

Too little, too late:

the experience of the last
stage of life across Australia

July 2024

A review of global research regarding the most relevant issues for people through the last stage of life (approximately the last twelve months of life)

violet

About Violet

Violet is a national not-for-profit organisation with a mission to transform the last stage of life. Violet helps people talk about, plan for, and navigate this stage of life, whether planning for themselves or caring for a loved one. Violet is balancing humanity and technology to address this at scale.

violet.org.au

Definition: The last stage of life

The period in which a person is now frail enough, or sick enough, that they might die. Acknowledging the inherent uncertainty, this is commonly agreed as the last 12 months of a person's life.

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Foreword

Dying is largely a societal event with some medical component.

However, over the last few decades, dying and death have increasingly become medicalised. My grandfather died at home in 1959. Most grandfathers died at home then. Acute hospitals then became the centre of medical miracles. Many previously labelled terminal diseases were curable. Even if they weren't curable, life could be prolonged with interventions such as surgery, chemotherapy and radiotherapy. As a result, we have a health care system focussed on curing until the person eventually becomes palliated, often late and when all else has failed.

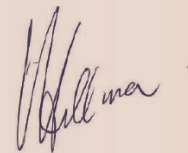
The Productivity Commission Report on End-of-Life in Australia, published in 2011, outlines the challenges in detail. Many of these are related to the fragmented and uncoordinated health care delivery and the fragmented governing systems, including at a state and federal level as well as non-government organisations. Not much has changed in over 20 years, with hospitalisation still being the current fall-back position for people in the last stage of life. They are subject to a conveyor belt from home to hospital, often ending on life support in an intensive care unit.

Whether elderly and frail, or managing a terminal or life-limiting illness, the person's preferences are not at the centre of the care decision made in that life stage, and that information is not shared with the patient, their families and their caregivers.

Ironically, most elderly Australians and many other terminally ill people do not want to die in a hospital. Many want to be managed in their own homes. The priorities, particularly of the elderly, often do not include living longer. Instead, their needs are society-based, such as a sense of self-worth, loneliness and a community support network.

We have witnessed a shift in birthing over recent decades. Soon-to-be parents plan for the birth with a strong sense of the right approach for them and their child and the knowledge that as circumstances change, so too must the birth plan. More recently, we have seen historically taboo subjects like menopause and miscarriage move into the zeitgeist. Conversations are opening up, services and supports are more readily available, and these are no longer invisible issues.

Now more than ever before, society needs to reclaim the last stage of life, death and dying. To echo the words of Hal Swerissen and Stephen Duckett, 'We need the courage to promote a discussion about a subject that we might dislike but cannot avoid'.



Professor Ken Hillman AO

Dual Foreword

Dying is undoubtedly inevitable, but planning and ensuring a safe and high-quality death is much less inevitable.

Our inability to plan for a high-quality death is odd at one level, given the majority of deaths are expected and that we seem to plan for other major life events (births, weddings). At another level, in the Western world, we have created a death-denying culture, which seems unwilling to acknowledge and allow for planning a high-quality death.

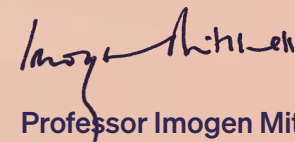
As such, as people physically deteriorate during their last stage of life, at home or in an aged care facility, without an understanding of what is important to them during that life stage, acute care hospitals become the default place of care. In acute care hospitals, healthcare professionals are programmed to “fix” patients even in their last stage of life. The consequence of such a paradigm is that patients, who are dying, receive non-beneficial treatments, which can often be invasive and painful in lieu of ensuring patients are comfortable, relieved of suffering and in an environment of their choice at the time of death. With the acute care hospitals bearing much of the load of the dying, it places an additional burden onto the already constrained public health care system.

To realise a safe and high-quality death requires numerous stakeholders to land on one page and appreciate that something needs to change. There is a burning platform for the need to change, given

the significant increase in the elderly population over the next 20 years and the number of people dying.

Changing the current dogma is going to be hard, and we need to think beyond palliative care as being the whole solution. It requires the community, primary care, acute care hospitals, aged care facilities, non-government organisations, academic partners, and state and federal policymakers to be engaged in a meaningful dialogue to realise safe and high-quality dying. It also requires novel approaches to care for the dying and their caregivers, given the stalemate of change over the last 20 years around dying.

Without changing the way we care for our dying, individuals and their carers are unlikely to routinely experience a safe and high-quality death.



Professor Imogen Mitchell

Preface

Many of my political and professional roles have intersected with Australia's health and aged care systems.

Despite this, when it came to caring for my own parents through the last stages of their lives I faced so many challenges, in having important conversations, planning for their future care needs and accessing the right services, at the right times.

My parents simply didn't have the experience that they wanted to have. I'll always regret the way this played out and I'm committed to leading an initiative that improves this for us all.

It is sad and disheartening for a nation like ours that so many individuals are denied the dignity of dying in the place and environment they would choose.

While we have established norms and comprehensive services and supports for all other life stages, the final stage of life remains taboo and overlooked. All too often, we do too little, too late.

Today's systems simply aren't serving us well enough. I believe it's vital that we change the conversations around what happens through the last stage of our lives.

Over the past few decades, we've seen incredible progress on social issues that impact health and well-being, from mental health awareness to smoking cessation. These advancements have fostered open

conversations, established new social norms, and built support systems that have led to better societal outcomes. Now, it's time to turn our attention to improving the experience of life's final chapter.

Compassion, choice, and control are vital through the last stage of life. A system-wide approach (healthcare, social services, communities) is needed to prioritise compassion, choice, and support for the dying. While palliative care is crucial, end-of-life care goes beyond medicine, encompassing wishes, social needs, and relationships.

There are important end-of-life supports, services and choices that people need to be aware of, such as Voluntary Assisted Dying (VAD) which is now legislated in all states and territories except the NT. People need help and support to talk about and plan for this stage of life, ensuring they can make informed and supported choices about what matters most to them.

I am passionate about addressing these needs to ensure that people have the experience that they want and deserve. I'm excited about the potential of new technologies to introduce novel, personalised and empathetic solutions to address this at scale.

It is time to assess both the human and the economic costs of this life stage and explore new models that relieve system pressures while improving care, support and outcomes for people and their families.



Many of the resources and systems are already in place but not aligned with the needs of people. Cross-government leadership is needed to tackle fragmentation, inadequate planning, funding issues and data gaps.

Violet supports a comprehensive and collaborative approach, essential to address the needs of the diverse tapestry of cultures and communities across Australia, and to sensitively and appropriately address the cultural and spiritual needs of our First Nations peoples.

This report endeavours to deepen the understanding of the common experiences of people in the last twelve months of life across the community and, in particular, across health and aged care settings. We hope to highlight inefficiencies and opportunities to inform industry and providers, guide government policy and investment, and underscore the need for new models that reduce expenses while improving end-of-life care, support, and outcomes for individuals and families.

A handwritten signature in black ink that reads "Kate Carnell".

Kate Carnell AO

Chair, The Violet Initiative

Deputy Chair, Beyond Blue

Former ACT Chief Minister and ACT Health Minister

Purpose

This report aims to understand the common experiences of people in the last twelve months of life across the community and, in particular, across health and aged care settings.

It seeks to highlight inefficiencies and opportunities amid the increasing demand from Australia's ageing population, inform industry and providers, guide government policy and investment, and underscore the need for new models that reduce expenses while improving end-of-life care, support, and outcomes for individuals and families.

Methodology

This research report has been prepared by The Violet Initiative and reviewed and endorsed by Prof. Ken Hillman AO, as a contemporary review that draws on the global evidence base as well as industry and consumer research conducted by The Violet Initiative.

The study identifies six key insights, highlighting the issues and opportunities for individuals, families, caregivers, and providers. The report proposes six actionable responses to ensure the best possible end-of-life experience for more Australians and their families.

Economic and system analysis

11%

of the Federal Health Budget is spent on the 1% of the population who die in that year⁴

\$4BN/year

is spent on unplanned, unnecessary and unwanted hospitalisations through the last 12 months of life, non-beneficial treatments, and extensive use of ambulance services⁵ as well as time cost and complexity for a range of industries and businesses.

The last stage of life is challenging for individuals and families, often marked by significant emotional and financial burdens. For most people, this life stage is a complex, disorganised, expensive and over-medicalised experience, often full of regret.

Despite its inevitability, the last stage of life is rarely discussed or planned for, leading to substantial human and systemic costs. The combination of a death-denying society and a cure-focused health system creates a hazardous complicity.

In Australia, a significant portion of the healthcare budget is devoted to end-of-life care. Approximately 11% of the total health budget is spent on the 1% of the population who die each year¹. This translates to a substantial financial burden, estimated at around \$4 billion annually², impacting both public and private healthcare systems and various industries and businesses involved in end-of-life processes.

Healthcare costs associated with the last stage of life are driven by increased hospitalisations, non-beneficial treatments, and extensive use of

ambulance services. These costs are notably higher in the final 6-12 months of life, with per capita healthcare expenditures up to four times higher than for individuals not at the end of life³. Additionally, the unavoidable administrative processes, or 'sadmin,' (sad administration) involved in managing estates, processing claims, and dealing with family dynamics further add to the financial and emotional strain.

The hidden and complex cost burden of end-of-life care drives up expenses and waste across Australia's health and aged care systems. As the population ages, this issue will intensify. By 2040, the annual number of deaths is expected to double, significantly increasing the demand on already strained health and aged care services.

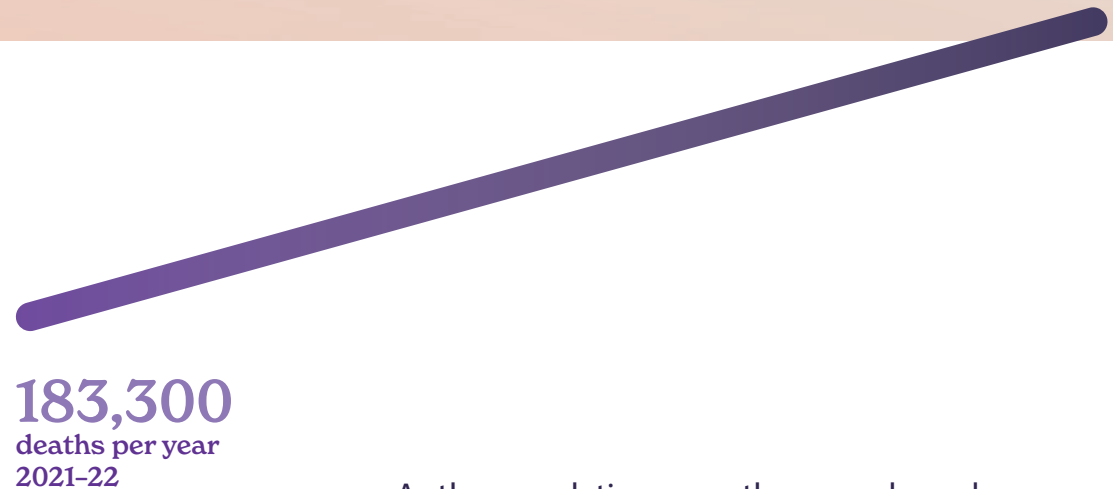
Across the country, public health systems are constrained and often dysfunctional, overwhelmed by admissions of elderly, frail and terminally ill people who are in the last stages of life. This results in hospital bed block, failure to conduct elective surgery, ED overcrowding, and ambulance ramping.

These inefficiencies and costs highlight the need for new models that reduce expenses while improving end-of-life care and support for individuals and families.

The impact of an ageing population

up to
402,800
deaths per year by 2040

The number of deaths in Australia is projected to double by 2040, significantly increasing the demand on the health and aged care systems.



As the population ages, the annual number of deaths is forecasted to increase from approximately 183,300 in 2021-22 to between 378,200 and 402,800 by 2040⁶⁷.

This significant growth underscores the urgent need for better planning and resource allocation to effectively manage the future healthcare burden.

Key insights

1. The last stage of life is a common, yet unsupported experience

The loss of a loved one is considered the most stressful event in a person's life, a universally recognised truth across all cultures and continents.

Over 180,000 people die across Australia each year,⁶ an average of 3,000–4,000 deaths per week.

The majority of deaths are predictable and can be planned for⁷. Yet we avoid discussing the inevitable, missing the opportunity to have meaningful conversations and adequately plan for the last stage of life.

Astonishingly, 95% of Australians have experienced the death of a significant other in the past two years⁸.

Despite how common this experience is, our society offers little support. This void leaves most people unprepared, uncertain and unsupported through the last stage of life.

95%

of Australians experienced the death of a significant other in the last two years⁸.

75 and over

A large proportion of deaths (67%) occur among individuals aged 75 and over.⁷¹

Over 180,000

people die across Australia each year⁶⁹



The majority of these deaths occur in hospitals that are focused on cures and not designed to manage the needs of the dying.

70%

of these deaths are predictable⁷⁰



As a result of Australia's ageing population, the number of deaths each year will double by 2040⁷²

Key insights

2. Many Australians do not have the experience they want or deserve

The way people die has changed dramatically over the last few decades. As deaths increasingly occur within hospital settings, the role of the community and families has diminished⁹.

More and more people are dying in hospitals, not only our least preferred place to die¹⁰ but also the least designed at any level to manage dying. Many caregivers and families regret how their loved ones experienced the last stage of life, contributing to complex grief and bereavement¹¹.

The Grattan Institute's 2014 Report 'Dying Well' found that because most people do not speak up about the way they would like to die, they often experience a disconnected, confusing and distressing array of services, interventions and relationships with health professionals.

When people in the last stage of life get seriously sick and deteriorate, the default response is to take them to the hospital¹². This transfer often involves a series of steps, like calling an ambulance, going to the Accident and Emergency (A&E), being admitted to the hospital, and sometimes ending up on life support in the intensive care unit¹³. Up to 38% of hospitalised patients receive non-beneficial interventions at the end of life¹⁴.

Surprisingly, these individuals are not often recognised as close to the end of their lives by their doctors, the healthcare system, or even themselves. One-third of all hospital emergency calls are for terminally ill patients who are not detected as being near the end of life until the last few hours or days of their life¹⁵.

The system managing end-of life is failing many people.

Key insights

The lack of planning, preparation, and support, rushed decision-making, poor communication, and excessive and unnecessary treatment during the last stage of life have a multiplier effect.

People in the last stage of life have experiences that do not align with their wishes and preferences

Families and care teams face moral distress

Non-beneficial treatment contributes to the already unsustainable cost of healthcare^{16 17}



70% of people would wish to die at home, surrounded by family, friends and supported by relevant services. Less than 15% get to do so¹⁸



1 in 2 people die in hospital in NSW, our least preferred place to die¹⁹



Only 14% of Australians have a plan in place for the end of life²⁰



A significant portion of patients, up to 38%, undergo treatments that don't benefit them in their final moments²¹



In the last 12 months of life, people average four hospital episodes and 33 days in hospital²²



Research shows that many dying patients receive high-intensity care without clear evidence of benefits, often at odds with their known preferences²³



Prudent healthcare principles suggest that healthcare delivery should be proportionate to need. Research estimates that approximately 20-30% of healthcare spending may be considered waste²⁴ This is mostly due to over-treatment and failures of care coordination

Key insights

3. Issues are compounded for elderly, frail people

More than at any time in history, most people die when they are old, and are more likely than past generations to know when in the near future they are going to die²⁵.

In Australia, elderly, frail people in the last stage of life often face a distressing cycle of hospitalisation following acute health deterioration²⁶. Nearly one-third of emergency calls involve patients nearing the end of life, most of whom are over 75²⁷. Typically, people are transported by ambulance from home or from residential aged care to the emergency department, admitted to the hospital, and often end up in intensive care on life support²⁸. Ironically, many of these older adults do not wish to be hospitalised and prefer not to die in a hospital setting²⁹.

Frailty in the elderly, particularly in the last stage of life, is a life-limiting illness often unrecognised as such. It involves a decline in physical and mental reserves, and increasing vulnerability to health issues.

Recognising frailty is crucial for providing appropriate care, improving quality of life, and improving management strategies and support systems.

The presence of a large number of elderly, frail patients in hospitals exacerbates ongoing crises, such as long elective surgery waiting lists, emergency department overcrowding, and ambulance ramping. Most people want to be cared for at home or in a home-like setting (including residential aged care).

As elderly, frail people reach the end of a well-lived life, they deserve comfort, dignity, and compassionate care in their place of choice. Sadly, today's system is not sufficiently geared towards these wishes and preferences.

Key insights

The default for people who are older, frail and near the end of life when they suffer an acute deterioration is often hospitalisation³⁰.

At least a quarter of all hospital beds are for patients in their last year of life, and most of these are for elderly patients³¹. They are placed on a conveyor belt of ambulance, Accident and Emergency (A&E), hospital, and often end up on life support in the intensive care unit³².

Almost one-third of emergency calls in hospitals are for patients nearing the end of life and most of them are older than 75³³.

Between 70 and 80 percent of deaths in hospitals occur in frail older patients who are admitted as emergencies³⁴.



95% of people entering residential aged care will die within 22 months

Over the last decade, individuals entering residential aged care have increasingly entered care older, with a higher burden of functional limitations, a greater burden of comorbid conditions, and significantly frailer³⁵ - thus, they often face a limited lifespan due to their advanced age and complex health conditions.



Residents in aged care facilities frequently require medical and palliative care, which is indicative of their deteriorating health status and short life expectancy³⁶

This underscores the need for better planning and support for end-of-life care in a place of their choice to enhance the quality of life for aged care residents and manage healthcare costs effectively.



Those who die in residential aged care incur half the costs of those who die in hospital³⁷

Hospital admission from residential aged care facilities is the current fallback position, many of which could be avoided by end-of-life support in the place of their own choice.

Key insights

4. The burden is borne by family members and caregivers

As our population ages, increasing numbers of people are taking on the role of caring for elderly relatives with declining health while also managing their own busy lives.

This dual responsibility, often called the “sandwich generation,” affects around 1.5 million Australians in their 40s and 50s. This group faces intense pressure between work and home life as they care for both their children and their elderly parents or loved ones, often without caregiver assistance or support from their employers³⁸.

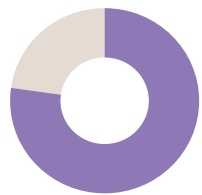
Caregiving can be a lonely journey, requiring individuals to gather information and coordinate care with little guidance. The burden of caregiving duties often leads to lost wages,³⁹ missed career opportunities, and significant out-of-pocket expenses⁴⁰. These issues disproportionately affect women, who comprise the majority of caregivers

(61 per cent) and are disproportionately affected by the income disparities associated with caregiving⁴¹.

For many, the stress from these overlapping duties can lead to significant health issues. This is an emotionally burdensome time, where people’s mental health and wellbeing suffer, as they feel unprepared, unsupported, uncertain, and often isolated and lonely. Approximately one-third to one-half of caregivers have been estimated to experience significant psychological distress, and they experience mental health problems more often than the general population⁴².

Research indicates that recognising the emotional experiences and support needs of families and caregivers may enhance the understanding of the ageing, caring, dying, and grieving pathway for older people and their families⁴³.

Key insights



83% of people who are currently caring for an elderly, frail loved one or someone with a terminal illness said they found it challenging to talk about and plan for this life stage and had difficulties accessing the services they needed⁴⁴



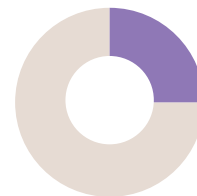
35% told us their mental health deteriorated⁴⁶



8 out of 10 people told us 'I just don't know where to start'⁴⁷



62% of people said they were negatively affected by the experience



25% of people told us they did not know what to do to help themselves



1 in 5 (20%) said they were strongly negatively affected⁴⁵



Only 1 in 5 sought help⁴⁸

Key insights

5. Grief and loss have enduring effects

Grief and loss have lasting effects, impacting emotional, mental, and physical health and can lead to long-term issues like depression and anxiety⁴⁹. Daily life, relationships and work performance may also suffer⁵⁰, and 20% of people cannot 'move on' after the death of a loved one.⁵¹ Support systems and therapy are crucial for coping and strengthening resilience⁵². Understanding and addressing grief is essential for healing and adapting after a significant loss.

Many caregivers and families often regret how their loved ones experienced the final stage of life, leading to complex grief and prolonged bereavement. Research indicates that inadequate end-of-life care, lack of communication, and unaddressed emotional needs can intensify these feelings of regret⁵³. Effective communication, compassionate care, and support services are essential in alleviating regrets and improving the bereavement process⁵⁴. Addressing these aspects can help families find peace and reduce the burden of complex grief,⁵⁵

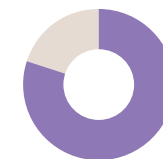
helping people to return to life, and work, more quickly after the death of a loved one.

Recent Australian research revealed that the quality of end-of-life and post-death care significantly affects a family's grief.⁵⁶ Families often begin grieving as soon as their relative enters aged care, with their grief intensifying over time. Involving families in the care process, maintaining open conversations about their loved one's health decline, discussing care options, helping them prepare for death, and ensuring sufficient support after death are all important elements.⁵⁷

There is a significant amount of research supporting the emotional toll of frequent death exposure on healthcare workers and its potential impact on performance and interpersonal interactions^{58,59}. Studies have shown a correlation between high death rates and increased absenteeism, presenteeism (physically present but mentally absent), and burnout⁶⁰. This can significantly impact the healthcare and aged care systems, reducing staffing levels and quality of care.



Up to 9
people are bereaved
for every death⁷³



20%
of people cannot
'move on after the
death of a loved one'⁷⁴

Key insights

6. Data and technology remain under-utilised

Data and technology permeate most of life, yet the later stages of life are largely bereft of technology, missing significant opportunities. Older adults, with unique needs, remain under-served despite high healthcare costs. Investment in technological solutions for this demographic is low⁶¹.

Harnessing data can personalise care plans, predict health risks, and improve communication among patients, families, and healthcare providers. User-friendly technology empowers individuals to manage medications, access support services, access services and stay connected. Systems must be navigable for older adults, non-English speakers, and Aboriginal communities⁶².

Simplicity can coexist with complex back-end systems for data security and tailored functionalities. Targeted investment in technology can enhance quality of life, reduce caregiver burden, and create a more equitable system.

Lack of robust data collection on end-of-life care exacerbates the issue. These data are often unavailable, hindering analysis of usage patterns, costs, and outcomes⁶³. Improved data collection and utilisation are essential for government oversight across aged care, hospitals, and community palliative care⁶⁴.

Enhancing information flow, data utilisation, and technology in later life stages can inform policy, improve quality of life, and reduce caregiver burden. AI and machine learning enable scalable, personalised healthcare, benefiting from big data and genomics, leading to inclusive, efficient, and patient-centric care.

Caregivers see technology as a helpful tool for making their jobs easier and easing caregiving burdens⁶⁵.

82%
are interested in
using it to manage
medications

78%
are interested in
using it to schedule
appointments

75%
are interested in
using it to access
educational
resources

**Over
70%**
of patients believed
digital health
tools improved
communication
with providers⁶⁶

Australia has an opportunity to lead the way in a new model of care for the last stage of life

Despite its ubiquity, significant system cost burden and the looming pressures of an ageing population, there has been limited investment and innovation through this life stage.

The 2022 Report of the Lancet Commission on the Value of Death: bringing death back into life calls for a new vision for death and dying, with greater community involvement alongside health and social care services, and increased bereavement support⁷⁵.

The cost of doing nothing is simply too high—for our health and aged care systems, for individuals, their families, and their caregivers.

While the issues are complex, actionable steps can be taken to make progress in the short to medium term. This section of the report aims to propose a series of feasible, sustainable, and practical actions that can be implemented to assist governments, health and aged care providers, and not-for-profits to begin to address these issues.

Leveraging this report's insights and our 25+ years of expertise, The Violet Initiative proposes six actionable responses for Australians, families, and caregivers to have the best possible end-of-life experience.

1. Help people to talk about this life stage

Help people to talk about the last stage of life, death, and dying so that they are confident enough to have meaningful discussions with loved ones and can make informed and supported choices about what matters most to them.

2. Provide tools and resources to build capacity

Give people the tools and resources they need to build capacity, put a meaningful care plan in place, and be better prepared and supported through the last stage of life – whether planning ahead for themselves or caring for a loved one.

3. Help with navigation

Help people navigate the health and aged care systems so they understand the range of services available at different stages through the last stage of life and can access them as needed.

4. Provide personalised and convenient support at scale

Support people in a personalised, convenient way, ensuring the support is tailored in response to their circumstances and level of emotional readiness, cultural context and language of preference.

5. Support health and aged care staff

Upskill and support health and aged care staff to feel more confident and willing to talk about, and help people plan for the last stage of life, and to be able to direct them to useful information and resources.

6. Improve information and data capture

Improve data capture, information flow and interoperability across systems in the care sector. Establish a unique data set about the last 12-18 months of life that informs policy and practice.

The Violet Initiative has over 25 years of experience helping people through the last stage of life.

Through the work of our national not-for-profit organisation, we've supported over 17,000 people to talk about, plan for, and navigate this stage of life, whether planning for themselves or caring for a loved one. There are over 1.6M⁷⁶+ people who need help with this each year across Australia. Violet is now leveraging the power of AI and machine learning technologies to enable scalable, empathetic, personalised, and responsive support.

We have established a national, scaleable model that includes:

- **A technology platform** that provides information, tools, stories and resources to help people to talk about and plan for the last stages of life
- **An AI-enabled Digital Companion**, 'Violet', that provides personalised, empathetic, and scalable support accessible to all Australians anytime, anywhere, in their language of choice.

- **A national network of dedicated volunteer Violet Guides** who are carefully recruited, trained, and supported to deliver evidence-based support programs to people over the phone from the comfort and convenience of home. These programs provide personalised emotional and practical help alongside navigation and guidance, and are tailored for people caring for loved ones in their final years or managing grief, loss and bereavement.
- **Training and education programs** and Communities of Practice for the healthcare and aged care workforces help build the capability and willingness to have open, honest, and frequent conversations about the last stages of life with residents, family members, caregivers and other care staff.

Violet can play an important role in alleviating the burden on the health system by helping more Australians to have compassionate and dignified deaths that align with their preferences and supporting their families and caregivers.

We look forward to working broadly with the government and the sector to change the way society manages the last stage of life.

Endnotes

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