Investing in Systemic Impacts to Improve End of Life Outcomes:
Summary Report

THE AUSTRALIAN CENTRE FOR SOCIAL INNOVATION

Introduction

The JO & JR Wicking Trust is seeking to strategically invest in initiatives that could result in more older Australians dying where and how they choose.   This decision aligns with a broader focus across Government and philanthropy to grow design of and access to effective end of life care and increase investment in services and literacy around dying and death in Australia.

Ensuring good dying and death experiences and outcomes will require joining together the growth and spread of dying and death literacy, ensuring that people have the practical know-how needed to plan well for death (The GroundSwell Project, 2016) and the building of a responsive system which offers options, choice and opportunity. These goals are fundamentally linked (as illustrated in the figure below).

Good death and dying experiences and outcomes.

Understanding, Action

Options, Choice, Opportunity

Knowledge, Skills

End of life System

Death Literacy

Creating an end-of-life system that is responsive to rising levels of death and dying literacy.

Building a death and dying literate community in Australia.

In 2017 The Australian Centre for Social Innovation undertook to scope where the JO & JR Wicking Trust could most effectively invest to maximise opportunities that could support innovative responses across both these goals.

This short report outlines the broad roadmap drawn from this scoping activity. It summarises the key headlines that signal areas within which investment could support better outcomes in death and dying and finishes with a proposal to harness the opportunity of collaboration to generate these better outcomes across Australia.

Special Thanks

We sincerely thank everyone who generously offered their time and insight to building this broad roadmap of the opportunities for investment to improve end of life outcomes. This picture came to life through the open and honest contributions of people committed to changing the experience of dying and death for all Australians.

Methodology Overview

The scoping involved a combination of design research and systems thinking activities as outlined below. Within this approach, we focussed on depth over breadth, aiming to understand the context key stakeholders operate within and to generate multiple insights and opportunities to respond to.

In-depth interviews

Twenty one in-depth interviews were conducted with key stakeholders from across the end of life system. Stakeholder backgrounds included palliative care, acute care, aged care, general practice, community health, funeral services, research, peak bodies, carers (with lived experience of dying and death), advocacy, private enterprise, social enterprise and social movements.

Information Scan

A rapid desktop review was conducted identifying:
1. Systemic impact thinking and efforts already underway in Australia. Documents scanned included published research, conference presentations and project outcome reports; and
2. Examples globally of systemic level collaboration. This included conversations with leaders involved in two of the international examples reviewed.

Systems Mapping

Using the qualitative data gained from the interviews and information scan, a multi-dimensional view of the end of life system was mapped to identify the opportunities for change.

Focus Group

A focus group was held bringing together stakeholders with a variety of backgrounds to test the potential opportunities for investment and the potential for collaboration.
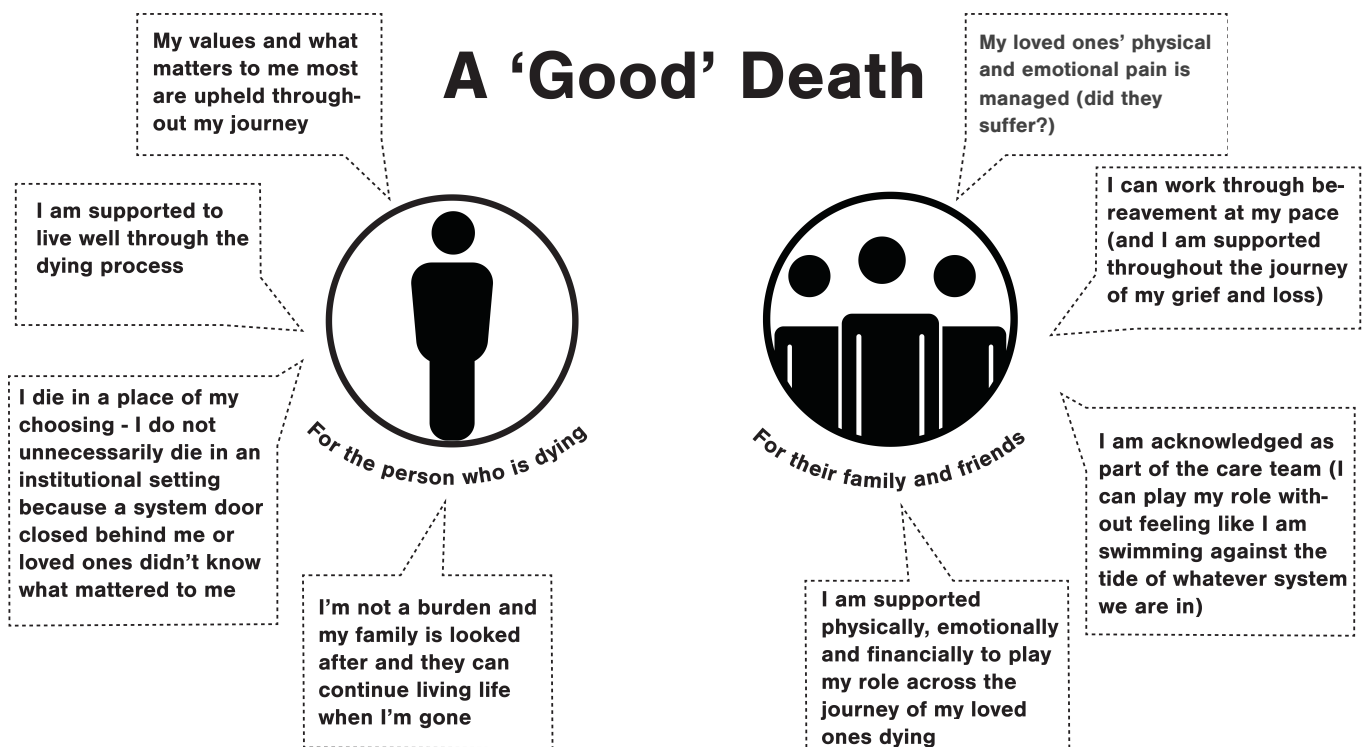
What makes good outcomes at the end of life?

"A good death gives people dignity, choice and support to address their physical, personal, psychological, social and spiritual needs."
Conversations - Creating Choice in End of Life Care ACHR

Death is unpredictable. It can be slow, sudden, traumatic, expected - we all hope for a 'good death'. What that means very much depends not only on our definition but on our circumstance, our support networks and on the nature of our death.

The definition and measurement of what a good outcome means at the end of life is not agreed across the health system. This in itself is an opportunity area. Some stakeholders are starting to experiment with new, more wholistic measures that contrast to currently used measures that are more medically oriented.

Across the stakeholders we interviewed, we heard that a good outcome in death and dying comprises the following key elements:

A 'Good' Death

My values and what matters to me most are upheld throughout my journey

My loved ones' physical and emotional pain is managed (did they suffer?)

I am supported to live well through the dying process

I can work through bereavement at my pace (and I am supported throughout the journey of my grief and loss)

For the person who is dying

For their family and friends

I die in a place of my choosing - I do not unnecessarily die in an institutional setting because a system door closed behind me or loved ones didn't know what mattered to me

I am acknowledged as part of the care team (I can play my role without feeling like I am swimming against the tide of whatever system we are in)

I'm not a burden and my family is looked after and they can continue living life when I'm gone

I am supported physically, emotionally and financially to play my role across the journey of my loved ones dying

Many of those we spoke with identified points in the current end of life system where the experiences of people or the system's capacity were more likely to compromise this outcome of a 'good death'. Often these points occurred because there were gaps when people transitioned from one part of a system to either another system, or from one stage of life to another - from health care to palliative care for example, or from aged-care to palliative care. What was highlighted was that there is not always good integration across the system. The question of what an integrated end of life system might look like was regularly raised as a broad goal for creating better outcomes at the end of life.

| Health Care | Dying / Palliative Care | Death | Bereavement |
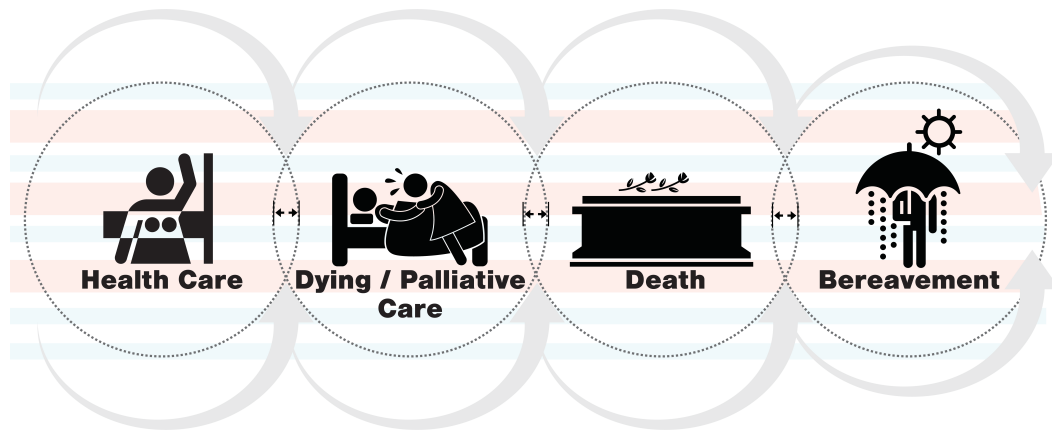
An 'integrated system' is one that provides supported transitions from pre-diagnosis through to diagnosis, curative care, palliative care, death and bereavement. Supported transitions between parts of the system are important to ensuring a good outcome for both the person dying and their loved ones. This is not the current experience of many people and families.

"Carers tell us - I can't deal with this, it is too fragmented, inaccessible and I'm overwhelmed."   Sally Evans, LifeCircle

Three types of transitions that effect good outcomes - personal, medical and funding stream - stood out for those we interviewed.

Personal transitions include progression of illness, grief and loss, changes in financial circumstances, responses of personal networks in taking on informal care roles.

Medical transitions include those between general practice, acute health, specialist health and community health.

Funding Stream transitions include between and within health care streams, aged care streams and disability support streams.

There was a sense that it was particularly at these key transition points where care pathways could become disjointed, options diminished and individuals' needs and wishes not considered. As we focussed our exploration on where investment into innovative responses could potentially shift outcomes in and around these transition points, five critical elements were repeatedly identified. Though broad, they could offer the JR & JO Wicking Trust and other investors some areas to develop and test as they seek to improve outcomes for older Australians who are facing end of life decisions. Each of these elements is outlined further below.

Education
Moving beyond 'information' towards broader capabilities across communities and professionals and more open engagement with end of life conversations across the lifespan.

Networks + Roles
Growing and enabling community based care requires networks of support and greater levels of informal care roles than are currently available to many people - particularly those who are marginalised from family or community.

Planning
Developing practical, flexible, values based approaches to planning so that more people have the opportunity to discuss and put into place what they need in order to live well until the end of life.

Navigation & Flow
Access to the right care, in the right places, at the right times is dependent not only on developing greater levels of death literacy, but also on ensuring that the various systems that people interact with at the end of life are responsive, able to be navigated easily and funded in ways that mean the flow of resources eases transitions between various stages and parts of end of life care.

Choices
Choice no matter who you are and what context you're in.

Education

"End of life conversations are the most important thing by far - the complex bit is what that looks like."
Rebecca Bartel, ACHR

End of life care has a relatively low profile in Australia. Information provision is often transactional and information not always readily accessible, particularly for certain groups of people. There are issues with the breadth and depth of reach when it comes to information and how it is provided. The nature of the information and who provides it can also create barriers for engagement. As a result, conversations about dying are happening too late in people's journeys, or not at all. Yet, the later we engage in conversations about values and choices in someone's end of life journey the more their options are diminished.

Building greater levels of both community confidence and professional capability to openly and responsively engage with people both before people are presented with a diagnosis or prognosis, and throughout their end of life journey could help to normalise death and reduce the societal taboos about discussing death that still exist in many parts of the community and the health system.

There was a shared view that education efforts that go beyond information provision and build both capability and confidence to take action are critical to creating the change that leads to better end of life outcomes for people. This in turn could lead to better choice and control and ultimately, living well through the end of life. This education needs to occur not only in community but with professionals across the system.

The opportunities and questions that arose from our discussions included:

How might we extend existing and create new opportunities for end of life education that builds capability and happens across people's lives (ie. doesn't wait for people to be faced with life-limiting illness)? This may include, for example: supporting literacy in dying and death at key points of life - at school, finishing school, marriage/partnership, employment, retirement, or at transitions in life where people get legal advice legal (eg. when people take out mortgages, or make investments). Further, what does education and information look like from very different perspectives? Many of the education offers are aimed at people who have strong networks or existing capacities - crudely, they are often about people who are middle class, Anglo-Saxon, literate, connected, and feel able to turn up and talk with a group. How can we ensure death and dying literacy is also available at the margins, in low income communities, with CALD groups, and what can we learn from Aboriginal approaches and other cultural approaches?

How might we use a public health approach to catalyse an integrated education effort? For example AHRC, The GroundSwell Project, Life Circle, LaTrobe and Palliative Care Australia each have frameworks and hypotheses that could be coordinated, deepened and broadened through collaboration. In combination, they have strategies that could reach households, health and community service professionals, communities, education institutions (schools, universities, TAFE), policy makers and politicians, employers, financial/banks, popular media and research institutions. Further, much of the 'literacy' and education is aimed at 'death' but what about dying? Death is the end point but the process of 'dying' is harder and messier, how can we ensure that dying is elevated in the discussion, so that the focus is not just the end point, but more the process of how we live and die?

Networks and Roles

"Enabling community based care is preventative, the more we can do death in the community the less we need the acute system." Jennifer Philip, St Vincent's Melbourne

Across the interviews there was a shared view that good outcomes at the end of life require a network of both informal and formal care around a person and their loved ones. What was highlighted was a distinct lack of options and solutions for those who have weak or no networks. This is concerning particularly as there appears to be a direct link between the strength of someone's networks and the opportunities they have for dying at home (or at the place of their choosing). If options and opportunities are going to be grown for more people to live and die at home there is a need for innovations that span informal and formal support, and that take a systems approach rather than continuing to perpetuate siloed responses.

The discipline of palliative care has became highly professionalised and specialised, which has resulted in recognition of specific issues facing people at the end of life, but which also presents some problems related to when, where and how people can access support and assistance that may be required before the last stages of life. Support and care associated with palliation can be required over a relatively long period of time, particularly if people have life-limiting conditions such as motor-neurone disease or dementia. However formal care and particularly funding of this care is skewed towards the last period of dying. People are asked to plan ahead, and many services want people to connect early in the process of dealing with life-limiting illness, but paradoxically people are also often told that they are not far enough advanced towards the end of life to access intensive palliative care support or specialised equipment and nursing care. There was a strong theme in our interviews that this needs to be flipped - so that people can access services and support when and where they are needed.

The opportunities and questions that arose from our discussions included:

How might we increase advocacy and self advocacy with groups who are currently marginalised from mainstream end of life support systems? How might we look towards innovative ways to create and support networks around people where they don't exist? For example the work of LaTrobe and Warrnambool's Hospice in the Home are seeking to explore answers to these questions.

How might we grow community capacity to better support people at the end of life, and explore innovative ways to engage a diversity of people in examining a wider suite of roles community can play in end of life support? For example, the Compassionate Communities Movement and The GroundSwell Project are seeking to answer this question.

Planning

It is clear that planning has a critical role to play in preparing for and ensuring that people are able to live well as they near the end of life. Planning takes a number of forms, including Advance Care Planning, End of Life Care Planning, Advance Care Directives, financial planning and more informal planning that considers people's preferences for living and dying well, as well as funeral wishes. There was a shared view amongst many interviewees that further innovation was needed to develop planning approaches that surface goals of care and what matters most to a person, and that this will empower them and their loved ones in their dying process and will ultimately lead to better outcomes around the end of life.

Many current planning processes are inadequate, ineffective or inaccessible. Lack of preparation and planning early in the journey can result in poor service access and decreased choice and control about where and how a person dies, and who is to be involved in their journey (personal and medical). Too many people have outdated plans - or plans that are not revisited when circumstances change. When this happens plans can become barriers to, rather than supporters of, choice and control. As one stakeholder argued, "Out dated written plans gazump any current verbal planning". Further, many people don't have the basic legals in place (for example, enduring powers of attorney), and this also impacts on outcomes for both people at the end of life and their families. Given that the acute health system is geared for 'treatment first' responses if a person with a life limiting illness ends up in this system it can be the case that their capacity for choice and control diminishes even when they have a care directive. Under these circumstances stakeholders identified that people can still be subjected to situations where they cycle in and out of acute care, or end up dying either in this system or on the way into it in an ambulance. Despite efforts at better planning processes, it is all too common that the experience of planning is transactional (not relational) and a one off 'event'.

The opportunities and questions that arose from our discussions included:

How might we create approaches to planning that are values based, more flexible and adaptive and enable people to make decisions or exercise choice and control under stress? People face many challenges along the end of life journey, so how do we create plans that are flexible and that can adapt to changed circumstances or the unexpected to improve outcomes? What enables you to access choice under stress?

How might we support people to consider end of life planning in a way that reduces fear? How do we plan for living when confronted by a life-limiting illness or the prospect of death? How do we ensure end of life planning opportunities reflect an individual's readiness to make these decisions and is at the right time for them?

Navigation and Flow

"Right care, right place, right time. " ACHR framework

Navigating a complex system and advocating either for yourself or for a loved one at a stressful time of life can be both difficult and lead to less than optimal outcomes. If people are to access the right care, in the right place and at the right time then this requires not only knowledge of available resources and supports, but also a system that is responsive, flexible and where pathways across systems are seamless (eg. from aged care to palliative care). While education and planning provide a good foundation without changes within the health and aged care systems happening in parallel, outcomes won't shift significantly. In particular, interviews indicated that ensuring the flow of resources and incentives do not create blockages as people transition across the system are essential.

One of the important areas for innovation in complex systems is the role of navigation. There are currently a number of barriers to better navigation of end of life systems in Australia. Carers and informal support networks are not always acknowledged or meaningfully included as people encounter parts of the system they need to navigate at the end of life (e.g. acute health, aged care). The knowledge informal support people have about the needs of a person may be critical, but they are not always considered as such. General Practitioners are often the most accessible interface people have with the health system. However General Practitioners are not trained nor compensated for engagement in all the aspects of end of life care - only those parts that are directly considered to be medical in nature. This means that any social, cultural or pastoral aspects of care for someone who is dying (and their families / carers) are excluded from the General Practitioners practice, and they often rely on specialists and acute health care providers to talk about death.

There is significant investment in acute care. However the acute care health system is set-up for a 'treatment first' approach and thus can result in unnecessary cyclic pathways for people at the end of life. The most regular phone call to palliative care services is from people who are informed there is no more active treatment available. They are often told by health care professionals that they should consider palliative care but many say that they are not guided to access the support they need. It was clear from interviews that too many people access palliative care late in the journey and wish they had known how to access palliative care sooner. We heard that many Residential Care Facilities (aged care and disability support) are providing hospice-like care but without the training and resources. In some instances this leads to ill equipped staff panicking and sending people into the acute heath care system; or stepping away as palliative services take over, not valuing their relationship and role in the end of life journey of the person in their care.

The opportunities and questions that arose from our discussions included:

How might we support and enable people and their carers to navigate and negotiate the system maze? What are the barriers to restoring the power of individuals in their interactions with the systems, institutions and processes they are likely to encounter in their end of life journey?

How might we enable seamless transitions across systems (eg. from aged care to palliative care) throughout the process of dying?

Choices

Currently choice and control at the end of life is not guaranteed, and is somewhat dependent on abilities for self-advocacy, networks and relationships, financial resources, and a degree of knowledge about how the system works. There is a need to examine, explore and innovate so that more people are able to exercise choice and control when it comes to where and how they wish to die. It is equally important to note, that simply having choice is not enough for those in marginalised groups - communication and cultural barriers, reduced self advocacy, fewer support networks, financial insecurity, poor mental health, lower educational status, insecure housing, and loss of family connections, all factor in to a person's actual access to support services and their capability to really make choices.

The Assisted Dying, Euthanasia, Assisted Suicide debate is, to a large extent, hijacking broader conversations about choice at the end of life. Yet this choice will ultimately be available only for the minority who will need it (1-2%). A deeper debate about the state of end of life care in Australia is needed to enable genuine choice no matter who you are and what context you're in, particularly in the context where poor outcomes for those most marginalised continue to exist.

The opportunities and questions that arose from our discussions included:

How might we create opportunities for more people to exercise greater levels of choice and control in relation to end of life pathways? What are the principles that can universalise choice in the end of life system - so that choice is not restricted to those who have the capacity to pay for it, but is available to all who are dying? How do we remove the barriers to choice that already marginalised people often experience? How might we create new solutions for enabling better outcomes for marginalised groups in end of life choices and pathways? For example, Melbourne City Mission have volunteer end of life carers. How might we create new approaches to assisted living that focus on figuring out how people can sustain the connections and joys that matter most through the process of dying? For example, LaTrobe's work in end of life in supported accomodation services (disability).

As the issue of assisted dying enters more broadly into political debate, how can we ensure that the choice is not binary - either suffer or choose assisted dying - but rather extends across the many options we have to live well until we die?

Opportunity for Collaboration

"We are inventing new ways for disparate people and unlikely partners to work together to solve our biggest problems." Cheryl Dahle, Future of Fish

The conditions exist to seed a national collaboration for systems level impact in end of life care and services. There are already great foundations for this kind of collaboration in Australia: knowledge about the problems; pockets of local, national and international innovation activity in progress; strategic and deep connections across the system; and passionate, determined leaders.

Yet these strengths exist alongside some challenges for change and innovation. Passion and strong ideologies have led to some blind spots about how change can happen and who can lead it. There are tensions and lack of trust between key players, and there are both professional and ideological resistances to so called 'outsiders' playing a part in change. We also heard many assumptions about other stakeholders in the system. We also saw the potential to build empathy across the system by supporting disparate actors to understand one another's drivers and intentions. There is potential for collaboration to build trust between parts of the system and see funding, resources and commitment aligned towards better outcomes for people at the end of life and their families.

What is missing is:
- innovation capability across the system;
- coordinated effort and investment;
- a space within which to safely but robustly challenge what is;
- coordination for influence and to scale efforts up, out and deep.

What is needed is a space that can hold the differences, especially in ideology, and move past this into agreed next steps for change across the systems where and with whom it is needed.

The theory of change on the next page outlines how we can build an action oriented collaboration (not another network, but a collaborative effort that respects diversity and aligns across this for action around essential change that could deliver better outcomes for people).

How we get there

The current system that stretches from health and curative care through palliative care, death and bereavement is fragmented. Many people don't have the knowledge or capability to navigate it, nor the choice and access that would enable them to experience a good end of life process. There are many gaps for people in moving both between the major transition points in the system, but also within institutions in a part of the system (e.g. moving from aged care to palliative care). And it seems increasingly difficult for people to negotiate these widening gaps of funding; legal and political divides; and jurisdictional barriers.

There are existing networks, peak bodies, interagency collaborations that are seeking to address key issues within current policy, practice frameworks and disciplinary frames of reference. These networks play a valuable role in the sector, but they are not necessarily able to address systemic issues or challenges.

What is needed is an approach that starts with the key stakeholders who have the mindsets, the influencing capacities and the capabilities to cross boundaries. Key stakeholders who are able to traverse some of the tensions that currently exist across the system, tensions that make it difficult for great outcomes to flourish.

The theory of change on the next page is based on taking an experimental approach - it is focussed on building coalitions of stakeholders, who have the capability to create shifts in parts of the system. Linking them through a virtuous platform (part virtual, part physical, based on a commitment to create better outcomes) to others who are also focussed on creating shifts in critical parts of the system. It does not require agreement about methods, only alignment around what outcomes are to be achieved.

This approach to collaboration across the system is based on inspirations from a handful of other initiatives around the world that are seeking to explore the most effective 'architecture' for creating systemic changes, including Future of Fish in the US, and Dark Matter Lab in the UK.

Underpinning assumptions of this approach are:
1. There are existing networks, peak bodies, interagency collaborations that are seeking to address key issues within current policy, practice frameworks and disciplinary frames of reference. These networks play a valuable role in the sector, but they are not necessarily able to address systemic issues or challenges.

2. Addressing systemic challenges requires bringing together people with the influencing capacity, the perspective and the mindset for working across artificial barriers such as disciplines, institutions, and traditional spheres of control; and
3. A systemic approach requires a bias for action and a capacity towards operating 'beyond brand'.

The Problem

Many Australians are unaware of options / choices they have for dying / end of life decisions, & death, & often don't engage until they are faced by circumstance to do so.

Systems / institutions are currently unable to offer people a range of choices options for dying, end of life & death - stakeholders in these instituons are aware of many of the limitations, but don't have the capacity of the infrastructure needed to create changes.

While there are networks & institutions that connect interest groups in the system, these are fragmented & not able to act to create systems change.

The Theory of Change

If we...	By...	This will lead to...	And eventually...
Build /design / test an architecture that can support diverse groups of stakeholders to learn, move & act on key elements or points of the system that have potential to improve outcomes	Identifying key elements / points in the current system that could improve or prevent good outcomes	Multiple sites / groups of actors who are working for change & identifying /addressing barriers	A diverse movement of people, organisations & institutions who are working towards breaking down barriers, & creating change in a multitude of spaces & contexts without having to agree on methods or processes
Recognise that our current networks & structures are designed for effectiveness & efficiency at institutional levels not systems levels; & are predominantly focussed on interest groups & organisational interests than on systems innovation & outcomes	Identifying, resourcing and building the capacity of innovators & disruptors who can draw people together around different explorations / actions to shift outcomes	Being able to track shifts & learnings across diverse contexts, cohorts & methods	
	Catalysing groups of actors who agree to take action in relation to any / each of these elements	Greater opportunity to draw together local actions towards scaled & systemic level changes on multiple fronts simultaneously	
	Building platforms to share learnings and leverage from actions		
	Connecting, coordinating & challenging across groups & platforms as needed to achieve outcomes		

The Broad Goal

All Australians have the opportunity to develop & realise literacy about dying, death & grief

All Australians have the opportunity, possibility & access to supports to live & die well

Your feedback is welcome

This report has played an important role in helping the JO & JR Wicking Trust have confidence that opportunities exist to invest in systemic initiatives that will result in more older Australians dying where and how they chose.

It is a foundation to build from as the Trust moves from making sense of the systems around dying and death to investing in action that brings about change. Thus, the Trust, and The Australia Centre for Social Innovation as grant partners, welcome your feedback and any contribution that helps advance the work of the Trust and their partners in creating good death and dying experiences and outcomes for more older Australians.

In the first instance, to contribute feedback or express interest in the collaboration activities please email us:

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