

16 July 2017

## **Response: Introducing Competition and Informed User Choice into Human Services**

Imagine ours is a death literate society, one where people and communities have the practical know-how needed to plan well for end of life.

The GroundSwell Project (GSP) is an international leader in death literacy, and has been at the forefront of this movement in Australia. We are passionate innovators focused on systemic long-term change around end of life care. Over the last 7 years, GSP has developed and delivered fifty-five community capacity-building projects and programs aimed at creating a cultural shift in the way Australians respond to dying, death, loss and grief. Additionally, we have been key stakeholders in the Caring at End of Life research program led by Western Sydney University in partnership with CSIRO, La Trobe and QUT. This internationally recognised research provides the evidence base for our work.

We work with two critical approaches:

1. Philosophy of Compassionate Communities. As part of the International Public Health Palliative Care Council, we progress capacity building in end-of-life care across the health sector and communities and through research and practice most recently evidenced by our joint hosting with Palliative Care Australia of the International 2 day Compassionate Communities conference in 2016 which attracted 190 attendees, 70% of them from the health sector across Australia.

2. Grassroots Campaigning through Dying to Know Day on 8<sup>th</sup> August. D2KDay is a home-grown uniquely Australian initiative. D2KDay is a national call to bring to life conversations about dying, death, loss and grief. It aligns with multiple state and national palliative care, end-of-life care, and advance care planning strategies. D2KDay has been endorsed by the Victorian Parliament (Legal and Social Issues Committee Inquiry into End of Life Choices - Final Report), the Grattan Institute 'Dying Well' Report (2014), and was recognised in the evaluation of the National Palliative Care Strategy as making significant contributions to community awareness. D2KDay has been at the forefront of disseminating information about end-of-life care along with similarly aligned community conversation projects just as Death Cafes, Die-alogue Cafes and Death Over Dinner. Over 330 cross sector events/collaborations have been registered and evaluated since inception in 2012.

As part of our innovative work, we seek to understand what conditions are required for a person to want to plan for their end of life and consider their values and wishes for end of life and more importantly, what it is that enables them to take action

We have recently contracted Western Sydney University to develop a population based social impact study through the development of a Death Literacy Index. Through local and wide scale initiatives, we aim to determine the current state of death literacy in Australia and provide a measure for interventions aimed at increasing death literacy of an organisation, a community, or even a nation. This will help us to understand what people already know about death and assist in planning projects that increase death literacy and end-of-life planning.

**Recommendation: 4.3**

*The Australian Government should promote advance care planning in primary care by:*

- *Including the initiation of advance care planning conversation as one of the actions that must be undertaken to claim the '75 plus' health check Medicare item numbers. As a minimum, this would require the GP to introduce the concept of advance care planning and provide written material in the purpose and content of an advance care plan.*
- *Introducing a new Medicare item number to enable practice nurses to facilitate advance care planning*

We agree that any mechanism and 'burden lifting' to allow GPs to have the conversation with their patients about advance care planning is helpful, however, any efforts to increase advance care planning conversations that rely on education and resourcing of the clinicians in a health care setting alone provide a piecemeal solution. And we fear if no funding is put into alternative, innovative ideas that build capacity for individuals, families and communities to engage and plan for their end of life, that we will not see any significant change in the numbers of Australians entering into acute care or aged care with little to no thought of their end of life.

**Why funding uptake of ACP education for health workers is not producing higher uptake**

1. Evidence suggests education does not change behaviour alone.
2. It focuses primarily on individuals. When health interventions target individuals, they do not necessarily alter the familial, social and environmental conditions and cultures that work against good end-of-life planning, but instead rely heavily on the individual's ability to navigate the health system.
3. Advance care planning continues to be primarily a hospital or health care-based activity and is separated from the primary place of end-of-life caring: the home and community.
4. Effective planning needs time, and most planning currently occurs during a health care emergency or when a family is in crisis. Planning ahead is clearly preferred.
5. Enhancing social networks of care at the time of a health crisis may do more to build capacity for the individual to cope, rather than focussing on completing an Advance Care Directive (ACD) (see case study below for a better approach)

**Case Study: an alternative way to deliver education that results in behaviour change**

GSP delivers an end-of-life workshop: "10 things to know before you go" which takes the attendee through the knowledge and skills they need to plan for the end of life. Most attendees are healthy and highly motivated to get their plans done as well as learn how to have conversations with the people that matter in their lives. 80% of attendees take action within 4 weeks, often communicating their wishes to family members and/or friends.

We believe this is because considering and planning for end of life is a social experience and falls outside of a formal health setting. We designed this workshop with community members. We listened to what they said they wanted to know more about.

## How can we better understand where to invest to produce higher uptake?

1. Social research into the triggers, skills and knowledge, and resources.

### Evidence for community capacity building efforts

1. There is evidence that community capacity building has an important role in improving the effectiveness of the current advance care planning initiatives and the work that clinical services are undertaking. This is because the impact is cumulative. *Community awareness through evidence based engagement activities can BOTH socialise AND normalise end-of-life planning.* This upstream approach sensitises and improves readiness within the community and has been shown to reduce healthcare costs in the UK (Abel, in press).

2. Community efforts are important for raising awareness and encouraging conversations about death. The Economist Intelligence Unit Quality of Death Index states:

*When it comes to the end of life, the role of the community is important. And when communities, volunteer workers and families take on more responsibility for care, it can reduce the costs associated with hospital stays and emergency admissions. The question for policymakers is how to create the incentives and support systems needed to encourage more community involvement.*

Australia is falling behind the international community when it comes to community awareness efforts. According to the Quality of Death Index (EIU, 2015), Australia ranked in 9th place internationally for community awareness of palliative care. This was identified as our lowest score because the “public has a somewhat good understanding and awareness of palliative care services”.

### Effective engagement is needed

Community engagement in end-of-life care is an umbrella term for a process which enables communities and services to work together to understand, build capacity and address issues to improve their experience of end-of-life, bereavement and related well-being. It exists on a spectrum of engagement that extends from ‘informing’ through to ‘empowering’, depending on a range of factors, such as the degree of participation from the local community and the intention of the work. Some of the most successful community events are those run in cafes, art galleries and neighbourhood centres.

If there were an investment into an innovation fund that would fuel the efforts of the small, yet effective community-based palliative care services (such as Warnabool District & Community Hospice) and other public health initiatives, we could see a broader, overall rise in death literacy and end-of-life plan readiness. Death literacy is part of public health approach and is defined as the “practical know-how needed to plan well for end of life” (Noonan et al., 2016); this includes having the knowledge, skills and ability to take action. Getting involved in end-of-life care and having conversations helps to build our death literacy.

Using the death literacy approach, we recognise the role that everyone has in end-of-life care and the positive impact that caring for the body before it is handed over to a funeral director. Having knowledge helps us make informed decisions about the care, and being able to act on that knowledge is empowering. Two key components of death literacy are knowing how to brace the subject of dying and death, and how to access palliative services. For many people, these are major hurdles experienced especially when caring for older parents and spouses.

We can have a positive effect on the low numbers of ACPs in the community if we strengthen the capacity for carers, volunteers, artists, educators, and community services to play a role in normalising and socialising the issue. This is a crucial part of the public health approach to end-of-life.

A public health approach as outlined by Kellehear (1999, 2005, 2016) holds that dying, death, loss, and care are everyone's responsibility. As such, the community is considered an equal partner in end-of-life care. This is an "upstream approach" and upstream interventions seek to change the social context for people who are dying, their families and communities. It is precisely this social change that positively impacts on the services delivering support. Further this work is done 'with' community and organisations rather than 'on' or 'for'. Effective community engagement therefore results in mutually rewarding partnerships and sustainable community outcomes.

3. A recent systematic review by Sallnow et al (2016) found evidence that public health approaches to death, dying and bereavement promote individual learning and personal growth and develop the community's capacity for end of life caring. This increased capacity has shown to reduce unnecessary hospitalisations resulting in 6% health service savings (Abel, et al., in press).

Evidence also shows that community conversations about dying, death, loss and grief have a role in better palliative care service utilisation and changing attitudes toward death and dying. They have been linked to the reduction in futile treatments, the uptake of palliative care and alignment between end-of-life preferences and care actually received (Bartel, 2016), thus improving health care outcomes that cannot be achieved without social change that is mobilised outside of, but in conjunction with, the health care system.

## **In summary**

We believe that the most effective change mechanisms for building people's awareness about dying and death, and increasing uptake of end-of-life planning (including ACD) are:

1. A community-development model of action-learning- Change initiatives are facilitated/enabled at a community level. Participants of the initiatives inform the design and participate in the delivery of activities, and are empowered to solicit engagement of their trusted social networks.
2. Investment in social research and the social impacts of ACP that will help us understand triggers for carrying out an ACP.
3. If we move from person centred care to network focussed care, we design interventions that ensure care is not only delivered to the dying person, but that capacity is built with those care providers and social networks engaged along the way (see Horsfall et al 2012). Dying is a

social experience essentially and there for, programs, training and data collection should always include the dying person and those I their life.

4. Funding that goes to building the capacity of those who are producing positive outcomes in end-of-life planning at the grassroots level should be considered.

### Case Study Dr Julian Abel

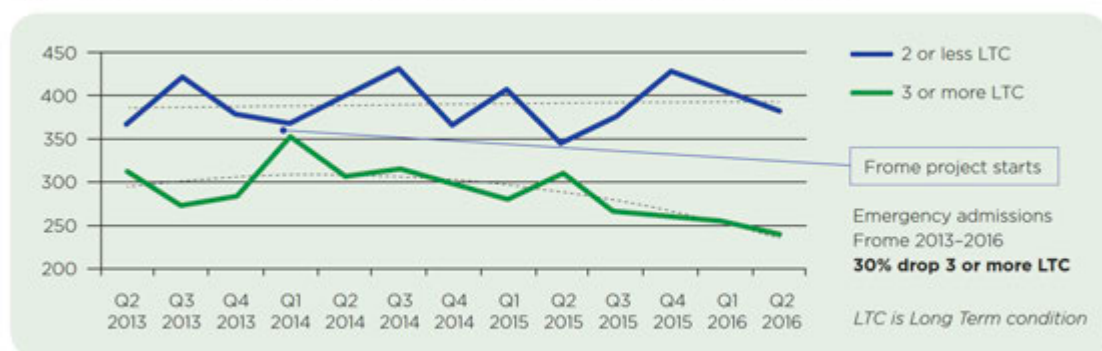
Dr Abel conducted a project is a small community in Frome UK, a town of 30,000 people. The project focussed on identifying vulnerable patients, mapping their networks, building community capacity to support people at the end of life through community development and implementing the Compassionate City Charter more broadly.

He found that the community of Frome experienced a 30% reduction in all emergency admissions to hospital admissions, compared to the rest of Somerset, resulting in savings of \$3.25 million AUD per annum in Frome alone. If these savings were made in a population as large as Australia, this could result in savings of \$2.6 billion per annum. Somerset Clinical Commissioning Group, which commissions healthcare for the 500,000 people of the county of Somerset in England, has set a target of achieving a 50% home death rate by 2026 through implementation of the Compassionate City Charter.

Dr Abel knows that the benefits are far beyond the financial, but that financial benefits can create a case for supporting this model of care. He found that over time, the strength of bonds increase, as people in supportive networks report their contribution to be a privilege and meaningful, rather than burdensome.

Those supportive relationships then naturally extend into bereavement and beyond, potentially adding joy and meaning to a carer's life many years after the death of a loved one.

Figure 2: The Evidence: Emergency admissions Somerset Q2 2013 – Q2 2016



## References

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- Noonan, K., Horsfall, D., Leonard, R., & Rosenberg, J. (2015). Developing Death Literacy. *Progress in Palliative Care*. <http://doi.org/10.1080/09699260.2015.1103498>
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## Presenters:

### 1. Kerrie Noonan, Director and Co Founder, The GroundSwell Project

Kerrie Noonan is leading this proposal for The GroundSwell Project. She will be responsible for managing timeframes, budgets and delivering this project. Kerrie is a social researcher, clinical psychologist in palliative care and a social entrepreneur. Kerrie has a long-standing interest in capacity building approaches to death, dying and bereavement, palliative care and how people can build their death literacy. Over the past 20 years Kerrie has led the delivery of multiple projects both in her role as a clinical psychologist, and with The GroundSwell Project. She regularly provides advice to government and non-government organisations on community development approaches to end of life care, death literacy and advance care planning. Kerrie is a member of the 'Caring at end of life research team' and recently led the publication of first publication about death literacy. She is an inaugural council member of *Public Health Palliative Care International*. She has a Masters degree in Clinical Psychology, a BA (Psychology), and a Grad. Dip. in Systemic Therapy (Family Therapy).

### 2. Jessie Williams Executive Director, The GroundSwell Project

As a learning entrepreneur, she works across commercial business, non-government organisations and social enterprises co-creating programs for social change. She has been on the board of the GroundSwell Project for 4 years and in the role as Executive Director since early 2015. Jessie is responsible for driving the growth and partnerships for social impact around end of life. She has a BA (Government) Sydney University, a Grad. Cert in Adult Ed. Training and multiple studies in innovative learning modalities. As GroundSwell's ED Jessie supports the delivery of all our major projects and programs.

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