



Palliative Care Australia

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PalliativeCare
AUSTRALIA

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Executive summary

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.¹

Improvements in health care mean more people than ever are living with life-shortening conditions. Disease trajectory may be difficult to predict for some chronic illnesses such as dementia, and studies have suggested a role for palliative and end-of-life care from the point of progression to a complex, chronic life-shortening illness². These factors are likely to lead to an increased demand for palliative care services.

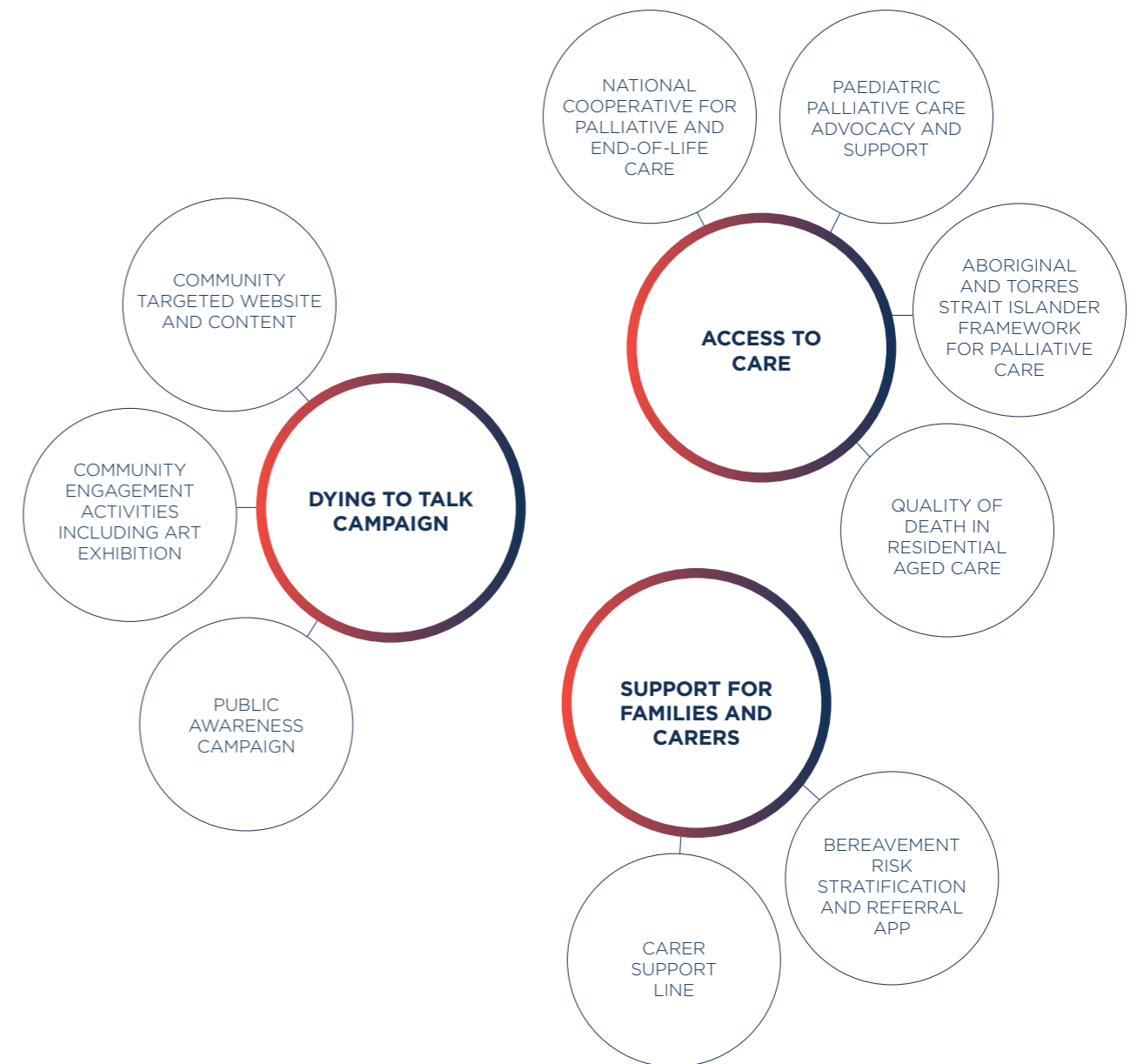
Palliative care improves quality of life for people who are dying, reduces the likelihood of developing complicated grief in the family and provides economic benefit to the health system. However, in spite these benefits, some people face difficulties in accessing care.

The current system is fragmented, with patients needing to move between state and federally funded services. This leads to gaps in service provision and difficulties navigating the end-of-life care system. There are also significant issues with recognition of advance care directives in different states.

The solution is for national leadership to support provision of equitable and high quality end-of-life care, requiring collaboration between states, territories and the Australian Government. Such leadership should be complemented by a targeted national campaign with the objective to seek to reduce the stigma associated with death and dying.

This submission outlines three priority areas for focus to achieve high quality end-of-life care. Palliative Care Australia is calling on the Australian Government to fund these important initiatives to support people and their families with the everyday complexities of living with life-limiting conditions. Investment in good palliative and end-of-life care has the dual advantage of improving the lives of people with a life-limiting illness through to their death, while also realising savings to the health budget.

Figure: Priorities to improve the lives of people with life-limiting conditions



Summary of projects

PROJECTS	ESTIMATED COST	BENEFITS
Access to care		
National Cooperative for Palliative and End-of-Life Care	\$40 million per annum	Evidence suggests that 70 per cent of people who receive good quality community palliative care can die at home rather than in hospital, with savings of an estimated \$233 million to be realised should this be achieved. ³ Reducing fragmentation and sharing risk reduces inefficiencies in the health sector, realising savings for all governments, while achieving improved outcomes for the patient and their family. National legislation regarding advance care directives would also assist in ensuring people's wishes are respected at end of life.
Quality of death in residential aged care	\$250,000	Around half of all people who die in Australia have accessed an aged care service during the 12 months before they die. ^{4,5} This study will be invaluable in understanding the quality of deaths in aged care facilities. It will provide the information to identify whether current policies need review and will provide the evidence to support such a review, should it be necessary.
Aboriginal and Torres Strait Islander Framework for Palliative Care	\$250,000	Studies suggest a lack of understanding of Aboriginal and Torres Strait Islander culture by palliative care service providers ⁶ and a lack of local palliative care services for Aboriginal and Torres Strait Islander people in remote locations. ⁷ Governments have committed to closing the gap. To support the Implementation Plan for the National Aboriginal and Torres Strait Islander Health Plan 2013–23 ⁸ it is necessary to develop an Aboriginal and Torres Strait Islander Framework for Palliative Care.
Paediatric palliative care advocacy and support	\$250,000 in the first year plus \$100,000 per annum	The death of a child has been demonstrated to have long-term effects on the lives of parents. There is a gap in resources and support available in Australia for paediatric patients, their families and health care team. Providing funding to Palliative Care Australia would realise economies of scale compared with the creation of a new organisation to provide such support.

PROJECTS	ESTIMATED COST	BENEFITS
Dying to talk campaign		
Community targeted website and content	\$185,000 per annum	The ability of health care workers to deliver high quality care is hindered by the difficulties and reluctance of the medical profession to communicate the risk of dying to people with a chronic disease and the reluctance of the community to discuss death and dying.
Community engagement activities including art exhibition	\$490,000 per annum	While Australia was ranked in the top two internationally for four measures of quality of death, Australia ranked ninth in community engagement, with a score of only 75 out of 100. ⁹ These three proposed projects have been developed with the objective of ensuring Australia is ranked in the top two countries for community engagement by 2018. Achieving this will facilitate discussions about end-of-life wishes and goals of care, leading to improvements in the ability to deliver patient-centred care.
Public awareness campaign	\$1 million per annum	
Support for families and carers		
Carer support line	\$425,000 per annum	Informal carers save the health system an estimated \$60.3 billion per annum by providing 1.9 billion hours of home care. ¹⁰ Supporting people to provide care for their family and/or friends would reduce costs to the health system by reducing emergency presentations that lead to higher rates of hospital admissions.
Bereavement risk stratification and referral app	\$270,000	Complicated grief results in disability and can hinder participation in activities such as work. This can have long term negative economic impacts. Complicated grief can affect people physically, mentally and socially, leading to complications such as depression, sleep disturbances and alcohol or substance misuse. Providing psychosocial support to people who are at high risk of developing complicated grief may decrease the longer term health and economic impacts.

Access to care

The Reform of the Federation discussion paper states: 'One of the largest problems intruding on the delivery of better services to Australians is how the current arrangements within the Federation are structured and the impact this has on the incentives within each sector.'¹¹

There is inequity of access to palliative care services brought about by fragmentation of care between primary and acute care, fragmentation between public and private care, and geographical issues. This fragmentation can lead to inefficiencies in the health system brought about by duplication of resources and cost-shifting between service providers.

Delivering the most efficient, high quality end-of-life care requires cooperation between states and territories and the Australian Government to share responsibility and risk. This is critical because investment by one area of health care may reap benefits, like cost savings, for another area.

While the Reform of the Federation requires significant debate and a long timeframe for implementation, Palliative Care Australia supports the proposal put forward in the discussion paper that some reforms could be implemented sooner, as part of an incremental approach supported by transition arrangements.¹¹ It is proposed that a National Cooperative for Palliative and End-of-Life Care could be an early activity in such reform and could be used to test the appetite for this level of cooperation between these two levels of government. One area to consider is unified legislation in relation to advance care directives.



Sue lives in South Australia. She received treatment for breast cancer in a private hospital. Her discharge planners were not able to provide access to equipment, nursing and allied health in the community.

Sue's family needed to separately arrange access to community health services. The family was very stressed that they could not give her all the help she needed. They considered whether they would be better off in the public system.

NATIONAL COOPERATIVE FOR PALLIATIVE AND END-OF-LIFE CARE

Palliative Care Australia is calling for the establishment of a National Cooperative for Palliative and End-of-Life Care to be implemented as part of the national reform agenda. The Cooperative would engage all governments in policy co-design for provision of end-of-life care and would provide for sharing of risks between governments to achieve the best possible service provision within currently available resources.

In good faith, the Australian Government would provide an upfront investment to both develop the Cooperative and provide initial resources to support changes during the implementation phase and prior to realisation of savings.

An example of the type of agreement that could be reached is for end-of-life care in residential aged care. The Australian Government may agree to invest in greater palliative care support in aged care facilities reducing emergency presentations, providing a saving for the state through reduced hospital costs. In return the states may agree to invest savings realised from reduced emergency presentations and bed days into supporting transitions to community care, and providing education and professional support to community care organisations, realising a benefit to the Australian Government.

The Cooperative would also be responsible for ensuring that the changes to palliative care service delivery and funding brought about by reviews including the Reform of the Federation, the Medicare Benefits Schedule Review, the Primary Health Care Review and the Private Health Insurance Review are all brought together in a manner that improves services and reduces fragmentation across the health sector. One important aspect of this is the inclusion of MBS items to incentivise general practitioners and other clinicians to support development of advance care plans, including a target for all residents of residential aged care facilities to have an active advance care plan. Further detail can be found at www.palliativecare.org.au/wp-content/uploads/2015/04/Nominations-for-MBS-Review_FINAL.pdf.

The objective of the Cooperative will be to deliver the best possible palliative and end-of-life care within existing budgetary constraints. Once an efficient and seamless service has been developed, it will be possible to assess whether additional resources are required to continue to deliver high quality palliative and end-of-life care into the future.

To support the development of the National Cooperative for Palliative and End-of-Life Care, it is proposed that Palliative Care Australia is funded to procure a study to:

1. Identify:
 - a. Options for models of service delivery taking into consideration best practice within Australia and internationally
 - b. The resources that would be required to be allocated to implement each of the service delivery models, both from a whole of sector perspective, and from the perspective of budgetary allocations given the current funding arrangements for health service delivery in Australia
 - c. The savings that could be realised from implementation of each of the service delivery models, both from a whole of sector perspective, and from the perspective of budgetary allocations given the current funding arrangements for health service delivery in Australia
 - d. Other benefits that could be realised from implementation of each of the service delivery models
2. Make recommendations about the most appropriate service delivery model for the Australian context
3. Propose a cooperative governance model that would include Australian Government and state/territory governments.

Advance care directives

The Cooperative could also begin progressing work in the area of advance care directives.

Advance care directives related legislation differs in each state and territory creating confusion for patients and health professionals alike and reduces confidence that health choices will be recognised in different jurisdictions.

The Cooperative could begin to work with the states and territories to implement nationally consistent advance care directive legislation.

The position for statutory advance care directives is governed by state and territory legislation, so whether an advance care directive written in one state is recognised in another state depends on what is contained in the various Acts in those states and territories. For example as New South Wales does not have legislation in place for statutory advance care directives and relies on the common law. Queensland legislation will recognise an advance care directive in Queensland if it is valid under the legislation of the originating state or territory, and if so, the document is treated like an advance health directive under Queensland legislation. That means that the limitations that apply under Queensland legislation will operate although those limitations do not exist in other states and territories.

In addition common law advance care directives (i.e. advance care directives that are not covered by legislative regimes) operate in most states and territories. This means that if a person makes an advance care directive that is not in a statutory form, it may be recognised in another state or territory.

It is therefore strongly recommended that there is Australian Government legislation or at least consistent and complementary state/territory legislation regarding advance care directives.

QUALITY OF DEATH IN RESIDENTIAL AGED CARE

Australia has been a world leader in providing high quality of care to people who are dying.¹² However, as the population ages health care needs change and Australia must continually assess and improve services to ensure they remain contemporary.

Three quarters of people who die aged 65 or older access an aged care service during the 12 months before they pass away.⁴ For this reason, it is important to ensure that these services are able to provide high quality care at the end of life. At present, there is very little evidence to assess this, particularly as it relates to residential aged care facilities.

Some organisations have expressed concern to Palliative Care Australia about funding arrangements for provision of palliative care in aged care facilities. However, there is insufficient data to assess whether these concerns are leading to poor quality end-of-life care, or whether service providers are able to work within the funding available. Such concerns include:

1. A lack of clarity on the activities to be scored under the palliative care item in the Aged Care Funding Instrument (ACFI)
2. A lack of alignment of the ACFI with contemporary approaches to palliative care
3. No additional funding available for provision of a palliative care program to residents where a score of 10 has already been reached
4. No funding mechanism in the ACFI for facilitating advance care planning and case conferencing.

It is proposed the Australian Government support Palliative Care Australia to conduct an audit of the quality of deaths in aged care facilities.

The audit would identify the services provided under the ACFI and the family experience with the death of their family member. Data analysis would include consideration of whether specialist palliative care support was provided, and if not, whether the aged care facility thought it would have been beneficial, the number of emergency department presentations and hospital admissions, and whether an end-of-life care pathway was started.

The study would provide benchmarks to assess the impact of future changes to the way palliative care is provided, while also identifying areas for improvement to guide future policy and program development. These outcomes would be considered in the development of the National Cooperative for Palliative and End-of-Life Care.



Frank is living in residential aged care in Victoria. He has multiple chronic illnesses and is approaching the end of his life. The state government funded a palliative care specialist to visit Frank in his aged care home to provide support to staff in managing Frank's pain.

Frank's brother lives in an aged care facility in another state. When he needs a palliative care specialist to manage his pain, he is transferred into the hospital. He is scared he will die in hospital with none of his friends around him and would prefer to be treated at the aged care home where he lives.

VULNERABLE POPULATIONS

Vulnerable populations are more likely than others to encounter barriers in accessing health care including palliative and end-of-life care. Barriers may include difficulty accessing services, or provision of services that are not sensitive to the individual needs of people. The increased focus on patient-centred care in Australia may go some way to supporting the country's vulnerable populations.

The two projects outlined below would support provision of patient-centred care to two of Australia's vulnerable populations: Aboriginal and Torres Strait Islanders, and paediatric patients. It is in these populations that Palliative Care Australia considers there is the biggest gap in providing resources to support delivery of high quality palliative and end-of-life care.

Development of a Framework for Palliative Care for Aboriginal and Torres Strait Islanders

The Implementation Plan for the National Aboriginal and Torres Strait Islander Health Plan 2013–23 was launched by the Australian Government in October 2015.

There is a domain in the Implementation Plan focussed on healthy ageing. Within this domain is an action to ensure "Culturally appropriate aged care models, including palliative care and end-of-life decision making for individuals, their families and carers, are developed and implemented".

The implementation of improvements to the patient journey from primary care to end-of-life decision making for individuals, their families and carers could be supported by development of a Framework for Palliative Care for Aboriginal and Torres Strait Islanders. The proposed Framework would be based on the Implementation Plan and provide high-level guidance and direction for organisations, governments and communities in the provision of end-of-life care and palliative care for Aboriginal and Torres Strait Islanders. However, there is a need to clearly describe the specific

cultural needs of Aboriginal and Torres Strait Islander people when accessing palliative care, including how to provide palliative care that supports people choosing to remain on country. There is precedence for the proposed Framework with the recent release of the Aboriginal and Torres Strait Islander Cancer Framework, developed by Cancer Australia.

To progress development of the Framework, it is proposed Palliative Care Australia work with the National Health Leadership Forum, and other peak bodies including Indigenous Allied Health Australia (IAHA) and the Congress of Aboriginal and Torres Strait Islander Nurses and Midwives (CATSINaM) and the National Aboriginal Community Controlled Health Organisation (NACCHO). The Framework could be used as guidance to support implementation of the National Safety and Quality Health Service Standards in relation to provision of palliative and end-of-life care for Aboriginal and Torres Strait Islanders.

Enhanced resources to support paediatric palliative and end-of-life care

Care for a dying child can be difficult for all involved. There is a need for specific support and resources targeted to carers of children with a life-limiting illness and to their health care team.

Differences between paediatric palliative care and adult palliative care include the lower proportion of those with a malignant disease, the protracted nature of many illnesses requiring integration of palliative care with curative care, the role of the family as caregivers, ethical issues relating to surrogate and supported decision-making and the greater risk of complicated grief for the bereaved parents.

In the United Kingdom (UK) there is an organisation dedicated to paediatric palliative care. While in Australia, paediatric palliative care comes under the remit of Palliative Care Australia, at present Palliative Care Australia is not sufficiently resourced to provide the resources that would appropriately support this group.

It is proposed the Australian Government provide support to enhance the Palliative Care Australia website to develop pages specifically devoted to paediatric palliative care in Australia. The website would bring together available resources as well as provide new resources that would be developed under this project. It is also proposed that Palliative Care Australia work with existing paediatric palliative care groups in Australia to develop a network of support for these health service workers. This network could include discussion forums and community platforms on the Palliative Care Australia website and would provide a means of sharing expertise and offering support to these people who provide health care that can have significant emotional impacts on the care provider.



CARE FOR A DYING CHILD CAN BE DIFFICULT FOR ALL INVOLVED.

Dying to talk campaign

The Quality of Death Index, by the Economist Intelligence Unit, evaluates 80 countries on their delivery of care to dying people. Australia placed second behind the UK in overall quality of death. While Australia was ranked in the top two internationally for four measures of the quality of death, it fell behind in its ranking for community engagement, placing ninth with a score of only 75 out of 100.⁹

Part of the difficulty in dispelling misunderstandings about death and dying is the reluctance of Australians to talk about death, particularly the death of ones they love. This reluctance is exacerbated by a lack of exposure to death. Each year in Australia, there are about 150,000 deaths. However, advances in medical practices mean that many people are not exposed to death as they once were. This can make broaching the subject difficult for families and their health care providers.

Implementation of the National Cooperative for Palliative and End-of-Life Care would benefit from an increased understanding in the community about what palliative care is, and how it can realise benefits for the patient, their family and the health sector more broadly.

Palliative Care Australia has a remit to change and improve the Australian culture in relation to engaging in discussions about death and dying, and has developed a small Dying To Talk campaign. However, there is much more to be done. It is proposed that the Australian Government support a campaign that promotes community engagement on issues relating to the end of life and to improve understanding of the community about the dying process so that it is no longer as stigmatised. The campaign will aim to improve Australians' understanding that dying is a normal part of life. The three activities are outlined on page 13 and have been developed with the objective of taking Australia to the number one or two position for community engagement in the Quality of Death Index by 2018.

Enhanced website for community engagement

It is proposed that the Australian Government support Palliative Care Australia to consult the broader community more directly through an enhanced website for community engagement. This would include development of a web-enabled platform to offer online forums and would require the development of content to stimulate discussion and engagement with the community. This would increase the literacy in the community about death and dying, and would enable people to better describe how they would like to be cared for as they are dying, facilitating delivery of patient-centred care.

Palliative Care Australia would also seek to establish a collaborative relationship with the Dying Matters coalition in the UK. This would enable sharing of resources and enhanced capability to develop innovative ideas about how to best engage the community, to discover what works and what is less successful. This collaboration would realise economies of scale by the two organisations working together to develop resources that would be amended to be relevant to the Australian context.

Community engagement activities including art exhibition

Palliative Care Australia proposes creation of a web-enabled exhibition and art space, bringing together and sharing work including photographs, poems, stories and other artwork. This would be similar to the 'When Death Comes' exhibition outlined in the case study. Art and other means of creative engagement have been demonstrated to increase community engagement, and may be a way to reach people outside of the health sector in discussions about the end of life.

The online art exhibition would be complemented by state and territory based festivals comprising live activities including photography competitions and workshops. These festivals would be implemented through grants from Palliative Care Australia to state and territory Member Organisations, providing a meaningful way to engage with their local communities and providing avenues for enhancing education activities conducted by these organisations.

Public awareness campaign

A national public awareness campaign would be conducted to complement the community engagement activities already outlined. The purpose of the campaign would be to normalise discussions about death and dying. The campaign would be similar to that conducted by BeyondBlue, adopting a community education approach to reduce the stigma associated with death and dying.

Through a comprehensive public awareness campaign it can be reasonably expected that the community's level of death literacy would increase, as would their level of understanding of the benefits palliative care can provide to family and loved ones.

The public awareness campaign would use innovative media and marketing strategies to make best use of available resources. The reach of the campaign as well as the success of the campaign in changing the attitudes of the public in engaging with death and dying would be measured through surveys, as well as through measurement of enhanced engagement including with the Palliative Care Australia website and social media channels.



'When Death Comes' is an art space and series of events in the UK where people can come together to think about, talk about, and create their own work about dying and living (www.whendeathcomes.uk).

"There are so many ways to respond to death and loss, and everyone will find their own way. But creating – in all its forms – seems to be something that brings comfort, insight and acceptance for many. It is a way to engage the community that may not otherwise be comfortable talking about death and dying."

Support for families and carers

Seventy per cent of people indicate they would like to die at home, while in some states and territories only 14 per cent of people actually die at home. In order to improve these statistics, it is necessary to provide better support at the place of care.³

Carers provide \$60.3 billion of unpaid care annually.¹⁰ If carers are not supported to provide care, they are more likely to seek formal care from health services, leading to increased health sector costs. Further, better support for carers may see an increase in people able to care for their dying family member in their home. This would achieve the result of supporting the patient's wishes while realising savings to the health sector.

In addition to providing support to carers while they care for a dying person, it is necessary to support them after the death. Access to support services may be limited by a lack of knowledge about available services and a perception among caregivers that it is embarrassing to ask for help. Providing appropriate support can reduce the symptoms associated with complicated grief, leading to improved health outcomes.

It is proposed that the Australian Government support two measures that would provide support to caregivers of people who are receiving palliative care and end-of-life care.

Carer support line

Australia does not do enough to support carers.^{3,13} This is particularly true for those people caring for a dying patient, whose role may come about gradually, and who may not identify themselves as a carer. Studies suggest that carers need additional support in physical care, information provision and emotion and spiritual support. The use of technology to support carers in their own homes is an area that is ripe for development and has largely not been embraced in this space.

Carers may feel more empowered to provide care if they knew they could seek advice 24 hours a day, 7 days a week. It is proposed that the Australian Government support the development of a national support line for carers of palliative patients that provides this immediate support.

The service could be accessed through the existing Carer Advisory Service and through the Carer Gateway. Carers of people with a life-limiting illness could call the line. They would be directed to either resources to support them, or to a person from the palliative care sector, who would be able to assist them with their questions or concerns.

Existing services could be explored as means for implementing the support line, such as expansion of the scope of the Decision Assist Advisory Line (subject to evaluation of this service) or use of state and territory services that could be assessed via a national phone number. Economies of scale could be realised by increasing the number of calls through these services, reducing the cost of providing this service to support carers.

Bereavement risk stratification and referral app

A recent Australian study identified a three tiered public health model for bereavement support and a risk stratification methodology to enable people at risk of complicated grief who could most benefit from provision of higher level bereavement services.¹⁴ This study found that people in the high risk group for complicated grief did not receive sufficient bereavement support.

It is proposed the Australian Government support the development of a web enabled app based on the risk stratification methodology. The app would ask questions to identify the risk group to which the person belonged, and would then recommend services

based on that risk group. The services would include existing bereavement services as well as services available under the Better Access initiative, which provide rebates for selected mental health services by general practitioners, psychiatrists, psychologists and social workers.

The app could be used both prior to the death of a loved one, to enable early intervention, or after the death of a loved one, to check whether the appropriate level of bereavement support was being provided.

Complicated grief is associated with functional impairment, medical morbidity, cognitive impairments and suicidal ideation. Complicated grief treatment has been demonstrated to be effective in reduction of complicated grief symptoms, thereby reducing costs to the health system by improving the health of bereaved Australians.^{15,16}







Sally is 35 years old and is the mother of three small children. Sally's husband died of leukaemia six months ago. Sally feels isolated and still cries every day. She often struggles to get motivated to get out of bed to look after her children. Sally doesn't know whether her feelings are normal or more severe than is expected, or where she can go for help.

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