

2021–2022 Pre-Budget submission

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The Violet Initiative

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The Violet Initiative is a national social enterprise that positively impacts the last stage of life so that more Australians are better prepared to die well.

Executive Summary

Many Australians are not having the end of life experience they want or deserve. At least 50% of Australians, their families, loved ones and friends who are experiencing the 100,000 predictable deaths (i.e. those that are the result of frailty or terminal illness) each year have regretful outcomes¹. This is where things do not go as planned, or indeed where there is no plan at all.

Whilst regret is a very personal emotion, in this instance it carries with it often immeasurable personal, social and financial impacts for families, businesses, the health and aged care systems and the Australian society as a whole.

Regretful outcomes in the last stage of life represents a \$1billion challenge².

A number of recent and high-profile Federal Government-initiated reviews and investigations have acknowledged significant gaps in the human and social aspects of palliative and end of life care in Australia. These same reviews have recommended active and urgent remediation both in terms of policy settings and service delivery.

The substantial and enduring impact of Covid-19 has further highlighted these issues, especially in the context of residential aged care settings.

The Violet Initiative (TVI) prioritises and addresses critical gaps for under-served Australians - people in the last stage of life and their families and caregivers. We offer evidence-informed and cost-effective solutions in a partnership model involving all relevant stakeholders.

In this budget submission, we request that the Australian Government approves funding to The Violet Initiative for a 24-month Proof of Concept of our National Aged Care Industry Solution (NACIS).

The proposed program will be delivered as a collaboration between Violet, industry, and government.

Further details of the Proof of Concept are set out in the proposal section of this submission.

¹ TVI estimate, 2020

² KPMG

Issue

Over 160,000 deaths occur in Australia each year³. Seventy percent of these deaths are predictable. Of these predictable deaths over 50% have regretful outcomes⁴. Multiple national and international surveys have identified that over 70% of people would prefer to be able to die at home, and that in Australia approximately 14% are able to have this wish fulfilled⁵.

Dying in Australia is becoming an increasingly institutionalised and medicalised experience⁶. People's experiences through the last stage of life, and death, are misaligned with their wishes and preferences. Across the system, the human, social and emotional aspects of end of life care are significantly under-supported, and are directly contributing to regretful outcomes in the last stage of life.

The need to overcome challenges in the human and social aspects of palliative and end of life care has been the subject of numerous publications and reviews. Most recently, the Royal Commission into Aged Care Quality and Safety, highlighting the significant gaps between the wishes and expectations of Aged Care residents and their families, and the experience of their last stage of life. The preliminary findings have included the following recommendations:

- A new Aged Care Act, including support for informal carers as part of the Aged Care service portfolio
- Dementia and Palliative Care training for Aged Care staff.

These recommendations are supported in the literature over the last 15 years, calling for improved services for Australians in the last stage of life and their families. Key findings are summarised below:

- A 2008 Productivity Commission report identified that most of the 160,000 people who die in Australia each year would benefit from appropriate end of life care, but that many do not receive care that fully reflects their choices or meets their demands. The report further highlights the challenges faced by the 60,000 people that die in residential aged care facilities each year, including multiple, ineffective transfers between aged care facilities and hospital in the last stage of life.
- The Australian- first, NHMRC-funded "Reducing Non-Beneficial Treatment at the End of Life Collaboration" reports that hospitalisation rates for people aged 85 plus increased by 35% for women and 48% for men in the decade to 2011, arguing that dying in Australia is becoming an increasingly institutionalised and medicalised experience.
- The Grattan Institute's 2014 Dying Well report notes:
 - Dying in Australia is more institutionalised than in the rest of the world.
 - About half of Australians die in hospital, and about a third in residential care.
 - Often, they have impersonal, lingering and lonely deaths; many feel disempowered.
 - Increasingly people are more likely than their forebears to know that they are going to die in the relatively near future.
 - We are not taking the opportunity to help people plan to die well. In the last year of life many experience a disconnected, confusing, and distressing array of services, interventions and relationships with health professionals.
 - Increased support for caregivers is a key element in improving outcomes and remains unaddressed
- A Matter of Care - The Aged Care Workforce Strategy published in 2018 argues strongly that a reframed care regime and workforce is vital to addressing current and future competencies and skills requirements. This includes more consistent training across the Aged Care Workforce, including in Palliative Care and end of life issues.

³ KPMG

⁴ TVI

⁵ Grattan Report 2014

⁶ Grattan Report 2014

Addressing the gaps

Drawing on our own 30+ years of practical experience and extensive literature, The Violet Initiative sees three critical gaps in the current last stage of life/end of life care continuum.

1. Inadequate recognition and communication around the last stage of life, in a manner and a timeframe that helps families & caregivers to be prepared and supported;
2. Inadequate support in the human, social and emotional aspects of end of life care; and
3. Inadequate support for caregivers (formal and informal).

Often missing from the myriad of reports and academic commentaries on end of life care is the vital role that families, carers, friends and loved ones play in helping prepare people for the end of their life. Also neglected are the short and long-term impacts of caring for someone in that last stage of life,

Caregivers are often key influencers & decision makers - and can have a significant impact on the nature of the outcomes experienced. They are currently uncertain, unprepared and unsupported as they care for family members or friends.

The Violet Initiative exists to address this gaping hole in the necessary fabric of comprehensive end of life care.

This is most evident in the context of residential aged care:

- Residential aged care is where 60k people each year will spend the last stage of their lives. In this setting, residents will inevitably become sick enough or frail enough that they might die. People are entering aged care later, with higher levels of acuity and are often living with multiple comorbidities.
- Families and friends of residents do not receive sufficient support
- The Aged Care workforce is widely acknowledged as not sufficiently trained in the social & emotional aspects of end of life care
- Targeted supports for families and carers in residential aged care settings are consistently missing from current service delivery models, including Federal Government-funded carer support programs (CHSP-funded Respite and the Carer Gateway).

No part of the system is currently addressing this need, despite the spotlight that COVID-19 placed on it.

In the same way that Beyond Blue and LifeLife provide national support for mental health and suicide prevention, Violet aims to provide national support for the last stage of life and end of life care to address the gaps detailed above.



The Violet Initiative

The Violet Initiative is a social enterprise that positively impacts the last stage of life so that more Australians are better prepared to die well. Violet guides people through the last stages of a loved one's life.

Helping people better prepare for what tomorrow may bring assists them to become more resilient when faced with the vulnerabilities of this stage of life. We deliver targeted and complimentary non-clinical support for the caregivers of people in the last stage of their life with a dedicated focus on supporting acceptance, planning and communication.

At any one point in time thousands of Australians are caring for someone with a terminal illness or who is elderly and frail - people who are approaching the last stage of life, where they are sick enough, or frail enough that they might die. For this group of people, sadly, death is an inevitability. The timeframes are uncertain - the last stage of life may be months or weeks for some, days for others. This is the life stage and context where Violet's work and support is anchored.

Violet leverages 30 plus years of practical experience and a significant global evidence base to guide, support and upskill people caring for someone in the last stage of life. In our work we essentially target three key groups:

- Friends and family (informal caregivers)
- Professional caregivers (GP's and clinicians)
- Relevant businesses whose work intersects with the final stages of life (including aged care providers, private health insurers etc)

Violet's peer-to-peer support drives behavioural change in three main areas:

- acceptance of,
- preparation for, and
- communication during the end of life.

We provide support when and where people need it, for example, at home, in aged care facilities or, in health care settings etc.

Informal caregivers can access Violet's Guided Support Program, free one on one support from trained Violet Guides as well as access to a growing digital library of personal and professional wisdom and guidance. For businesses, we provide training and education to key staff so they can better support customers and employees through this last life stage. Violet support is proven to increase relief and resilience and reduce regret.

We offer system-wide benefits to health and aged care, positively impacting servicing/care costs as well as productivity in relevant businesses. Violet's early intervention system of support enables both government and industry to simultaneously redistribute costs and achieve better human outcomes.

Violet's approach targets three main audiences



Informal caregivers Unsupported

Commonly aged 50-75yrs, often female, caring for a partner or a parent.

They are key decision makers with high levels of influence.



Professional Caregivers and Clinicians Undertrained

Working in aged care & health care settings

Experts in clinical care but have capability gaps in non-clinical care & difficult conversations. They hold significant authority and can make a big difference to the eventual outcome.

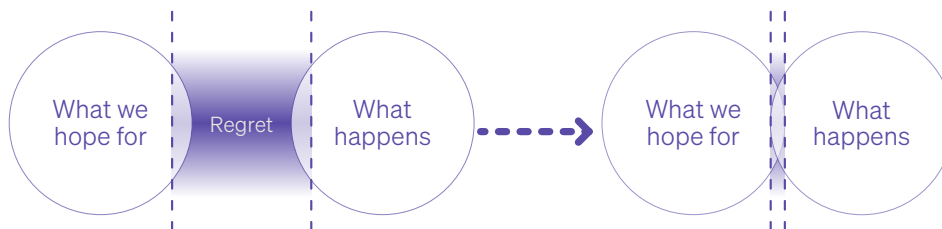


Referrers Uninformed

Working in organisations relevant to last stages of life.

Motivated to help & support customers and employees - yet are unaware of the support Violet can provide and how to correctly and sensitively refer people.

Violet reduces regret in the last stages of life.



Without Violet

The last stage of life can often have a very clinical focus, and this is often at the expense of a more human, social and emotional one.

With Violet

While death is inevitable, the regret caused by lack of planning, acceptance and communication in the last stage of life can be reduced.

A specific response to aged care

The issue of regretful outcomes through the last stage of life is pervasive, persistent and deeply felt in aged care contexts. Australia's ageing population will result in a doubling of deaths each year within 20 years which will continue to add further financial and emotional burden to a system already under significant strain. This is a priority issue.

The community is increasingly demanding new approaches and improved outcomes in aged care settings. Investment in a specific response that can be scaled and embedded into models of care across all providers is needed to:

- Help the aged care workforce to more confidently and willingly identify when a resident is entering the last stage of life
- Develop appropriate skill sets to enable key staff to have open and sensitive conversations with families & caregivers
- Establish trusted referral pathways for families & caregivers to Violet to access targeted Guided Support Programs.

The Violet Initiative has developed a suite of products and programs that address these issues. Leveraging over 30 years of experience, practice, wisdom and insights, together with a global evidence base, we have partnered with a number of leading businesses and aged care providers over the last 2 years to co-design a range of targeted solutions.

A market validation process was completed in late 2020 with a diverse range of aged care providers. The appropriateness and desirability of Violet's targeted products was confirmed. Providers are willing to invest in training products but the current and ongoing financial challenges of the pandemic limit their ability to fund Guided Support programs.

A partnership between government, industry and The Violet Initiative represents a market-leading step forward towards offering holistic support for people that are in the last stage of life and their family, resulting in better outcomes for families, Aged Care staff and the sector. The following outcomes are anticipated as a result of this work:

- Aged Care is better understood and positioned as a place to live well, and to die well
- More Australians have compassionate and dignified deaths, where experience is aligned with preferences
- Families and caregivers are better prepared and supported, are more resilient, have fewer regrets and a less complex bereavement and are able to return to their lives, more fully
- Aged Care staff have increased skill and support as they care for people in the last stage of life, through to their death.

The Violet Initiative's solutions have been successfully tested in other industry settings (financial services, life insurance) and are currently being implemented. This submission seeks government support to establish proof of concept for these solutions in an aged care setting, so that they can be implemented rapidly and at scale.

Proof of Concept — National Residential Aged Care Solution

We believe that Violet's evidence-informed palliative and end of life care model would provide significant value as past of the Australian Aged Care industry's response to both COVID-19, and to some of the predictable and key recommendations from the Royal Commission into Aged Care Quality and Safety that specifically address end of life, palliative care and workforce capability.

Through The Violet Initiative Model, we offer significant benefits to Australia's health and aged care systems, positively impacting servicing/care costs and productivity within relevant businesses such as aged care. Our early intervention system of support enables both government and industry to simultaneously re-distribute costs and achieve better health and social outcomes.

TVI has completed human-centred design work with leading businesses and aged care providers over the last 2 years, resulting in a sustainable and scalable solution that we are now seeking to prove out within the Aged Care sector.

2020 Market validation — Residential aged care

In late 2020, TVI completed a process of market review & validation with 12 leading aged care and home care providers. Key learning from this process have informed the iteration and improvement of Violet's products, services and cost structures. These key learnings included:

- Aged Care is an environment that is confronted on a regular basis with the realities of experiencing a high death rate with the overwhelming majority of residents who enter Residential Aged Care Facility expected to die there.
- The hurdle to uptake to Violet's offerings is not that the need is overserved but rather that it is underfunded.
- Aged Care is an environment with high staff turnover – influenced directly and in part by the intensity of the work environment for staff. Often nurses are tasked to rely on their own moral compass and life experiences to guide them as they care for residents at the end of their life. This is often particularly difficult for Support Workers and Personal Care Assistants perhaps even more intensely because of their lack of targeted training regarding the essential concepts of end of life care - when most of a residents' personal care is provided by them – leading to staff feeling isolated and stressed.
 - Over 90% of aged care staff experience moral distress related to end of life issues
 - 75% of staff have not received any training to assist with this⁷
- Psychological claims in the workplace are increasing at 15X the rate of physical claims⁸
- Adverse sector publicity and market growth constraints impose increased pressure on consumer purchasing behaviours and workforce employment selection criteria.

A three-way partnership between Violet, Government and Industry is a leading step towards improving experiences and outcomes for aged care residents, families and the workforce. Scaling Violet's model across the industry provides an opportunity to positively reposition the residential aged care industry as a place to live well, and to die well.

Without government funding via existing mechanisms e.g. ACFI or a new grant sourced through TVI – partnering with Violet on commercial terms is essentially an additive cost to an aged care. Whilst this may be partially offset by repurposing an existing training budget / pastoral care services etc the value proposition needs to be clear and compelling in the current challenging market.

⁷ Burston 2017

⁸ Burston 2017



National Aged Care Industry Solution (NACIS) Proposal

Violet's mission is to improve end of life experiences and reduce regretful outcomes for 10,000 people by 2022. To do this, we are seeking government investment to scale our evidence-informed suite of services nationally through Residential Aged Care Facilities.

On the basis of over thirty years of experience, practice, wisdom and insights, we have developed a range of industry training programs, referral pathways & Guided Support programs. We are confident of the quality of the services offered through our initiative. We have been heartened by the universally positive response from recipients of Violet's services, as well as from our generous and committed funder organisations who have seen the practical value for staff of their engagement with Violet.

We have been cognisant since the outset of our journey of the need to ensure that the critical work we are undertaking has been underpinned by a robust evidence-base, consistent with international best practice, and oversighted by acknowledged Australian clinical expertise. It is for this reason, we have assembled a dedicated Clinical Committee with local and international industry experts steering the development of Violet's model.

Our core services include:

- **Violet Academy**, offering Staff training and support: building capability and confidence to have challenging conversations with individuals and families, easing the emotional burden of conversations regarding the last stage of life and providing a referral option for families in distress.
- **Violet Guided Support**, individual and family support: specialised, nonclinical coaching delivered by volunteers with lived experience. Guided support focuses on acceptance, planning and communication with the goal of reducing regretful outcomes.

These services are delivered as a package of support, with training resulting in referral to Guided Support. Our products are deliberately digital, providing equity of access for those in rural and regional Australia as well as those with complex caregiving arrangements.

Our budget submission seeks financial support from the Australian Government to establish and evaluate a targeted, high impact Aged Care Pilot of Violet's Guided Support Programs. The setting for the Aged Care Proof of Concept will be Commonwealth funded Residential Aged Care Facilities (RACF's):

Proof of Concept:

- A total of 1,000 caregivers / family representatives per-annum over a two year period will receive Guided Support programs provided by Violet, incorporating three Guided Support sessions.
- Geographical coverage for the NACIS will include metropolitan and regional settings.
- Six provider organisations will be chosen for the NACIS, covering 60 sites with a 70/30 metropolitan regional split.
- A comprehensive independent evaluation of the NACIS will be undertaken in collaboration with the Australian Government and other stakeholders.

Partners

- Leading for-profit and not-for-profit providers in metropolitan, rural and remote locations (relationships established and interested confirmed)
- Leading research & evaluation partners (UNSW, ANU) (relationships established and interested confirmed)

Outcomes:

- Improved resilience and wellbeing for families enrolled in the pilot, and for staff of Residential Aged Care Facilities.
- Quantitative and qualitative evidence of increased levels of acceptance, preparation, and communication as a result of the Violet National Aged Care Industry Solution (NACIS) Interventions.
- Quantitative and qualitative evidence of dignified and compassionate death aligned with individual preferences and linked directly to the Violet National Aged Care Industry Solution (NACIS) Interventions.
- Evidence of a reduction in ‘regretful’ end of life outcomes (both human costs and financial costs) linked directly to the Violet National Aged Care Industry Solution (NACIS) Interventions.
- The evaluation protocols will include examination of impacts of the Violet National Aged Care Industry Solution (NACIS) Interventions on staff burn-out and, increased levels of staff skills and a reduction in regret associated with end of life.

Proposed sequencing of Violet (NACIS) Interventions

	Year 1	Year 2	Years 3 & 4
Implementation & full evaluation of NACIS (funded by this proposal)			
Roll-out NACIS across RAC industry (not funded by this proposal)			

A subsidised approach to ‘ramp-up’ industry adoption

The aged care industry has been severely impacted both financially and operationally by COVID-19. Whilst the situation has considerably eased at the time of writing the future remains uncertain. Violet’s recent market testing confirms that the industry’s ability to invest deeply in new initiatives beyond the immediate requirements of the pandemic remains limited.

However the need is immediate and growing.

A number of leading industry partners confirmed their interest in and ability to fund the training costs of Violet’s model. With Govt investment, effectively subsidising the cost of Guided Support for 1000 families over two years, Violet can move quickly to roll out the model, immediately supporting families, upskilling staff, and building an evidence base.

This ‘ramped approach’ makes it possible to:

- increase industry investment in Violet’s model over time, post-Covid, when occupancy rates have recovered and providers are more financially certain, and
- assist Violet to become a sustainable social enterprise, delivering nationally.
- work with the Government to determine the appropriate mix of government and industry investment going forward.



Costings:

Establishment of the Violet (NACIS) Interventions will include:

- Confirmation of the trial sites
- Contracting of technical platform development
- Recruitment of staff
- Purchase of equipment
- Development of evaluation framework

The establishment costs will total \$300,000.

The implementation and evaluation phases of the Pilot incorporating the Guided Support elements will total \$2million over 2 years.

Cost of staff training will be covered by Industry.

Summary budget

A summary budget is provided below.

A detailed budget has been provided in the Appendices.

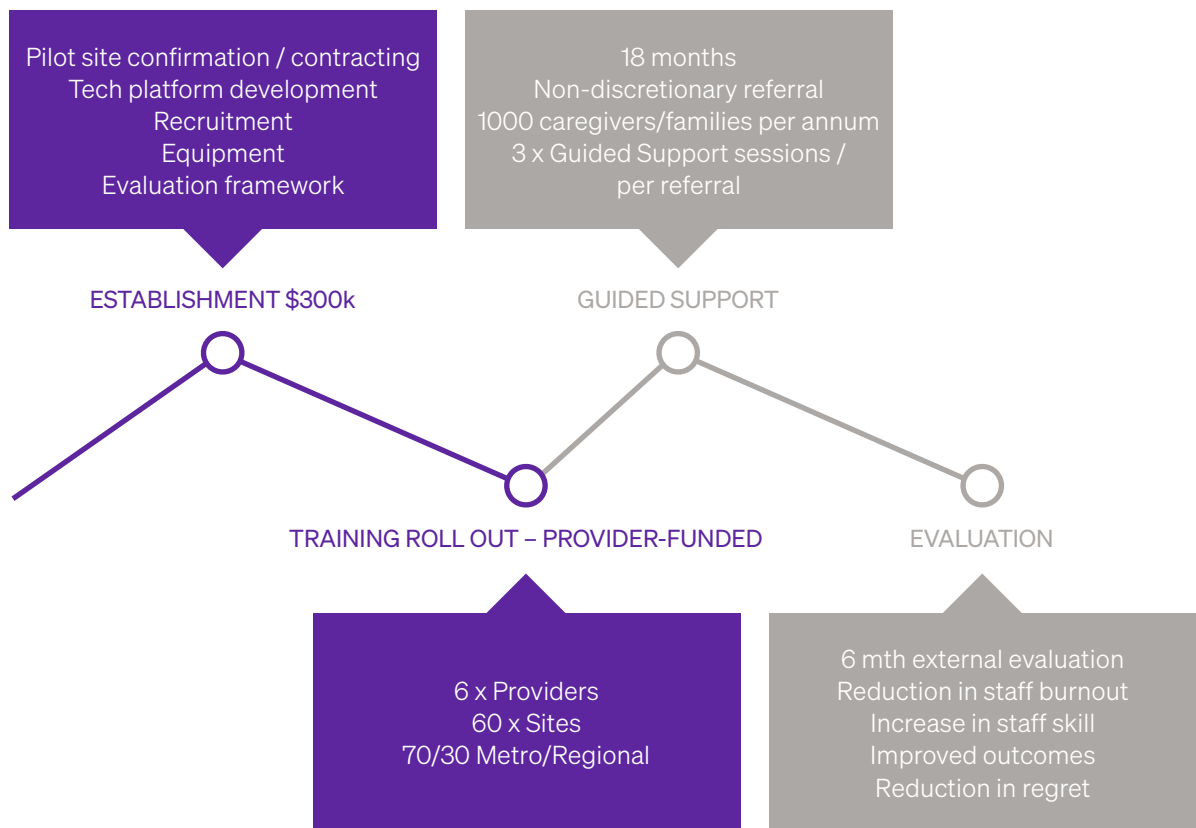
Item	Year 1 cost	Year 2 cost	Totals
Establishment	300k	nil	
Program costs	865k	762k	
Evaluation	150k	150k	
Overhead	118k	108k	
	\$1.433m	\$1.02	2.4m

Violet - National Aged Care Industry Solution (NACIS) Targeted and high impact 24-mth collaboration between Violet, Industry and Government

- National pilot - covering metro + rural and regional Australia
- 1000 families accessing Guided Support programs
- Comprehensive evaluation to prove outcomes

OUTCOMES

- Improved resilience + wellbeing - families, aged care staff
- Help with acceptance, preparation and communication
- More Australians have a dignified and compassionate death, aligned with their preferences
- Reduction in regretful end of life outcomes



NATIONAL AGED CARE INDUSTRY SOLUTION (NACIS) PROPOSAL - \$2M OVER 2 YEARS

violet

Appendices:

(1) The Violet Initiative:

Reducing regretful outcomes in the last stage of life

(2) The Violet Initiative:

Violet Guided Support Program overview

(3) Budget overview:

National Aged Care Industry Solution

Violet's mission is to reduce regretful outcomes through the last stage of life.

The Violet Initiative is an early intervention system designed to reduce regretful outcomes in the last stage of life.

Regretful outcomes are often characterised by the following scenarios:

- Families struggling to accept, plan, prepare for or talk about the declining health and eventual death of their loved one.
- The attitudes and preferences of the person in the last stage of life are not discussed, understood and advocated for.
- Things don't go to plan, or there is no plan.
- There are unwanted, unnecessary and unplanned days spent in hospital.
- People are not able to make the most of their time together.

Beyond the human impact of regretful outcomes, the economic cost of non-beneficial treatments, extended stays in acute care and workforce burnout is rising towards \$1billion. The work Violet does, when scaled effectively, can significantly reduce these costs.

At Violet, we call the necessary changes through the journey of death and dying our new truths, required for structural and cultural change:

- **The last stage of life is and should be recognised as a life stage;**
We need to talk about it, plan for it, and be supported through it.
- **All people, whose death is predictable (100k pa), will go through the last life stage;**
Whether frailty or terminal illness brings them there.
- **The last stage of life is a human experience, with clinical and non-clinical needs which must be addressed equally;**
improved education and support are vital.
- **We need to talk about death and dying;**
in a supported way,
at a pace people can tolerate.

Violet Guided Support

What is Violet's Guided Support Program?

Violet's Guided Support Program is designed to fit into the time-consuming and physically demanding life of a caregiver.

Over three sessions, carers receive personalised support from a trained Violet Guide, who has walked a similar path and understands what they're going through.

- All sessions are delivered over the phone, or via video-conference
- Sessions are 60 minutes in duration and can be scheduled anytime between 8am and 10pm;
- The program runs over 3 sessions, with the option to continue;
- All sessions are 1:1 and carers work with the same Guide throughout the program;
- Carers receive emotional and practical support that is personalised to their needs;
- All Violet Guides are fully trained and lived experience having cared for a loved one;
- All calls are 100% confidential.

Meet The Violet Guides

Each Guided Support Program is led by a Violet Guide who has undergone our proprietary training curriculum grounded in an evidence-based communications framework. And, just as importantly, they possess the ability to bring their personal wisdom to their role, while maintaining a safe, judgement-free space.



“We as guides have walked along a similar path and we have some idea of what's ahead.”—Rose Dillion

“Think about a caregiver as somebody traveling along a mountainous path,” Violet Guide, Rose Dillion explains. “We as guides have walked along a similar path and we have some idea of what's ahead. We have some idea about the tricky parts, somewhere that someone might stumble and somewhere that might be a good place to rest and regroup, and maybe enjoy the moment before moving on.”

“We're there to support and listen, and gently guide the person along that path,” adds Wendy Stocks, Violet's Guide Practice Manager.

How Violet's Guided Support Program Helps Carers

The Guided Support Program focuses on three anchoring themes: acceptance, preparation and communication. Here is some feedback from caregivers who have completed three sessions.

“Everything is more clear. I'm moving forwards, instead of being frozen in fear and grief” —Sandra

“It's been extraordinary! I think with any sort of help there has to be some kind of match – that the person's going to listen to you the way that you need to be listened to” —Jane

