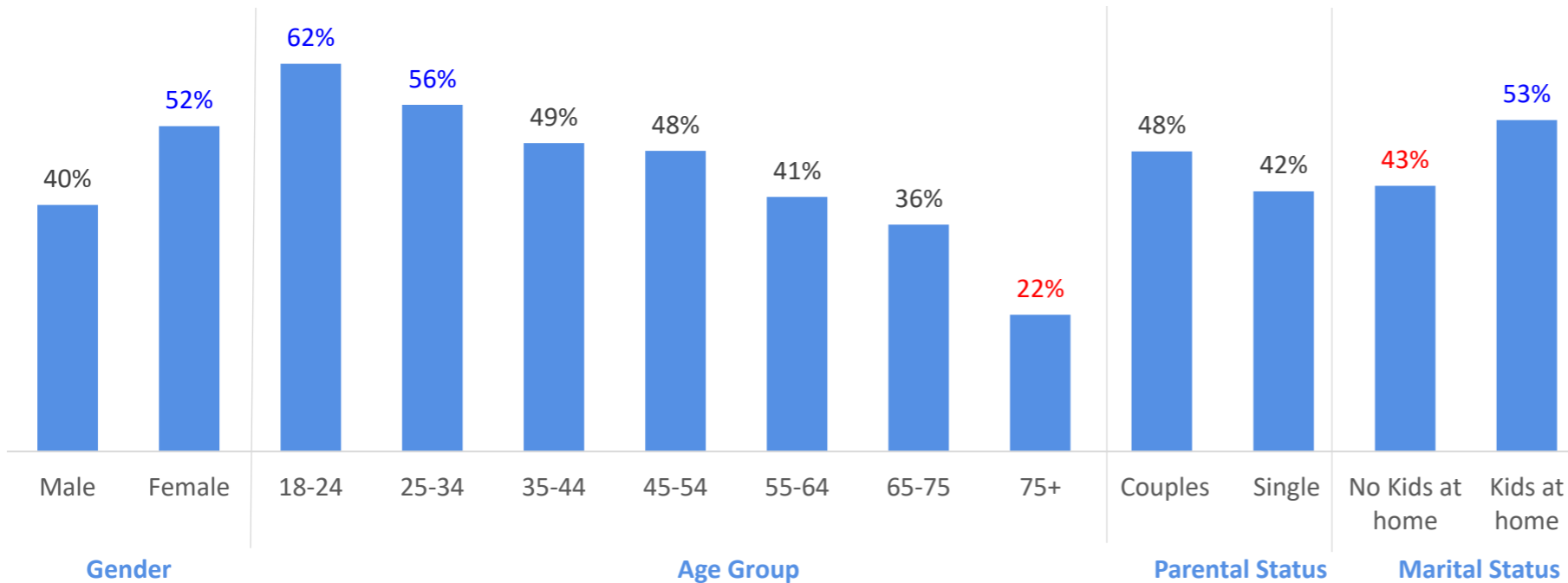
Although 45% agree there is sufficient support to helping with the emotional impact of death or dying, that still leaves just over half who disagree.

From the EVE conversations, people often commented that:

- They didn't know support was available
- They assume it is expensive or otherwise inaccessible to them
- They don't know where to go to find it

Fear of death declines as we age – women and people with children have the greatest fear of death

% agree / agree strongly 'I am fearful about my death



Insight

These insights confirm what is intuitive in nature, namely:

- Younger people fear death more than those over 65's
- By the age of 75, our fear of death has reduced considerably with over half of this cohort disagreeing that they are fearful of their death
- The fear of death is slightly higher for couples than for singles
- Those with children also cited a higher fear of death than those with no children:
 - In the EVE conversations, people often mentioned concern for the partners, children and families they leave behind



An Example Conversation with EVE

EVE is powered by artificial intelligence and can actually hold a conversation!



I'm really keen to hear about your experiences with death and dying including the period leading up to death. Specifically, I would like to understand how your experiences with death and dying over the last 2 years has affected your emotional wellbeing. Can you please tell me your story and experiences and how they have affected you?

After my wife contracted cancer I cared for her and was very well supported by my employer which enabled me to give her the care she needed. After she died I felt that I was **grieving** forever. I still miss her every day and sometimes get very **depressed** thinking about her. I also experience profound loneliness, particularly in the evenings when it just used to be the two of us at home. Now living **on my own** I feel very **isolated** despite **friends and family** being around.



Can you tell me what you found the most emotionally difficult aspect of this experience? How did this impact you?

Dealing with her passing was a massive thing for me. I **couldn't talk** or even think about her without getting **emotional**



It sounds like you're talking about things that were or are difficult. Can you please tell me more about that?

Not much more to say, we lived our lives very closely, and now it is **difficult** to live life without her



Thank you so much for sharing. Before we finish, please tell me about a memorable experience you have had with support resources for death and dying, and how you feel about how much support is available.

I did get excellent support from the nurses in the local **palliative** care team up to my wife's passing. Then it all just stopped. After her death I didn't know who or what to **turn to** to help me through it. (Single, 55-64, Male)



How it works

Eve's probes are configured to explore topics across our sample but autonomously controlled by AI

EVE Tags this as feelings and wants to know more, seeking clarification with a probe

EVE then asks a general probe about the most emotionally difficult aspect to help flesh out more of their story

EVE then sees that the respondent has mentioned difficult emotions and probes on that

Topics are also tagged in analysis even if they are not probed - talking about it, services



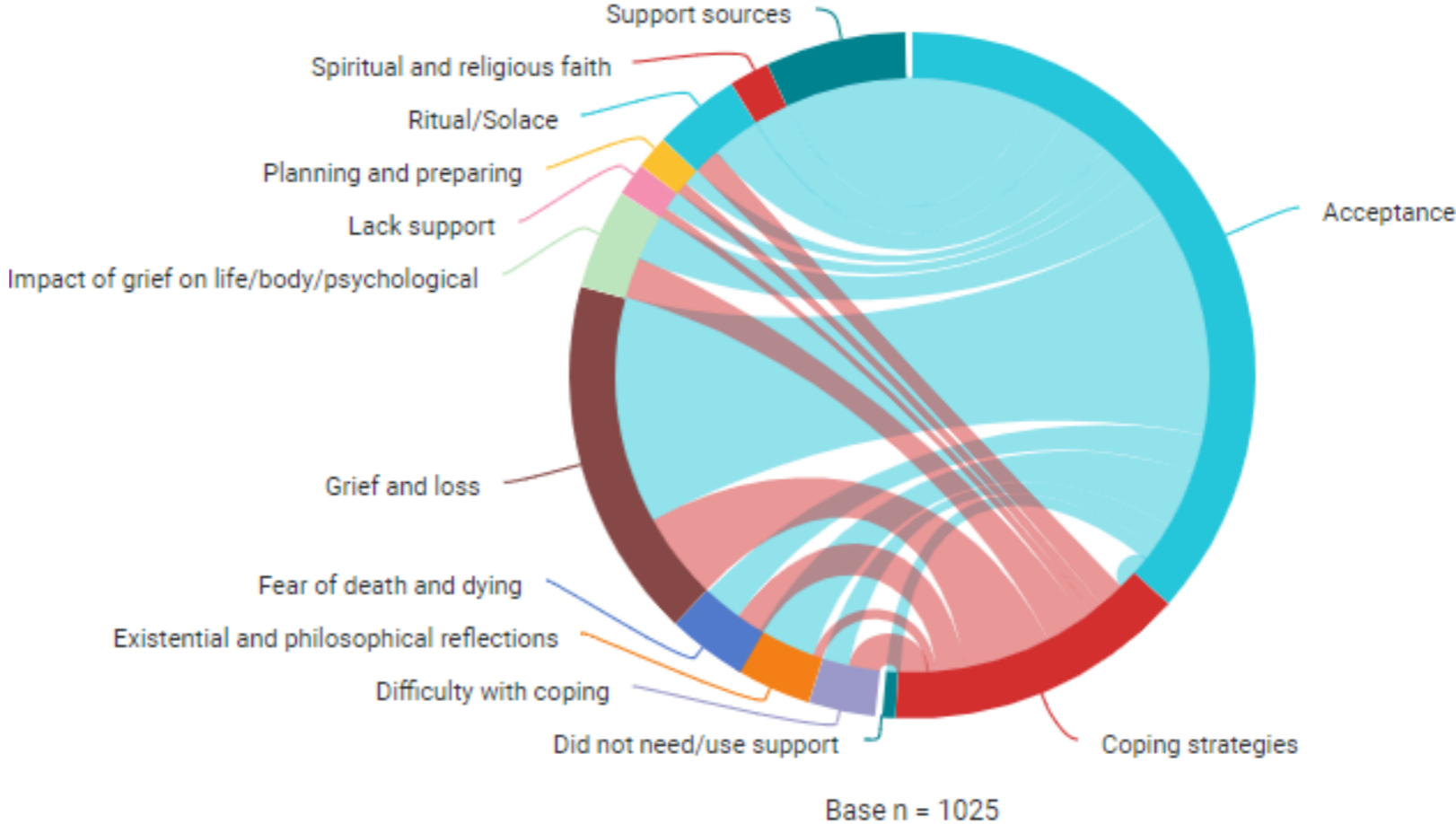
The key discussion points about death and dying are Grief and Loss and the coping strategies that lead to Acceptance

Somewhat akin to the stages of grieving, this validates the need for people to find ways to understand death and in doing so, not allow it to undermine their happiness or engagement with life

An array of other factors assist with this, whether it is support resources, planning, ritual and solace, reflections on the nature of death or developing one's own coping mechanisms

Text Analytics Explainer

A Chord diagram shows the prevalence of different topics in the conversations and how they relate to each other. IN this chart, we can see acceptance is the most common topic mentioned in conversations and that it is strongly related to grief and loss and support. Coping strategies are key and are linked to the experience of grief and loss.



We turn to rituals, religion and control through planning and preparation to cope with our feelings of grief and loss

Support is also particularly negative when mentioned in the context of a perception that it is not needed or is lacking

Text Analytics Explainer

This chart shows how often each topic occurs in conversations and death and dying (vertical axis) and the average sentiment of the topic when mentioned (horizontal axis). This allows us to see clearly what experiences and issues are contributing to the overall experience of death and dying

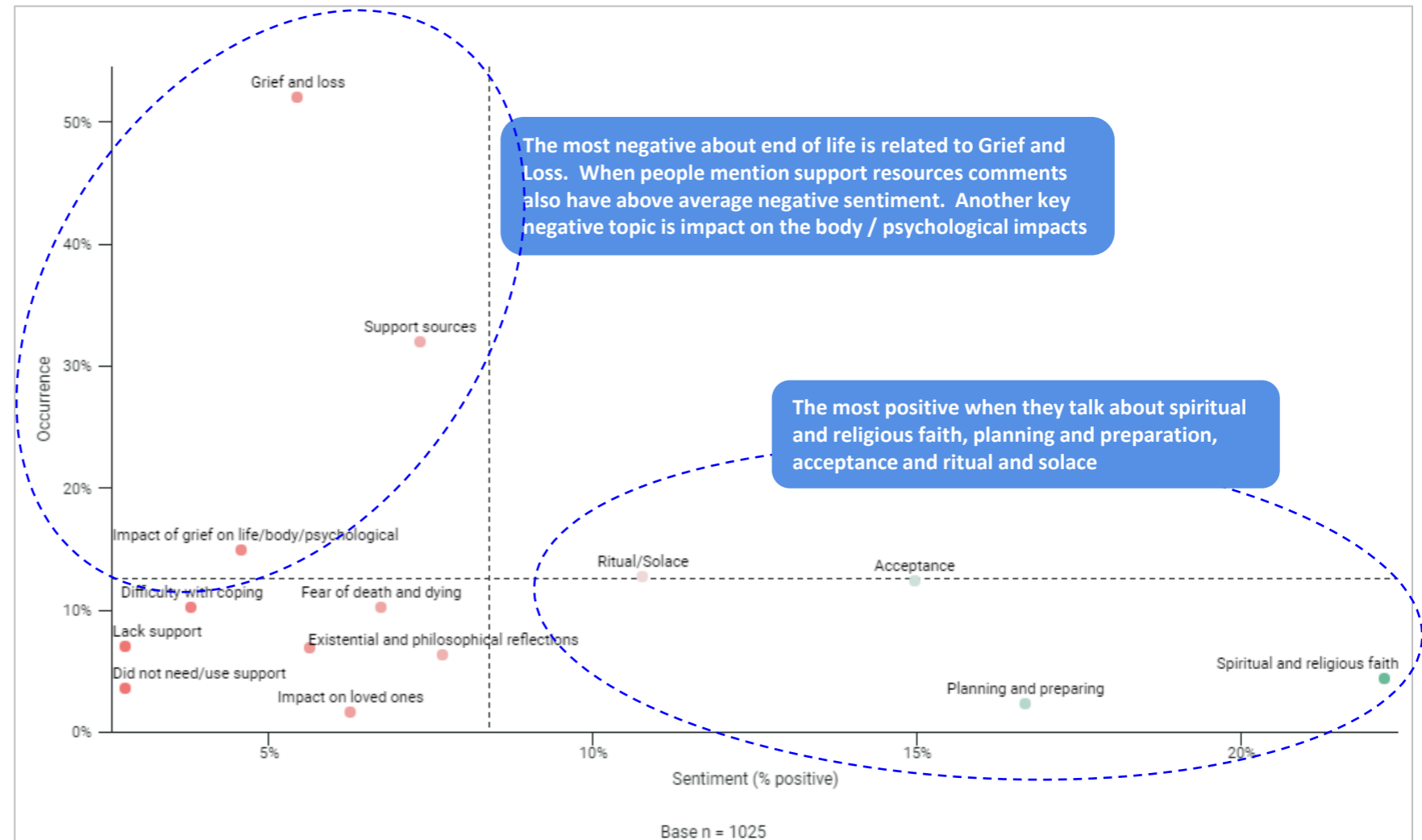
"There are minimal support services available for people who are grieving, they take time and financial resources to obtain." Male)

"I had no actual support during that time. I know through My Gov there are people who can help you but I didn't know of any at the time." (Female)



PRIVATE
THOUGHTS

Key topics discussed with EVE about death and dying versus sentiment



The most negative about end of life is related to Grief and Loss. When people mention support resources comments also have above average negative sentiment. Another key negative topic is impact on the body / psychological impacts

The most positive when they talk about spiritual and religious faith, planning and preparation, acceptance and ritual and solace

The single strongest driver of acceptance is Ritual and Solace, followed by support resources

Those least likely to feel acceptance were more likely to mention existential reflections, coping strategies and religion and faith

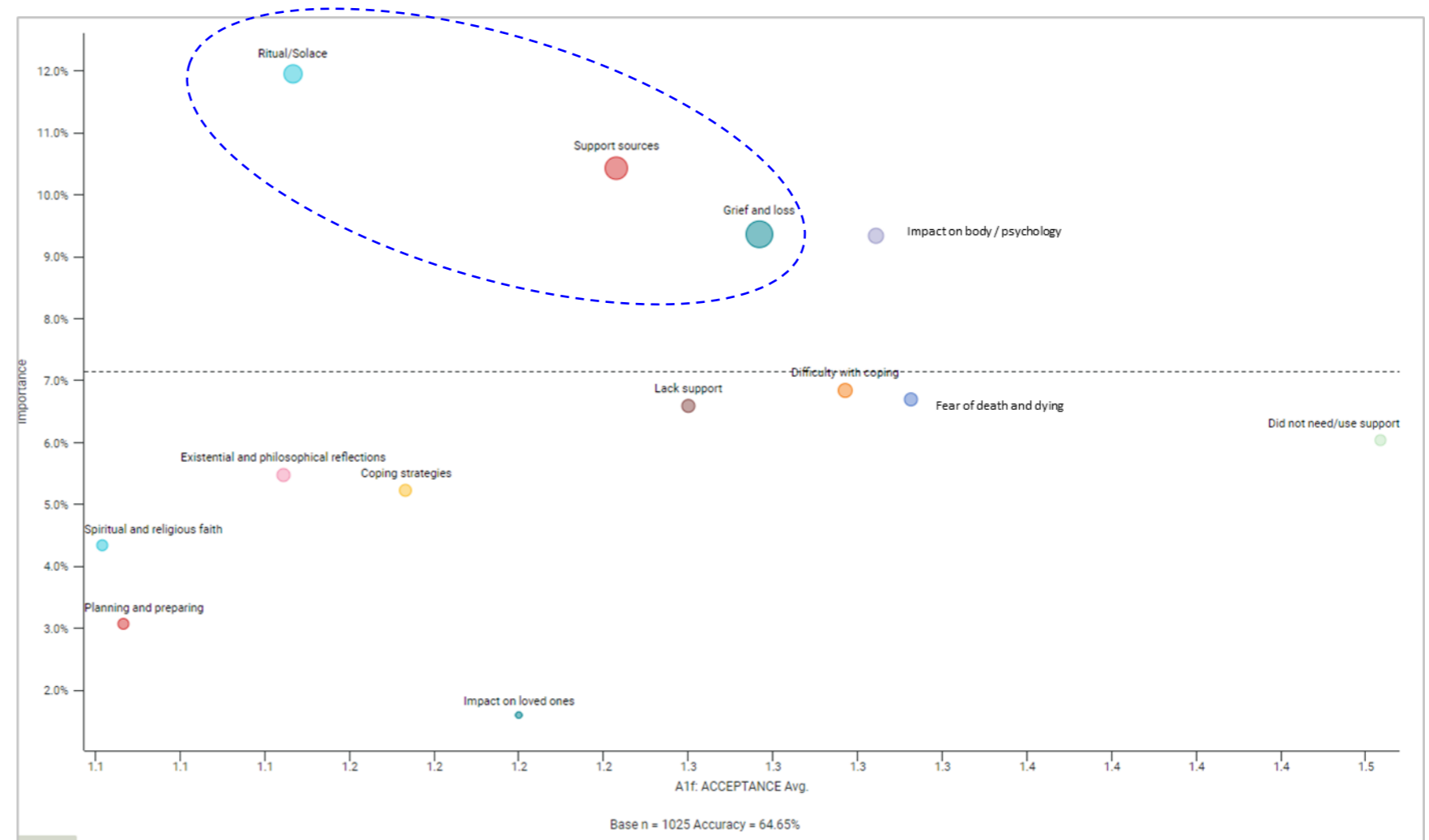
Text Analytics Explainer

This chart is a form of driver analysis – it tells us what experiences of death and dying are likely to increase the level of acceptance. The vertical axis is the 'importance' of each experience and the horizontal axis is the level of acceptance when the topic is mentioned. The size of the bubble indicates how often the topic was mentioned.

"I googled lots of methods for dealing with death and dying. I talked to my local council nurse about emotional support. I found their service were great." (Female)

"Good support was given by the funeral director, very understanding" (Male)

Impact analysis – topics and how they drive acceptance



Women have a lot more going on than men when experiencing death and dying

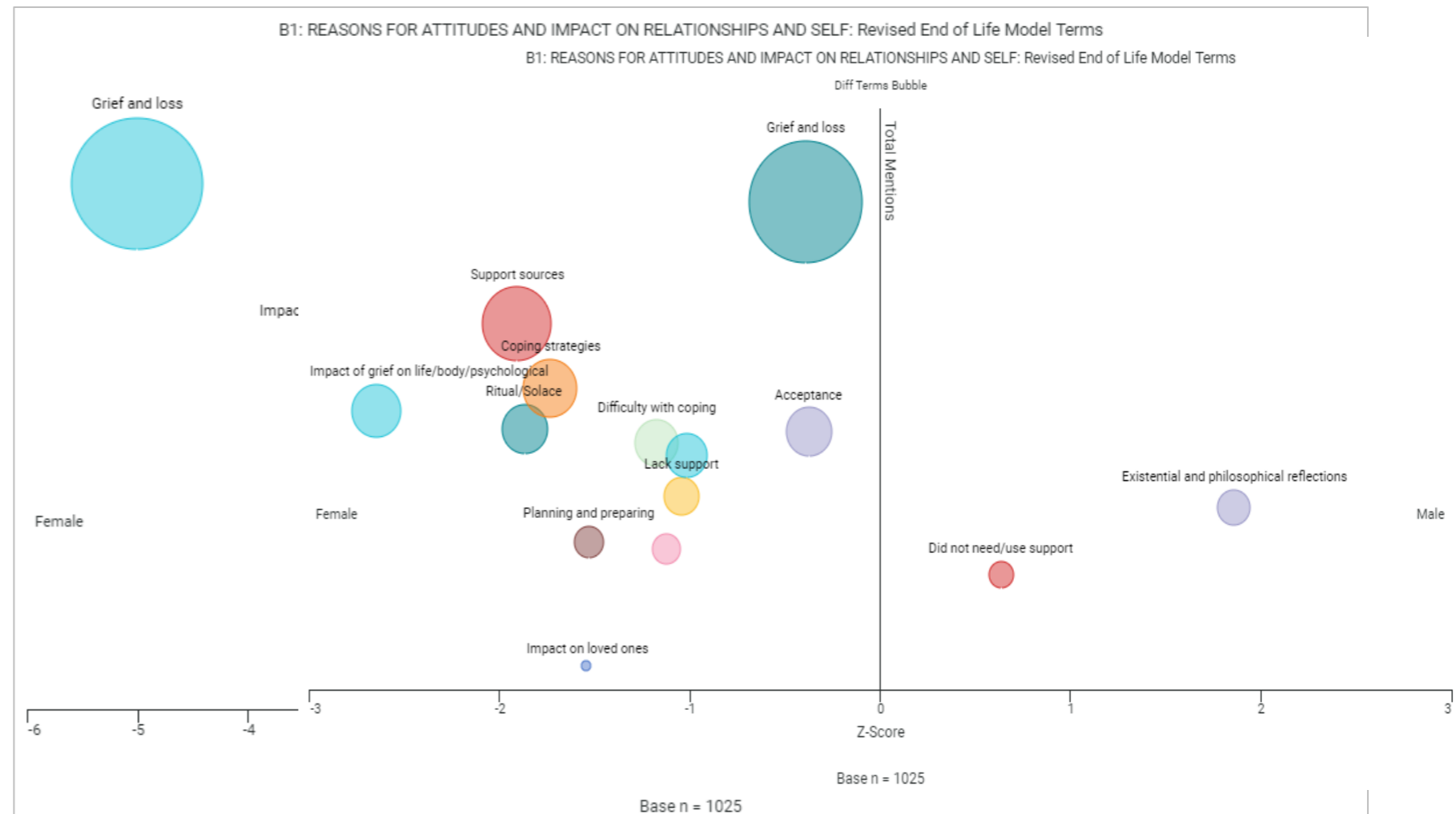
They think and talk about it more, feel it more and do more than men. Men, of course, also suffer grief, however, they are more likely to reflect philosophically and are less likely to need or seek support.

Text Analytics Explainer

This chart compares text between two groups to identify the terms that are different between them. The terms on the left are mentioned more by women and those on the right by men. The size of the bubble indicates how often the topic was mentioned.

"It was a traumatic and challenging time, with high emotion and high need for support from family, friends and services. Losing someone, it left me alone and isolated. It's nice to have comfort and closeness with another, when you lose someone you lose that closeness, comfort and connection you had. Not enough support is available." (Female)

"I have accepted the death as it is part of life. Beforehand I had a well-balanced view and approach to death, so it did not severely affect me. It has reminded me to cherish life. (Male)"

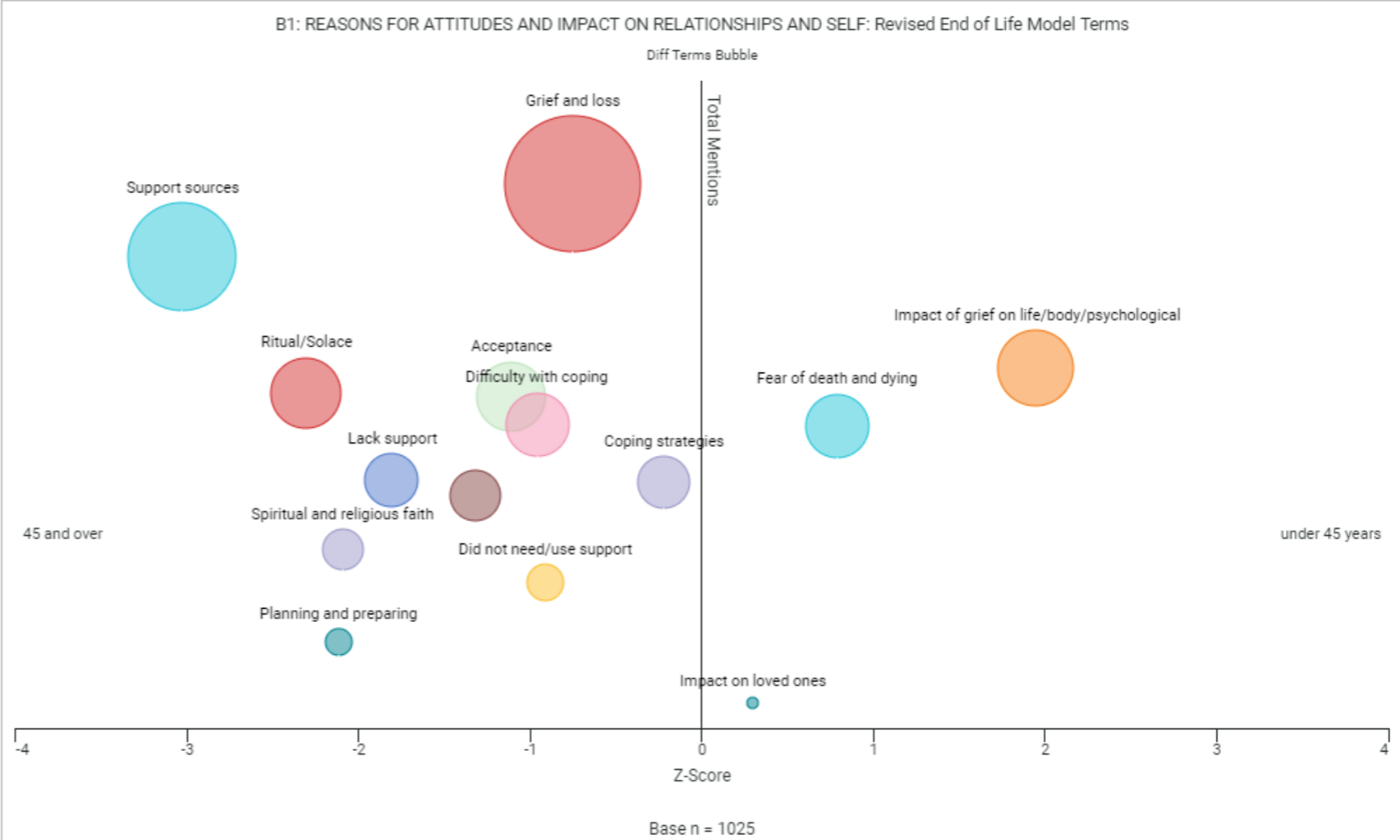


Those aged 45+ have more experience and a broader perspective of grief, death and dying than those under 45 years

Younger people fear death and dying more and tend to talk about the impact of grief on one’s life, body and state of mind. Older cohorts talk about the many things that go along with death and dying, especially the emotional impact of grief and loss and support services.

“I get very anxious about dying it’s very scary and I would hate to leave my family behind. It impacts my mental health and anxiety. There is some support from agencies but with anxiety it’s hard to approach.” (25-34 years)

“I experienced my fathers death years ago and took a long time to come to terms with it and when my mother was dying I had a more realistic approach and acceptance, though I do miss her because it left a hole as I looked after her for quite a few years.” (65-75 years)



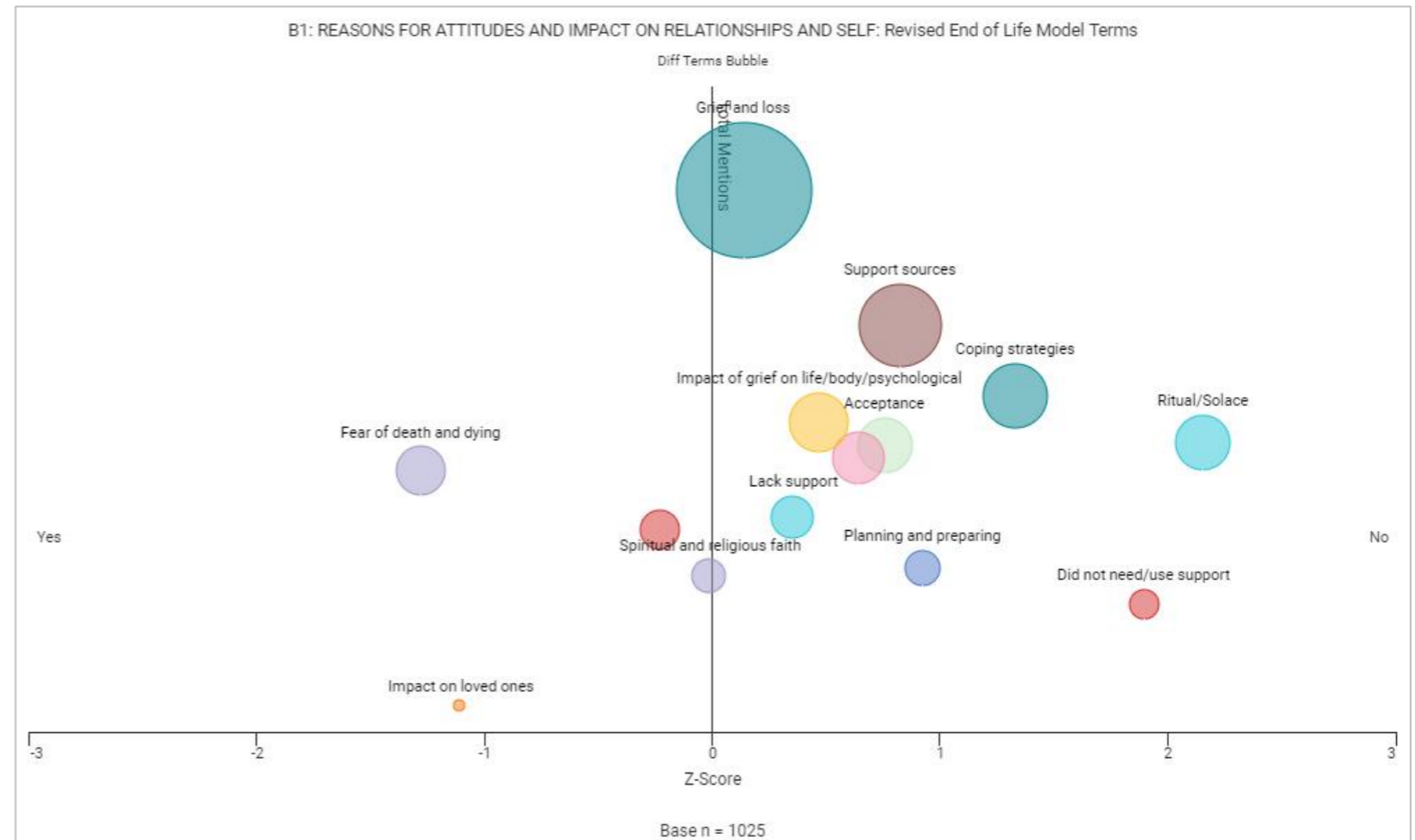
Parents of dependent children express more fear of death and dying and the impact it would have on loved ones

There is a natural fear about what would happen to one's children and loved ones in the event of a parent's death. It becomes a top issue on one's mind.

"The death of my father has made me overprotective of my children (two of which have life-threatening diseases), to the point I'm sure they feel suffocated. I have nightmares about losing my father and my children as a result. I suffer a lot of anxiety."

"Makes me think about how my children will cope with my death. Makes me plan to do more things with my family. Discuss wills."

"A number of people I know have died over the last two years, of varying ages. Been to two funerals in the last months of women in their forties with young children. Thinking about their children and the impact on their lives."

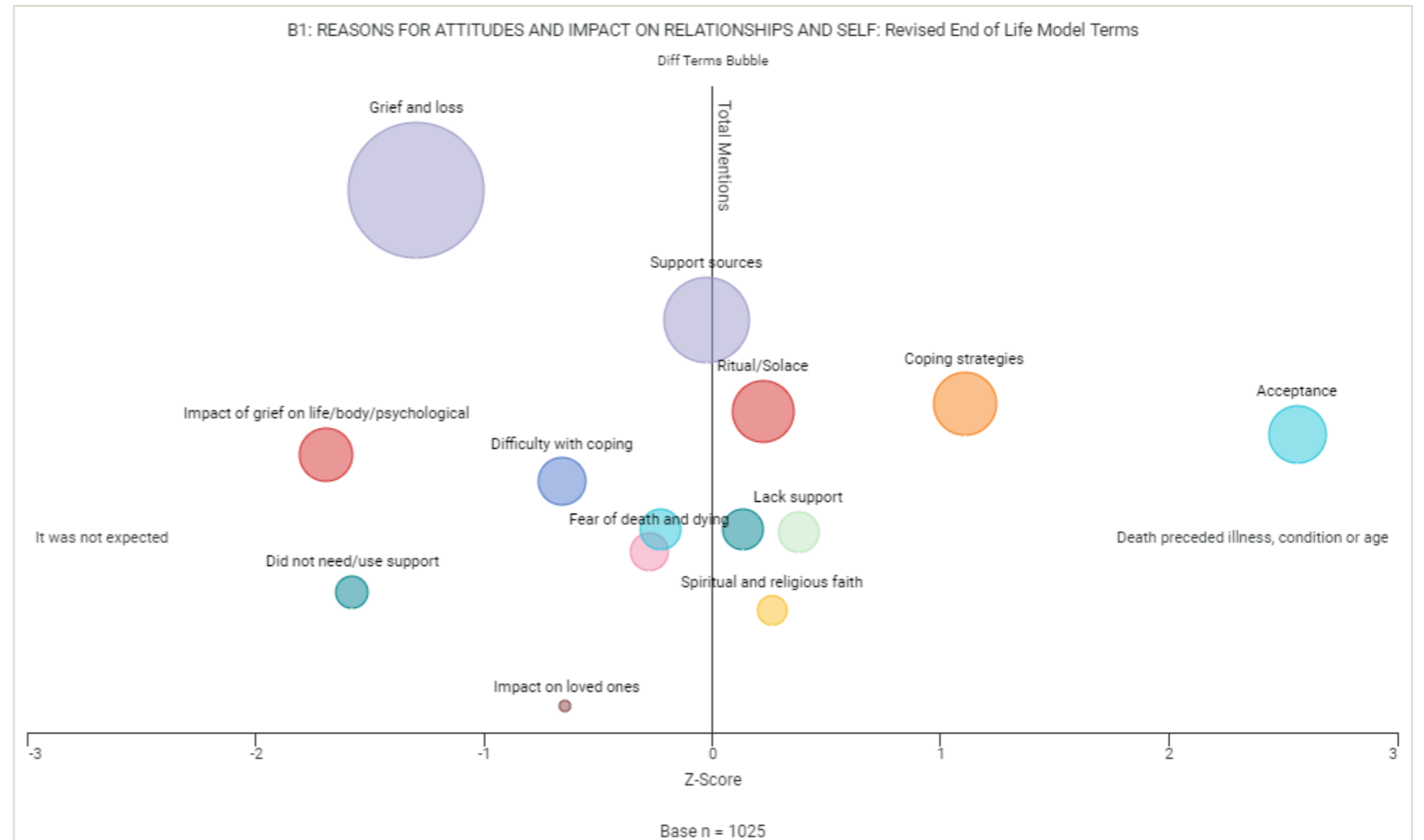


Acceptance is easier when a death is expected

There is ample time to develop coping strategies, seek support where needed and find solace in ritual and spirituality/religion. An unexpected death, though, can trigger a fear of death and people talk more about the difficulties they experience in coping afterwards.

"My brother-in-law was diagnosed with blood cancer. It was a slow lengthy period of treatment and we could cope with the thought that he might pass away but hoped it would not be soon. We thought life would go on while he was being treated and we would be able to plan holidays together with him. Suddenly the diagnosis was terminal with days to live. We were all in denial. How could someone so strong and active be going so quickly. The suddenness of his death has left us unable to cope / understand/accept that he has really gone."

"He was very active and strong. How could someone so healthy develop cancer and die so suddenly. He died 10 days after his final diagnosis so we had little time to actually understand / comprehend / accept that he would no longer be here. Our families did everything together and now he wouldn't be there."



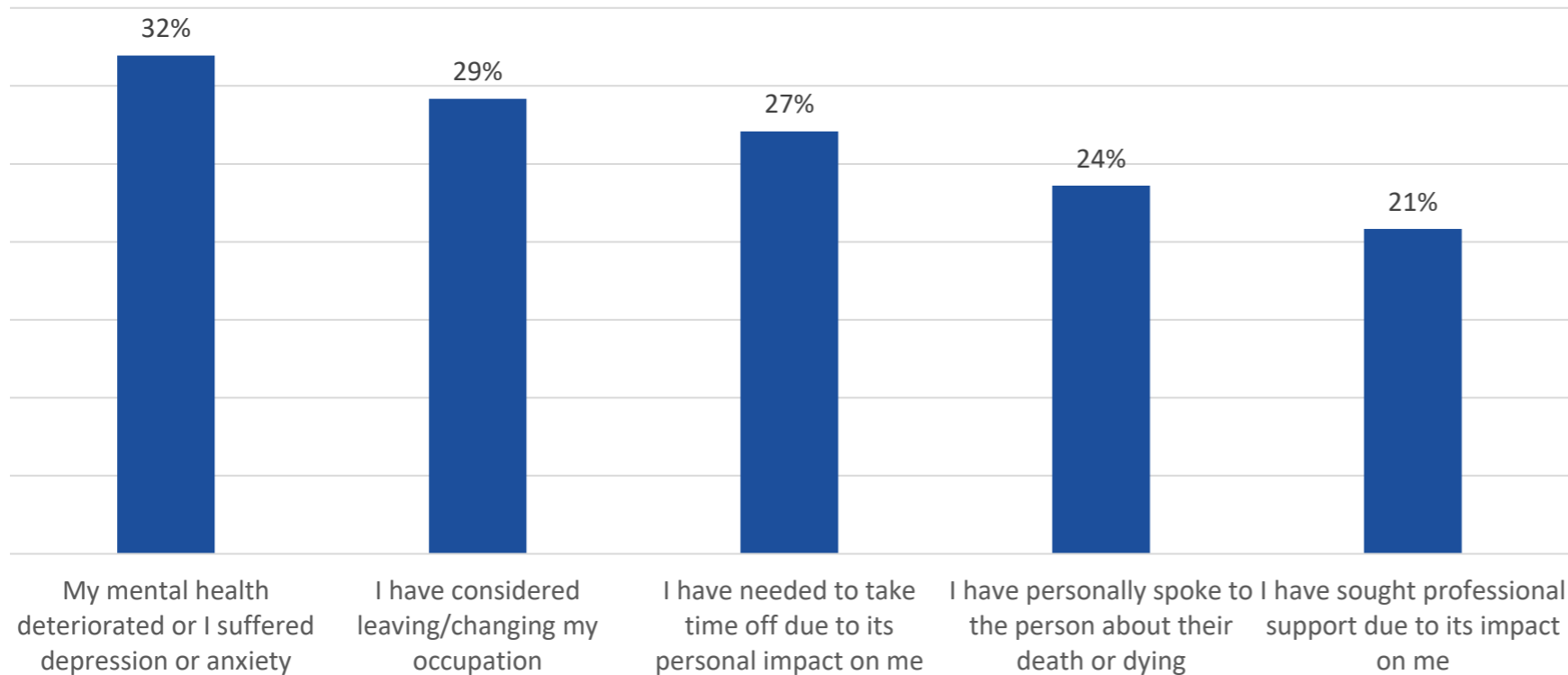
Part 2

Working with death

Working in a job where you are exposed to death or dying takes a toll

This suggests many people don't ever fully adapt to this side of their role, with almost a third saying they have considered changing occupation - often these are the people supposed to help others.

Impacts from significant other death experience



Insight

Working in a profession where you are exposed to death can be bittersweet. These workers told us that it can be rewarding taking care of ill, old and frail patients, but it also takes a mental toll.

We heard from those who work in animal welfare and they can be greatly affected by seeing animals die.

While they also talk about their knowledge of grief processes and have workplaces that support their wellbeing, still only 21% have sought professional support to help through the impact of death and dying.



Working in a job where you are exposed to death or dying

“

My grandad is really old, frail and has dementia and an array of other health concerns. Recently he broke his hip from a fall and is extremely close to death.

I have been struggling to care for patients who are similar to my grandad as it hits too close to home. I have been struggling because I have realised how short life is and I am really fearful of losing the ones I love. It is making me really anxious about losing my loved ones. I am really anxious and it is affecting my work which is leading to more anxiety.

I don't have much support available. My friends have been as supportive as they can but they have busy lives. (Single, 18-24, Female)

“I work in mental health and my area has had a lot of deaths by suicide. It was difficult to manage the community response. I felt responsible to prevent more death. It was also extremely sad because it was young people dying so I felt lost. I feel okay about it. It's my job. However, it is sad and had an overall negative impact on my community. I have heard very positive things about grief counsellors in my community.” (Couple, 24-34, Female, NSW)

“

“I am a mental health nurse and exposed to suicides of patients. [The hardest part is] Feeling I failed them. Support is through debriefing with colleagues.” (Married, 35-44, Female, Melbourne)

“I work in aged care and am involved in looking after people in the end stages of life. I look after these people sometimes for many years and become close to them and their families. When they are near the end it can become overwhelming as I watch the changes occurring. It's also very emotional being around family as they are going through this difficult journey they will often be in denial and ask you a lot of questions which technically I am not allowed to answer. The hardest thing to control is not crying when you are attending a resident that is close to death. After a death I can feel sad and have feelings of how unfair life is sometimes.” (Married, 55-64, Female, Melbourne)

It's been a bit of a learning curve as its a predominant part of my job moving forward, just learning to adapt. Its initially a bit jarring and then you have to sit and reflect on the emotions. I think its tough because sometimes you don't want to seek support. (Single, 25-34, Female)

Working in a profession with animals has led to many examples. The exposure to animal related deaths has really negatively affected my mental health, it made me feel so lonely and detached. Employee assistance services counseling has been very supportive and helpful in dealing with high pressure and stress with deaths in the industry. (Couple, 25-34, Female)

“

I am a nurse so death is part of my everyday life. I guess I am a little detached when it comes to death unless of course it is my own relative when I find it difficult to cope. Losing somebody who has heavily influenced your life and adjusting to the fact they are no long around to offer words of wisdom when you need them. Offering palliative care at work using all of the amazing resources my hospital has (Couple, 25-34, Female)

A few of my patients at work have died from cancer over the last few months. They were incredible people and I was devastated and very upset when they died. It was very emotional and upsetting. Many tears were had. Well it was upsetting at the time it happened even though I knew their condition was terminal. Death can be a wonderful thing when someone is ready to die. (Married, 35-44, Female)

As a nurse i have been there up to and including the point of death. I am comfortable talking about and dealing with death. it is part of the cycle of life. the only issue i have is when there are more than 1 event in close proximity to each other that can become overwhelming. Death can be in any situation in my job and i have learnt to deal with it as it comes. (Single, 45-54, Female)



Part 3 How we respond to the end of life



Grief and depression – the twin impacts of death

01

There is no getting away from grief when it comes to death and dying. They go hand in hand and it is something that we must all go through. The depth and length of grief is dependent on many factors, including the cause of death (unexpected vs expected) and how close we felt to the dying/deceased person.

Acceptance is as much to do with the situation as one's attitude towards death and dying

02

When the person dying or deceased is or has been suffering, death becomes more of a relief. Acceptance is easier because there is no more pain. Those who expressed an attitude towards death as being part of life also seem to be more accepting overall.

Ritual, religious/spiritual beliefs and/or saying goodbye brings solace and can help with acceptance

03

Acceptance is easier to achieve when we engage in a ritual or some activity that brings solace. The most prominent is attending a funeral. Funerals, as one of humanities oldest rituals, have a profound effect on us and they are often the moment that healing and acceptance begins. Final farewells can bring about closure and eventually acceptance.

The experience of death and dying forces us to face our own mortality and that of our loved ones

04

This can have either a positive or negative effect on us. Where positive, a death can make us realise the importance of life and engaging in what is important to us. On the other hand, a death or life-ending diagnosis can trigger a fear of death which can have a debilitating effect on one's mental health and life. Parents with dependent children also express a fear of how their family would cope if they died.

Support comes from family, friends, work, religious and spiritual communities, as well as medical professionals

05

We need support to get through grief and loss and this can come from a range of sources. Mostly, people spoke of family, close friends and their communities. Medical and professional support was instrumental in helping people cope with death and dying experiences. Although, many people also spoke of not being able to access support because of lack of finances, they don't know where to go or they may have a bad experience with support workers in the past.

Grief and depression – the twin impacts of death

Grief comes in varying degrees but we cannot escape it

“

My mom is already old and having more illness as well as my cousin has cancer. I felt very **lonely and sad** because I cannot help them physically as I migrated to Australia. I can only provide financial and spiritual support. Since I just started here in Melbourne, it adds up to my emotional baggage. There are moments that I **break down** and cry by myself or with my partner. I **feel lost** most of the time.

My partner and my family back in our country supports me. They talk and discuss things with me that deals with my deeper emotions. (Couple, 25-34, Female)

My significant other died due to cancer. I hit **rock bottom** because i lost someone i loved. I **couldn't bear the grief**. I went into **seclusion and depression**.

The hardship was emotional mental and financial. Extreme stress as i dont know many people and friends. Difficult in almost everything i could think off.. **i thought i would rather die** to make me feel better. I had no support. (Married, 35-44, Male)

“

My husband died 10 years ago after a long battle of cancer. That was a difficult experience from which I have not completely recovered. Now I have to face my own mortality as my health has been deteriorating and I am not dealing with the turmoil I am experiencing as well as I expected. Am feeling **alone & lost & disappointed** in my life & the choices I made which I realise now were not the right ones. **Being misunderstood** - not having someone to communicate with openly without fear of being misunderstood - my good intentions not being recognised by those nearest & dearest to me - **feeling totally alone & hopeless**. (Single, 75+, Female)

I was **very stressed, in depression and couldn't cope with my sadness**. Feel really bad, very stressed, **depressed**, didn't want to eat and sleep. Very **sad and frustrated**, feeling **hopeless**. Not much support was available and I couldn't afford seeing psychologist. (Couple, 18-24, Female)

My poppy was diagnosed with bowel cancer. His wish was to die at home. So we stayed with him at home. 3 weeks of care before he eventually passed. Watching a person die **is extremely hard mentally**. Mentally the experience of watching a person die changes you. **You'll never be the same again**. If you go looking for it there is support but not without effort. (Married, 25-34, Female)

“

I got sepsis and had to have emergency surgery. If I didn't call the ambulance I would be dead. **Scared me a lot**. Felt **scared afraid nervous unloved**. (Couple, 35-44, Female)

My best friend and grandfather both died within 4 months of each other they were both the closest people to me in this world and I felt lost for a long time until I realised they weren't in any pain anymore! The complete loss of both of them, it sent me into a **depression**. The feeling of being **overwhelmed** with not having them anymore sent me into that depression which took me a while to get out of. There is a lot of support out there none of which I used as I couldn't afford to see anybody. (Married, 35 to 44, Female)

BITE BY THE SNAKE AND IT IS THE MOST DANGEROUS TIME I HAVE EVER FACED. I FEEL LONELY AND NO ONE CAN REALLY HELP ME GO THROUGH THIS PERIOD. NO ONE CAN REALLY HELP YOU. NO SUPPORT AND I NEED HELP. (Married, 25-34, Male)

“

I have lost 4 significant people in my life over the past 2 years. My father who was unwell for awhile and that was easier to accept. My uncle in the UK who I was about to visit then Covid happened. My Uncle in my city that had Alzheimers but passed away suddenly after hitting his head and my stepfather who I was very close to who was diagnosed with a blood disorder that was terminal. The last one was the most difficult to accept and I still can't and miss him terribly. **Can't accept it. Can't move on. Depressed. Can't sleep. Don't socialise. Isolate myself. Depression, suicidal**, wish I could join him. (Single, 55-64, Female)

It has affected me **mentally and struggling to understand** how I survived the motorcycle accident. Been to see a lot of people for help but so far no one has been able to help. Coming to terms that I am alive. I am making the most of my life now. Support from the doctors. (Married, Male, 35-44)

It's all I think about. I **struggle to sleep, eat and function** on a day to day basis. The stress and grief is completely overwhelming. I'm **completely overwhelmed by grief** and struggling to function. I'm not coping. I haven't received any support and none has been offered to me. (Married, 35-44, Female)



Acceptance is as much to do with the situation as one's attitude towards death and dying

An unexpected death gives us no time to prepare or say goodbye, making acceptance more difficult.

“

My experience confirms that **death is part of living. This helps me deal with** my inevitable death in an accepting way. Being able to support someone as they passed proved invaluable for my emotional well-being. (Single, 55-64, Male)

I see death as a natural event and part of living, **we all die at some stage, so enjoy every day** whatever happens. There was a hole that was occupied and now is not in this physical world, I felt a little sad but not for long, so this did not impact me for long. A counsellor once made some impactful statements which allowed me to accept what happened. Most people require some time to accept death as it is a subject not spoken about much in our society. (Single, 75+, Male)

It hasn't affected me as dying is part of life and we can't escape it, so my thinking is **accept it for what it is and get on with the living bit.** (Single, 75+, Female)

... It was all emotional, but because **we had a long time to think about it, it did not have a huge impact.**



“

I have been diagnosed with cancer but I am in remission, I have suffered from a pulmonary embolism, I am chronically obese and suffer from chronic osteoarthritis. These have been issues I have faced and so far survived. I do not fear death as it happens to all of us. I am **usually in a positive cheerful state of mind because that is my way.** I have **never given in to anything.** My Doctor asked me how I coped with the news about cancer and I told her **there are only two options, live or die and the Devil isn't ready to meet me yet.** So far so good.

I have no fear. Death is the result of living. I would **rather die after having a short happy life than dying after years of suffering** by just being kept alive.

I haven't had any other [support] than my loving wife of 40 years. We are there for each other. (Married, 65 to 75, Male)

If anything it has **helped me accept my own mortality** and how I would like to spend my final days. It has made me **realize death is not as bad as the suffering** that often proceeds it. (Married, 35-44, Male)

“

I lost a close friend and she didn't want anyone to know about her health issues which weren't physically visible so it was a shock when she died very suddenly. According to her children she **kept a lot of her health issues to herself.** I think it **makes grieving harder** when this situation happens. The fact that the death was so sudden and not knowing the personal health issues my close friend was going through. The whole situation for her family and friends was bewildering at times. She died alone at home with no one with her. When you **lose someone suddenly it makes it harder to accept.** (Married, 65-75, female)

I lost a friend due to heart attack. It was sudden and unexpected. I felt unwell for days after hearing this news, but have come to terms that we all die one day and to be content with what ever life gives you...life is too short. **It hurts more when death of a loved one comes unexpected.** (Married, 35-44, Female)

“

My mother had suffered from dementia for ten years and was in aged care. She died at 103 years so I was well prepared. After her death my sleep patterns changed. I now wake at between 4am and 5am and cannot get back to sleep, **I also feel some guilt.** While I visited my mother regularly I **didn't ever speak about her dying. I was also not there when she died.** I left the nursing home in the late afternoon thinking I would be back in the morning but she died during the night. Not being available when she died made me feel guilty

I do not show emotions and **I am sorry I did not show my more emotion.** I would have liked to have thanked her but I couldn't do that. The funeral was very comforting. It was the type of funeral my mother would have wished for. (Married, 75+, Female)

Several members of my family have died. My father died first which upset me the most as it was a new experience and **I grieved for a long time.** As more members of my extended family died, I was able to accept death more quickly. The most difficult to accept was that they **were no longer with me** and I would never see them or talk to them again. I belong to a church and the members gave me a lot of support when I needed it. (Married, 75+, Male)

Ritual, religious/spiritual beliefs and/or saying goodbye brings solace and can help with acceptance

Spending time with someone dying, or old and frail can help with the grieving process.

Attending a funeral is one of humanities oldest rituals that can have a profound impact on us. They are the place of final goodbyes and where we wish the deceased to rest in peace. It seems to have the effect of making us fully realise that life will now go on without them. It is the moment that acceptance begins for many.

Having religious and spiritual beliefs and foundations was also spoken of as helping one accept death.

“

The person I am linking this question to died of a terminal cancer. Although the diagnosis was at first a shock, they were accepting right from the start that they were dying and they coped very well. They were not fearful and their religious faith played a large part in the peace and calm with which they approached their death. **The time before their death became for me a very special time of sharing memories, assisting them with their illness where I could.** It made me think a lot more deeply about my own death and how, if I had time, I would deal with it.

Speaking with other people close to the dying person and supporting them as well as dealing with their range of emotions. This was sometimes more difficult than working through my own. (Married, 65-75, Female)

A good friend died and I felt guilty about not reaching out to him when I know he was ill. That I didn't find the time to see him while he was alive. I went to the **funeral** on line and it **helped a lot** to see the photos of him and hear his children. (Married, 75+, Male)

I was diagnosed with bowel cancer and had successful surgery. Before my op I spoke to family and friends and **planned my funeral**. I felt calm and ready. I was a volunteer for many years in a nursing home and my role was spiritual carer. I have a strong christian faith. **It was good to choose the ritual** and exercise my creativity. I am a spiritual person and **my faith** is very much part of life and so of death too. (Single, 75+, Female)

“

One event is my bestfriend's grandmother passed away, I am very close to her and her family, so was there to support wherever I can. I tried to help my friend grieve and made opportunities for her to see her grandma to say our goodbyes. We knew she was old as she was over 80 years old, but it is also hard to see it happen as it is someone that we grew up with. A sense of relief was felt after the burial when we knew that it was our last farewell.

The lead up to funerals is always a bit overwhelming and crazy as there is so much to do, plan and sometimes **even though funerals brings families together**, there is also a lot of opinions on what to do and what not to do for funeral preps etc. It did feel like a lot. To be able to put on a strong face as well as to be able to grieve was hard. You know that life still goes on, and it makes you wonder what would happen if you all of a sudden left the world, will your loved ones be taken care of?

It was difficult as you had normal life and funeral, death etc to handle so it takes a lot of mental load. (Married, 35-44, Female)

“

I am a member of an older men's golf group and over the last couple of years we have had a number of our members die. With each death and due to my advancing age I consider myself fortunate to still be alive and able to continue to play. As the secretary for our group I am sending sympathy cards to the deceased member's family expressing our best wishes on behalf of the group. I think most of us cope well with the fact that death is a part of life and eventually everyone of us is going to experience the death of a loved one or friend. Having a **strong religious belief also helps** in the realization that death is only another step in our mortal journey and that we all have the opportunity of being able to be resurrected and share in eternal life due to the atonement of our savior, the Lord Jesus Christ. (Married, 75+, Male)

A guy I met at school 58 years ago, and have been in contact with ever since, died from cancer 4 days ago. I visited him regularly since his diagnosis, and watched his body slowly fail, but his brain was as sharp as ever. We were good mates, and had good times together. It was hard to watch all that we had experienced during our lives, coming to an end. **I had his last beer with him, and was able to say "goodbye Old Friend"**, two days before he passed. Watching his body die, while his mind & memories were still very sharp, and knowing that I would die one day too. I was quite sad he left. (Married, 65-74, Male, Brisbane)

Note: all verbatims are as written by the respondent, no errors have been corrected and no content has been changed.

The experience of death and dying forces us to face our own mortality and that of our loved ones

It can also trigger fear of death and/or what would happen to our loved ones in the event of our death

“

Over the past two years I more fully understood the finality of death thanks to the deaths of a few loved ones and friends of mine. I would say that my mental health has been heavily damaged as a result of **developing a crippling fear of death**, which resulted in me being afraid of sleep. The most emotionally difficult part was dealing with the very concept of the fact that some day, **I will cease to exist** with no memory of anything, and no knowledge of the afterlife. I've never really done proper research into support resources for death and dying, but I feel there is not enough discussion of it in the modern era. (Single, 18-24, Male)

I think about death more now than I like and **it worries me missing out** on a lot of things. I feel there are a lot of things I still would like to do before my death. (Single, 65-75, Male)

Has made me more aware that **death** can happen to **anyone at anytime and anywhere**. (Single, 18-24, Male)

Death never use to worry me, now I am fearful of it since I have my son. Losing my Mum has been really hard and it seems to get harder. I don't want. Y son to go through that and at a young vulnerable age.



“

I get very **anxious about dying** it's very scary and would hate to **leave my family behind**. It impacts my mental health and anxiety. There is some support from agencies but with anxiety it's hard to approach. (Couple, 25-34, Female)

I recently lost a very close friend which left me in a state of shock and at times quite depressed. I was unable to visit my friend due to Covid restrictions which made it even more heartbreaking, it has caused me **to face not only my own mortality but my loved ones as well**. The thought of never seeing or spending time with my friend ever again. (Married, 55-64, Female)

I had problems for the first time with my heart and being in hospital was really scary when getting checked up and waiting on the results. I started to reflect on life and what would happen if I was to die. Thinking about death in general and **what would happen to my family if I was to pass.** (Married, 65-75, Male)

I had an incident where a vein ruptured in my leg and I couldn't stop the bleeding, I literally thought I was going to die and I called the Ambulance on 000. It made me think that **anything can happen to anyone at any given time** and I should make sure all of **my affairs are in order**. (Single, 55-64, Female)

“

I was in a serious car accident that saw the vehicle I was in written off. Luckily for myself and all others in the car no major injuries occurred but it could have been very different. Makes you think about **the fragility of life** which in turn make you think about **what would happen to those around you that rely on you if you had an untimely passing**, its a scary thought to handle.

What was most difficult to happen was what would happen to those around me if I were to have died, or I were to die unexpectedly. **How would they cope in my absence** without my income and what I provide. It's daunting. (Couple, 25-34, Male)

“I have a few relatives pass away recently so that has **heightened my own feeling of mortality** and what could happen to me as a result of my health and mental issues. It really brought the thoughts of dying or becoming very ill.” (Single, 45-54, Male)

Though death is a certainty I'm still **very fearful of it** unfortunately. Just the mere thought that one minute one is hear and the next they can be gone is emotional draining. They have assured me that life is a journey. We born, we live and ultimately we die. We got to accept that reality. (Married, 45-54, Male)

Coping with death and dying is difficult – many people need support to help them get through

“

My brother-in-law was diagnosed with blood cancer. It was a slow lengthy period of treatment and we could cope with the thought that he might pass away but hoped it would not be soon. We thought life would go on while he was being treated and we would be able to plan holidays together with him. Suddenly the diagnosis was terminal with days to live. We were all in denial. How could someone so strong and active be going so quickly. The **suddenness of his death** has left us unable to cope / understand / accept that he has really gone.

He was very active and strong. How could someone so healthy develop cancer and die so suddenly. He died 10 days after his final diagnosis so we had little time to actually understand / comprehend / accept that he would no longer be here. Our families did everything together and now he wouldn't be there. (Married, 65-75, Female)

CARING FOR A CLOSE FRIEND HAS BEEN CHALLENGING. Looking after their well-being. **Trying to cope is often a real struggle.** Trying to get help or support can be overwhelming. (Single, 55-64, Male)



PRIVATE
THOUGHTS

“

My brother passed away at 50 and then my dad died a month later **really struggled** with my mental health. Losing a younger brother was horrible. My mental health went down so bad that I attempted suicide. The hospital sent me to a psychologist which has helped a lot. (Married, 55-64, Male)

My son was in a serious accident and was in a coma for a month then hospital and rehab for another 6 months, he has a severe TBI and came so close to dying. **It has shattered me.** I am **scared all the time, financially broken** from the time I had to take off work. Despite the social workers at the hospital trying to be supportive I felt very alone and overwhelmed. I have been provided with counseling through the TAC but more support would have been helpful. (Single, 55-64, Female)

my youngest surviving child died on fathers day at 33 years old, this followed the death of my daughter some years ago at 21 years old. Coping with the second unexpected death of one of my children. I am **still trying to cope. Unexpected deaths are hard to deal with.** no support and not enough available. (Married, 65-75, Male)

“

Losing a close family member was distressing, heart breaking and draining. I had the chance to speak to the loved one before her death and felt while this helped me it also traumatised me. The weeks and months afterwards trying to cope with the immense loss. This made me exhausted, feel down and seek support from those around me experiencing the same situation. It took a while to get through it.

I felt like I coped as well as I could during this traumatic time. **I coped as well as I could on my own and sought support from others when I needed it.** Haven't had any professional support but found leaning on others and feeling love and support from others around me helped me a lot. Knew I was able to access employee counselling services if needed. (Married, 45-54, Female)

Had a heart attack and the people near me told me to just man up and keep working. My father had a stroke and nearly died. **Men have no empathy towards each other.** So I now have less empathy towards them. There is no solution. Only kids dogs and women are cared for unconditionally. And us men are very well aware of that. No 1800 number or ad campaign will change that. (Single, 45-54, Male)

Note: all verbatims are as written by the respondent, no errors have been corrected and no content has been changed.

Support comes from family, friends, work, religious and spiritual communities, as well as medical professionals

“

I am a Christian, so have quite a positive attitude to death, but the death of a family member really impacts a person. I have had so much experience with funerals, arranging and speaking at these - family, friends, church members. I counted up once and I have been to more than 64 funerals. The recent deaths came as a shock, make one think of ones own mortality, and are very sad. Supporting other family members, who do not have my faith can be distressing.

The loss - knowing that person will be missing from our lives. **My faith sustains me, and friends from church**, but there is sadness, and others in the family are more distressed, as they have no beliefs. [Support from] church friends, who understand completely - we have all lost family members. (Married, 75+, Female)

I belong to a **church** and the members gave me a lot of support when I needed it. (Married, 75+, Female)

I haven't had any other [support] than my **loving wife** of 40 years. We are there for each other. (Married, 65-74, Male)



“

After been married for 49 years my wife was diagnosed with cancer and was responding to all the treatments great but one night she fell and when she stopped herself from hitting her face on the ground my beloved wife Jared her brain dislodged from the socket, causing her to have a brain bleed. After she was put on a life support machine for 3 days, it was the most hardest decision we ever had to make. Losing what I think was the best woman on this earth and having to make a decision to turn off the life support machine. The impact on me was the hardest thing in my life, but with the support from my very close family and friends and the church we both attended.

Only the support from **my very close family and friends** and the **church** we both attended. The support from all the **doctors and nurses** was absolutely great and they were with me with all the questions I had. (Married, 65-74, Male)

A very good **support network of family and friends** to help during the difficult times. (Married, 55-64, Male)

It is a an emotional time and words are often hard to find as you move through the final stages. Being the only **relative** to provide support. I know that there are **agencies but it is not the same as family**. The palliative care context was the most supportive and comforting experience. (Single, 75+, Female)

“

I was very stressed, in depression and couldn't cope with my sadness. Feel really bad, very stressed, depressed, didn't want to eat and sleep. Very sad and frustrated, feeling hopeless. **Not much support was available and I couldn't afford seeing psychologist**. (Couple, 18-24, Female)

My mom is already old and having more illness as well as my cousin has cancer. I felt very lonely and sad because I cannot help them physically as I migrated to Australia. I can only provide financial and spiritual support. Since I just started here in Melbourne, it adds up to my emotional baggage. There are moments that I break down and cry by myself or with my partner. I feel lost most of the time.

My partner and my family back in our country supports me. They talk and discuss things with me that deals with my deeper emotions. (Couple, 25-34, Female)

family member died i had an emotional breakdown. Couldnt eat as if i did i brang it back up went to hospital as lost all movement control. They did lots of tests came to conclusion it was emotional breakdown. I met a person at **hospital** and they helped me understand everything. (Single, 65-74, Male)

Coping strategies are learned, varied and personal

01

People cope in their own way to death and dying. They talk about staying positive, being brave, fighting or taking a spiritual point of view. Some, though, go into denial. Strategies for how to cope are learned and this is often from counsellors, psychologists and through their religion. Coping can also be a matter of learning to understand death in the context of life overall.

Existential and philosophical reflections

02

Death and dying can make us think and reflect upon life and our own lives. People, men in particular, shared a multitude of philosophical views about death, e.g. "You live to die, you die to live." It also makes us reflect on or re-evaluate what we want, how we have lived and how we want to live hereon.

Accessing professional support and resources

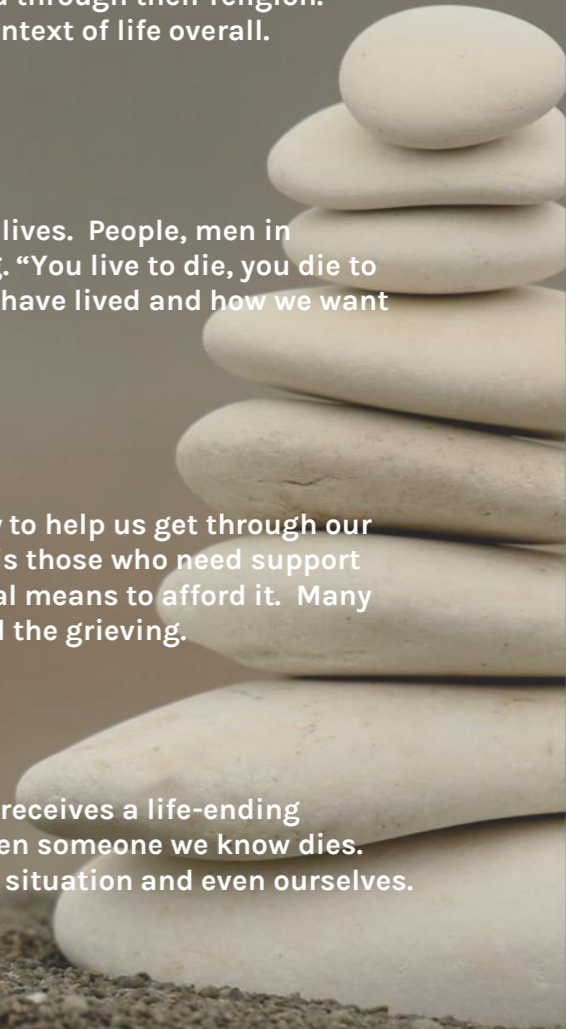
03

Often, but not always, support beyond family and friends is necessary to help us get through our experiences of death and accompanying grief and loss. The problem is those who need support don't always know where to find it and/or they don't have the financial means to afford it. Many people spoke of there being insufficient support to help the dying and the grieving.

Planning and preparing

04

We can be stirred into preparing for death when we or someone close receives a life-ending diagnosis, has a close call with death, reach a certain older age or when someone we know dies. Planning and preparedness gives us a sense of being in control of the situation and even ourselves. We are better able to cope when we plan for what is to come.



Coping strategies – what do people do to help them cope with death and dying

Coping mechanisms of the person dying and/or carers and those close to them, often include:

- Being positive
- Being brave
- Fight
- Being the rock for others
- Spirituality

Some people go into denial about dying and keep their condition private/secret until the end.

Coping strategies are learnt and not always something that comes naturally. People often spoke of learning how to cope through counsellors, psychologists and religion/religious leaders. Understanding death better is also a way to deal with it better.

“

Managing my emotions and **being supportive / the rock** for my family. (Couple, 25-34, Male)

My approach to **dying is fight to the end** but I have loved ones that believe ending your life because you can no longer cope is reasonable. Respecting that another person's opinion is different to mine but just as valid. (Single, 55-64, Female)

My wife (87 years old) had an infection that resulted in sepsis throughout her body and was critically ill when taken to hospital. Given she has other long standing health issues there was a lot of concern that she may not survive and naturally I was very stressed and **trying to keep positive** was a challenge. I have been her carer for 15 years and we have been married for 52 years, so a huge part of my life was being threatened. As her needs involved my continuing carer role once she came home from hospital, **I needed to try to remain positive and able both physically and mentally to continue that care.** I also deal with ongoing health issues which are progressively worsening so it is challenging.

Maintaining a positive outlook to her to keep her spirits up despite being in poor health myself. I felt unable to help her physically but could provide emotional support, but recognised I had to try to **maintain my efforts to improve my own health** so that when she came home, I could care for her. (Married, 65-75, Male)

“

My ex-husband recently committed suicide. It was a terrible prolonged and violent death. Our adult children are suffering dreadfully as am I and my partner. The grief is overwhelming sometimes **and I need to be able to support our children first.** It is very difficult to **be strong for them while I am suffering** so much. **I need to be able to help myself as well** as them. It's not easy but **I see a psychologist** who helps me. My children are also receiving professional help. (Couple, 65-75, Female)

After much medical intervention, my mother's condition has improved from seeming a day to day proposition. When blood pressure is 250 on the top for weeks, you are prepared for the worst.

Going into her bedroom every morning to get her up for the day not knowing IF she was dead. I have been preparing for her death since commencing care for her in 1999. My own police career was the investigation of suspicious deaths, 400 plus of them till I was discharged HOD, permanently and incapacitated in 2004. There is nothing I do not know about death, what needs to be done.

My treatment has provided coping mechanisms. My career is gone, yet how I handle the anxiety associated with death is better

Existential and philosophical reflections

Death and dying makes us reflect and think about life

“

I found the death of someone a complete shock, but I understand that it is a **normal part of life**. It is inevitable and I find comfort in knowing the person is no longer suffering. I am a very philosophical person and know that **everything happens for a reason**. Once someone dies, I know that **their time has come**. (Married, 24-34, Female)

I am not afraid to die at all, **you live to die you die to live**, I have had an experience in the past. (Single, 25-34, Male)

My focus became our mortality as human beings and it immediately made me realise **what is important in life**. The most difficult aspect was realising how **we are merely a speck in this cosmos and life really is very short**. I turned to spirituality as my support. (Single, 55-64, Female)

Death happens to everyone. Nothing can be done about it, so no need to stress. (Married, 75+, Male)

It has made me **value life** a lot more better than I use to. (Married, 35-44, Male)



PRIVATE
THOUGHTS

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Has made me **realise that life needs to be lived to the fullest now**, not put off till a later date that may never come. Made me realise **what I'd miss out on** if I depart early. (Couple, 25-34, Male)

Not sure i guess trying to **live in the moment** more. Realisation that life is short. (Couple, 35-24, Male)

I was involved in a vehicle accident whilst travelling in my company car as part of my work roll. Luckily nobody was injured but it did cause me to rethink my work role. Made me think that **we are all here for a relatively short period** and it made me **realise to enjoy life more**. My family all helped me to deal with the reality of enjoying life more. (Married, 55-64, Male)

The loss of my grandparents **opened my eyes** up to the fact **time is limited**. (Single, 18-24, Male)

The experience make you **take stock of what is important** in life and make you **contemplate your own life**. Thinking about missed opportunities to say what you really want to say to the person. (Married, 35-44, Male)

“

My Sister developed breast cancer, and had all the treatments available, operations and chemo, which kept her alive for 6 months or so. I visited her constantly in a Blue Cross establishment. I was actually with her with my Son when she passed away. It was hard.. but when she passed away it was a great comfort to all the family to know that she no longer suffered the pain. I still think of her often....but life must go on, and the memories will always be there.

When my time comes to pass over, I hope that it will be pain free and quick, after all the pain my Sister went through, and that **my family accepts that my time is up, and remember me always with love**. (Single, 75+, Male)

It has caused me to **reflect on my purpose and pursuits** in life. I have become more **aware of the limited time** that i have. (Married, 35-44, Male)

Every close death makes you, to a point, **reevaluate your own life and how you act towards others**.” (Couple, 75+, Female, Qld)

It really **highlights the inevitability** of dying and there is nothing you can do about it except **be prepared**. (Single, 75+, Male)

Note: all verbatims are as written by the respondent, no errors have been corrected and no content has been changed.

Accessing professional support and resources

Not everyone needs to access support:

- Family and friends are providing all they need
- They are self-contained, prefer to deal with things in their own way

Many people also told us that they were not aware of support resources available and would not know where to start looking.

Others did not believe they could afford support such as counselling or grief therapy and that those offered free were difficult to get into.

Those that did seek and receive support found them useful and helped them understand and cope with death and grief.

“

Caring for someone who is terminally ill makes me feel like I am experiencing the same thing. People ask me how I'm coping which is nice but all I get is what are you doing about it.

I feel very alone, lonely and feel like my life is getting sucked out of me. I fear I will have nothing left of me when the inevitable happens. I feel like I can't express myself as this upsets the person I am caring for and makes that person feel worse because as in they are ruining my life. Problem is that person is my life. But I feel like I am dying with that person. I have to do everything alone, going out together is not an option. The person doesn't want to use a wheelchair or anything so we can do things together. It's just all too hard.

Honestly, I'm at the point where I don't actually care about myself any more. **I feel that I will have to wait until the person I care for actually dies before I will get any real help.** (Married, 65-75, Female)

My mother and three remaining grandparents passed away due to health and age-related issues. I felt powerless to prevent their suffering but gave all possible support that I could. Their suffering, and a feeling of loss, caused me to feel sad and scared. My own feelings were not especially important to me at the time, but have become difficult to manage since then, as I have not yet dealt with the grief.

There are **minimal support services available** for people who are grieving, they **take time and financial resources** to obtain. (Couple, 45-54, Male)

“

I was very stressed, in depression and couldn't cope with my sadness. Feel really bad, very stressed, depressed, didn't want to eat and sleep. Very sad and frustrated, feeling hopeless. **Not much support was available and I couldn't afford seeing a psychologist.** (Couple, 18-24, Female)

The **stress of dealing with different medical specialists** in the public health system is immense. They never return calls and never give you more than a few minutes if their times. You are always searching for answers. Being incredibly tired all the time. Being incredibly stressed all the time. Feeling like **I didn't have information to make the right decisions.** Feeling hopeless, lost, scared, overwhelmed, burdened. It's a sad and overwhelming experience generally. **I found a great social worker** who listened, cared and was able to **guide me to other support services.** She was wonderful and gave personal care. (Single, 25-34, Female)

It puts into stress and makes you scary ... It disturbs you and affects your life ... **Support is there but only for a few days then you are left for yourself.** (Couple, 65-75, Male)

After the death of my Nan I had to sort counselling as I took it extremely hard. **Through the support available I was able to come to terms with her passing.** (Couple, 35-44, Female)

Planning and preparing

People talk about planning and preparing for their own death, when:

- Diagnosed with a life-ending illness
- Reached an age where death is more likely to happen, e.g. 65+
- Prompted by the death of someone known to them (e.g. and of the same age)
- They have a close call with death

Preparation includes:

- Discussing wishes/how they want to die
- Preparing a will
- Funeral plans/organising
- What family/friends are to do once they are gone

“

Makes me think about how my children will cope with my death. Makes me **plan to do more things** with my family. **Discuss wills. Looking at finances.** Looking at wills. Planning fun trips before it's too late. Planning trips away to do before death. Planning finances. **Writing letters** to family. (Married, 45-54, Female)

My mother is very elderly and frail and **has discussed her wishes** with me concerning her end of life and funeral. What she wants done if she can't look after herself and how she wants her funeral. I might have to have her live with me. I will be **organising the funeral.** (Married, 55-64, Female)

My impending death is due to Dementia a disease that I inherited from my father. How I came to terms with the fact that I would die within a certain time frame and **what preparation I needed to do.** I was able to speak frankly with a psychologist who gave me answers to all my concerns. (Married, 65-74, Male)

Another person close to me - also with a terminal illness - chose to die at home with the help of a local Hospice organisation. The way the person and their family and friends were treated - with such respect and dignity, as well as all their medical needs being met - was wonderful. I don't think these services are widely available though and for the population as a whole there could be much **more discussion about preparing for death and dying** - rather than waiting until it is needed. (Married, 65-75, Female)

“

Suffered a heart attack in April 2021 resulting in a quadruple bypass, recovery went well, have discussed our plans for end-of-life with wife and family, **quite content that we have discussed it and plans in place.** Now retired. None really, just wanted to discuss plans with family to ensure all were aware of what to do. Family acceptance of plans and willingness to discuss. (Married, 75+, Male)

I was diagnosed with bowel cancer and had successful surgery. Before my op I spoke to family and friends and **planned my funeral.** I felt calm and ready. I was a volunteer for many years in a nursing home and my role was spiritual carer. I have a strong Christian faith. It was good to **choose the ritual** and exercise my creativity. (Single, 75+, Female)

My mother died about 18 months ago, just prior to my diagnosis of terminal pancreatic cancer. 12 months ago I had half my pancreas and my spleen removed and, after having chemo-therapy for five months I was told that not all of the cancer was removed during surgery and has not been killed by the chemo, so I will not live longer than 6-12 months. I had to accept my forthcoming death, **get my affairs in order,** put in place a DNR and assure my wife that I would try and live as long as possible. Yes OF COURSE it has been hard!!!! (Married, 64-75, Male)



Want more information?

This report has been produced as part of our 'Private Thoughts' research initiative.

For more information, email info@theevolvedgroup.com

Appendix 1: Methodology and Sample Profile

We spoke to a total of 1,025 Australians aged 18 years and over in an online survey conducted on the Pureprofile online research panel

Age	%	n	Marital status	%	n
18-24	10%	103	Married	48%	487
25-34	19%	198	Couple, live together (de-facto)	14%	145
35-44	17%	174	Couple, don't live together	3%	31
45-54	16%	168	Single	35%	362
55-64	14%	147			
65-74	12%	121			
75+	11%	114			

Gender	%	n0
Males	50%	516
Females	50%	508
Non-binary/gender fluid	0%	1
Different identity	0%	0

Location	%	n	Have children	%	n
NSW/ACT	33%	342	No	69%	707
VIC	26%	268	Yes	31%	318
QLD	20%	209			
SA/NT	8%	83			
WA	10%	101			
TAS	2%	22			

- The study was conducted in August 2021 amongst a representative sample of n=1,025 Australians. The average duration of the combined survey and conversational AI was 7.8 minutes.
- The format was online with a mix of traditional survey questions that precipitated a conversational AI discussion to qualify ratings of overall sexual satisfaction. We also asked respondents to rate the attitudes to several important sexual topics.
- The AI was configured to explore over 40 identified topics of interest, spanning over 1,500 specific reference terms.