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Reimagining Death Care for Our Ageing Population

By Rebecca Lyons
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‘Together we can fix the crisis in aged care.’¹ – Prime Minister Anthony Albanese, 21 May 2022.

As many as 70% of Australians want to die at home and yet comparatively few achieve that.² Overwhelmingly people are not achieving the end of life they desire. Australian society would benefit from community-centred and family-focused approaches to both the care of the dying and the dead, and the integration of these with existing health care approaches.

To this end, Australia needs a national interdisciplinary roundtable to develop strategies for the integration of informal (that is, non-medical based services that

focus on social and spiritual wellbeing) and formal (that is, medical services) supports and services in end of life and death care. The purpose of the roundtable is to provide wider options and greater support for the growing numbers of people predicted to die in the next four decades.³

The formal and informal systems of care are inextricably linked. People who are nearing end of life require both kinds of supports and services to achieve the death and death care they prefer, including the ability to die at home and to be able to remain there, in the care of their families and friends.

The integration of formal and informal services at end of life (and in death) is an important step toward meeting the growing demand on existing services in the future.

Background

By 2066, it is estimated there will be more than 430,000 deaths per year, compared to about 163,300 deaths registered in 2020.⁴ Not only is Australia's population ageing, but so is our workforce. If current procedures are continued, Australia will need to significantly increase numbers of doctors, nurses, palliative care wards, places in nursing homes, aged care workers, hospice programs, hospital beds, non-medical supports, providers, workers, equipment-hire schemes, and potentially funeral homes, to support the numbers of people projected to die. This is not something that can be done easily or quickly, so these issues require an urgent response, particularly in professional fields where high levels of training are required.

Currently Australia's dying and death policies are split across several domains. The portfolios of health care are state based, while aged care and other public health measures fall within the purview of federal government, and services such as home care packages receive a mix of funding. To develop and implement a comprehensive national strategy on dying and death, both levels of government need to come together to look at how both the formal and informal services across all sectors can be integrated to provide better overall end of life and death care for Australians.

In 2014, the Grattan Institute released a report⁵ that highlighted the limitations of the medical system alone in addressing all the needs that arise at end of life, and found that there was a need for non-medical care at the end of life. In 2017, the Australian Productivity Commission released a report⁶ that also recognised people's access to services they wanted at end of life were limited, including people not being able to die where they wanted. The Grattan Institute report three years earlier had focused on good death outcomes and went as far as proposing where funds could be found to introduce the formal and informal supports to allow home based death.

The recent Royal Commission into Aged Care Quality and Safety (Royal Commission into Aged Care) highlighted the suffering that can come with long waits to access needed services, echoing the Australian Productivity Commission findings. There are eight National Palliative Care Principles,⁷ which have been designed specifically for aged care facilities. This is helpful to those who reside in care, however, they do not adequately or comprehensively address the access to and provision of integrated formal and informal supports and services in care facilities, nor do they address the needs of those people

residing in the community. The Australian Commission on Safety and Quality in Health Care has also established the need for an increase of services. None of these frameworks, however, address a holistic approach to end of life and death care. At present, there is no public policy that addresses the integration of formal and informal approaches to end of life and death care.

Consideration of the issues

In dying

Australia's hospice and palliative care services have the majority of their focus placed in health care. Successful end of life care requires both formal and informal services to be available regardless of the location – home, hospital or care facility.

At present there are 31 Primary Health Networks in Australia working to streamline health services. They also deliver a program called Greater Choice for At Home Palliative Care.⁸ This program acknowledges that access to community based services is required to address wellbeing at end of life; what is missing is the acknowledgement that palliative care in the home is more than just a medical service.

The funding of hospice/palliative care at home programs should enable people to access formal and informal services to support them to die at home. The subsidising of access to private carers, hospice services, community care, social support, spiritual comfort, and medical outreaches would ease the burden on hospitals, nursing home facilities, and aged care services and their workers. Further, the integration of informal services such as end of life doulas (EOLDs) into formal end of life care models would add a valuable layer of support to a person's ability to experience the end of life they want.

The health care system has not yet fully recognised the validity of the role of EOLDs. Current research endeavours to both define the role of EOLDs and carve out a space for their services. A study by Krawczyk and Rush (2020) on the role of EOLDs and their practices undertaken in four countries found that:

*'For some, EOLDs offer a promising way to 'suture' the current division of health and death care which have been enshrined within end of life care in the global North ... [It is] important not to prematurely foreclose inquiry into how EOLDs may continue to develop alongside, but separate from, formal bureaucratic frameworks of professionalised care in the global North.'*⁹



Figure 1. What home funerals can look like: The gentle care of the deceased done by the family in a home setting. *Image credit: Courtesy of Rebecca Lyons.*

This resonates with the Australian experience. EOLDs potentially have a significant role in providing much needed informal support at end of life and can be a valuable addition to palliative care and other formal models of care. EOLDs can provide a range of informal supports and services, including advance care planning. At present, this is a missed opportunity – while EOLDs can be funded through aged care and NDIS packages, there is a critical lack of public education around EOLD services. The uptake of these services depends on how effective an advocate the individual doula is.

Another consideration is around service provision. There is a distinct lack of actual end of life and palliative care services providing tangible support to people at home and within the community. This has only begun to be addressed through the Primary Health Networks and there is a long way to go. The Australian Productivity Commission Report in 2018 found that people's needs at end of life were not being met and community based palliative care services needed to be expanded.¹⁰ Services are underfunded and overburdened, and people can die while waiting for service availability. Most recently, the Royal Commission into Aged Care found that:

*'The effect of a lengthy wait can be profound – there is a clear danger of declining function, inappropriate hospitalisation, carer burnout, premature admission to a residential facility, or even death ...'*¹¹

The Australian Commission on Safety and Quality in Health Care has also acknowledged the need for increased service provision and developed tools¹² to assist in bettering end of life outcomes, which are a part of their Comprehensive Care Standard.¹³ This standard and the tools do address the need for 'wellbeing' but do not consider the integration of formal and informal services.

In death

When considering the increased number of people estimated to need end of life care in the next four decades, there is another question yet to be addressed – how will we cater and advocate for 'wellbeing' in death and death care in a climate where people are regularly making choices based on their economic circumstances more than their social and emotional needs.

In some cases, funerals are becoming increasingly unaffordable and funeral poverty is a concept people are rapidly becoming acquainted with. Still, the ritual and ceremony of a funeral plays a vital role in grief and bereavement within our society and this has led to people searching for more affordable, environmentally friendly, and personal alternatives. In 2017, reporting on their investigation of death care and the funeral industry in Australia, van der Laan and Moerman highlighted the increasing costs of the funeral industry.

They recommend that government:

*'Develop guidelines for the information disseminated to those with authority to make arrangements that includes alternatives, such as direct committal, not-for-profit and community providers, as well as do-it-yourself options.'*¹⁴

At present, there is a gap in the information provided to the public, and as such, people are not always making informed choices. Without equal representation of not-for-profit, community based, and family led options, people are left to choose from a limited set of offerings.

As a direct result of the findings of my Churchill Fellowship report,¹⁵ the Australian Home Funeral Alliance (AHFA) has been established to address this gap. AHFA exists as a peak body with a view to educating and empowering people to seek out alternative approaches to conventional funerals, and skilling them to achieve it.

One of the ways AHFA promotes addressing the wave of death to come and the often unrealistic cost of funerals, is to move all or part of the after death process back into the hands of family and community using a family led home funeral approach (**Figure 1**). This informal service of home funeral is designed to empower and skill a family to care for their person in death as they often have in life, and it has emotional, social, and financial benefits.

AHFA define a home funeral as being -

*'... where a family, community and/or executor of a person deceased stay involved in the arrangements and give care to their person ... A home funeral occurs when family, friends or community are involved with conducting any aspect or ritual in caring for a person's body ... Participation in a home funeral can be as much or as little as any one person is comfortable with and prepared to do ... The duration of a home funeral may be hours or days, and each one is unique.'*¹⁶

The modern funeral industry is only about 120 years old and in that time we have shelved more than 5,000 years of knowledge about caring for the dead. There is now a growing movement aimed at reclaiming this community knowledge.

As I found on my Churchill Fellowship, this is a sentiment echoed by an increasing number of people worldwide. Normalising home funeral and after death care has been largely grass roots led, but is gaining traction as people's awareness of end of life options increase. As conversations about advance care planning are becoming normalised and death literacy levels are improving, people

are slowly beginning to realise they can have agency and control over decision making about both their dying and after death plans.

Stakeholders for consultation

Alongside the major state and federal government departments and national health care organisations, various informal grassroots and national bodies exist to promote community based approaches to end of life and death care. These should all be invited to participate in the roundtable proposed in this paper.

The following entities have been consulted and/or agreed to be stakeholders at the roundtable:

- The Australian Home Funeral Alliance
- The Natural Death Advocacy Network
- Holistic End of Life and Death Care Australia (HELD)
- End of Life Doula and Allies (ELDA)
- Social Health Australia
- Flinders University - Research Centre for Palliative Care, Death and Dying
- La Trobe University - Public Health Palliative Care Unit
- The GroundSwell Project
- Melbourne University - Death Tech
- Death Literacy Institute
- University of Western Sydney - Caring at End of Life Research Team
- Palliative Care Australia

Other potential stakeholders who should be extended an invitation, include:

- Meaningful Aging Organisation
- Aged and Community Services Australia
- Leading Aged Services Australia
- Australian Aged Care Collaboration
- Australian Centre for Grief and Bereavement
- Council of the Aging
- Royal Australian College of General Practitioners
- Carers Australia

Policy recommendations

It is recommended that the Commonwealth Department of Health and Ageing engage the Primary Health Network¹⁷ to establish and facilitate a national interdisciplinary roundtable to develop strategies for the integration of formal and informal supports and services at end of life and death care. Both formal and informal service providers

should be represented. This roundtable, when considering the growing demand on end of life and after death care services (and taking into consideration our aging population and workforce), can be tasked to formulate an integrated model of service delivery for end of life and after death care, including:

- investigating the infrastructure needs to adequately support people to die at home, meaning, at-home services and with end-of-life doula support
- developing the resources and education required to support families and communities who choose community and family led home funeral and after death care
- formulating strategies to promote the inclusion of EOLD services as part of aged care and NDIS packages
- expanding the scope of existing death literacy and advance care planning programs and services to include the non-medical supports for end of life care, such as end of life doulas and the option of home death care and home funeral.

This policy initiative of integrated end of life care would be an Australian first. Undertaking a roundtable would demonstrate the Australian Government's commitment to supporting public health and wellbeing in ageing. Following a roundtable and development of an integrated and inclusive plan, a combined commitment from federal and state governments is recommended to fund the implementation of a launch of Australia's first integrated model of care project.

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Bec Lyons is an advocate, educator, TEDx Speaker, funeral director and end-of-life-doula, not necessarily in that order. The subjects of death and dying, natural burial, and the DIY approach to death care are her passion and she loves being out in the community raising awareness and promoting good honest conversations. She is a dedicated advocate for positive change.

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