

RESEARCH INSIGHTS: AGED CARE

LifeCircle insight sharing series

LIFECIRCLE IS A NATIONAL SOCIAL ENTERPRISE WHOSE PURPOSE IS TO PROFOUNDLY CHANGE THE EXPERIENCE OF DYING AND OF DEATH.

Our focus is on those who are living the experience - the person caring for the person who is dying, and the people around them. Our 40 years of experience and our evidence base tells us this is where we can have the most impact to change this experience.

LifeCircle's work is not clinically focused, nor is it centred on the practical processes around end of life such as estate planning. We believe these aspects of death are very important, and are already generally available through other organisations. Our focus is on the social, emotional and human aspects of dying and death. This is where we believe most of the work needs to be done.

The issues around end of life care are complex, systemic and emotionally charged. It is difficult work. There is immeasurable passion and goodwill inherent in the industry. However two things are very clear to us:

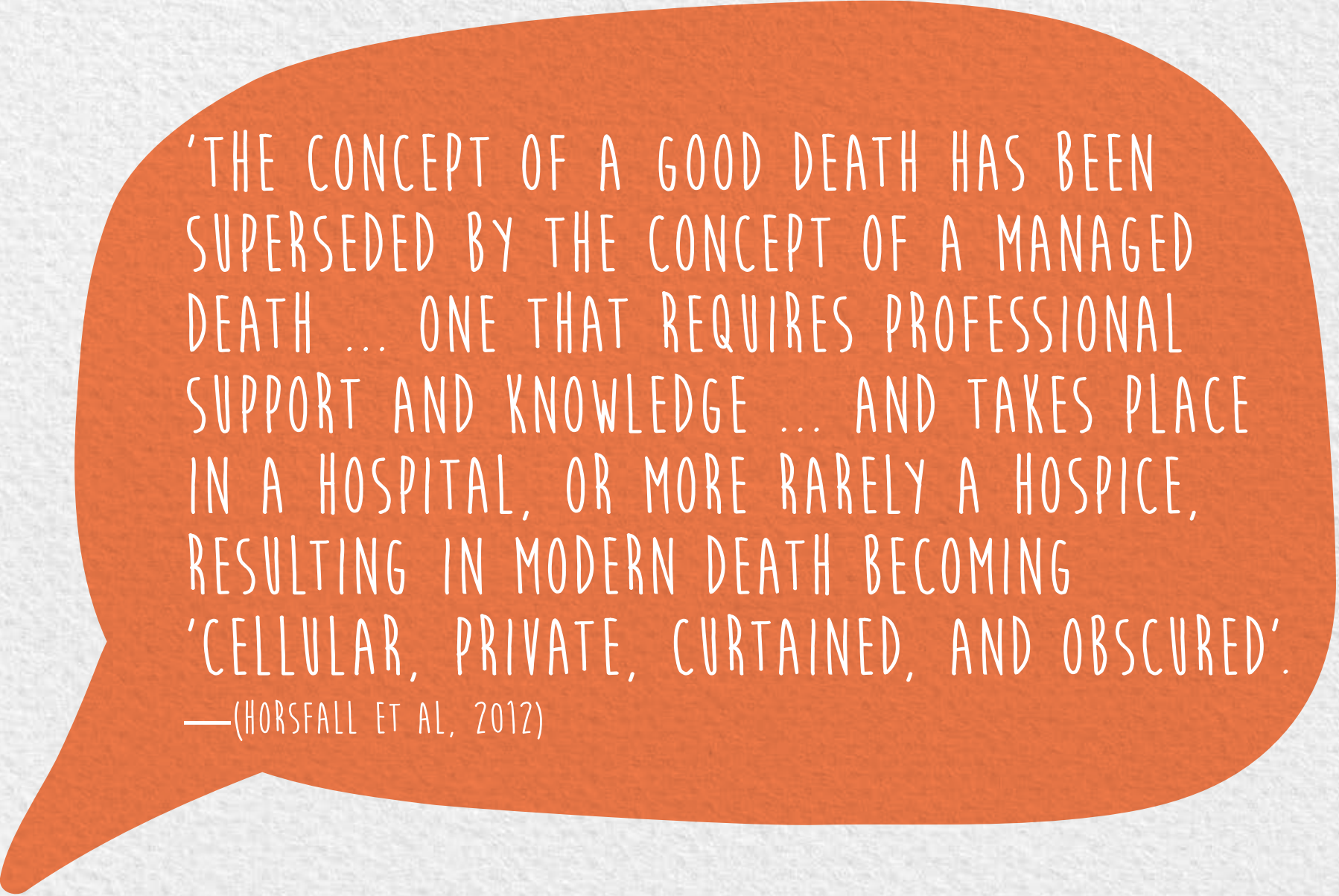
Firstly, that the number of people who will die each year in Australia will double over the next 25 years. Our current systems don't have the capacity to meet these future needs.

Secondly, there is very little evidence of any real innovation in the design and delivery of services at the end of life. Broadly speaking, things are done today in the same way that they have been done over recent decades.

LifeCircle acts as a collaborator and an aggregator, bringing the right partners and stakeholders together to reimagine the experience of end of life in Australia.

We work through a series of strategic partnerships with businesses whose work intersects in some way with the end of life. We shape programs and interventions that change the experience of death and dying across different industries. We facilitate, connect and build capacity around death and dying for the circle of people our partners work with and for: clients, customers, employees, volunteers and the broader community.

We believe that the vision of an Australia where dying is more openly discussed, better prepared for and less institutionalised, and where carers and families are empowered and consequently more resilient, is worth striving for.



'THE CONCEPT OF A GOOD DEATH HAS BEEN SUPERSEDED BY THE CONCEPT OF A MANAGED DEATH ... ONE THAT REQUIRES PROFESSIONAL SUPPORT AND KNOWLEDGE ... AND TAKES PLACE IN A HOSPITAL, OR MORE RARELY A HOSPICE, RESULTING IN MODERN DEATH BECOMING 'CELLULAR, PRIVATE, CURTAINED, AND OBSCURED'.

—(HORSEFALL ET AL, 2012)

THE EXPERIENCE OF END OF LIFE IN RESIDENTIAL AGED CARE

The Aged Care industry in Australia is undergoing massive and rapid change, involving a necessary rethink of existing models and modes of delivery that have dominated the industry for years.

These changes are brought about by the changing demographics of our ageing population and the shift in behaviours and expectations of people as they age.

LifeCircle have formed a partnership with Opal Aged Care to rethink the experience of end of life in an Aged Care home.

Over half of Opal's residents die each year under their care. How might Opal positively change that experience, for the residents, for the families and also, importantly for Opal's staff and volunteers?

Led by the key insights of the experiences of Opal staff and families, we have designed and developed prototypes which are being piloted in Opal Centres from February 2017.

These solutions are designed to:

1. Help Opal staff build the skills, resilience and capacity to better support residents, families and themselves through end of life
2. Build trust and support to enable honest and open conversations that allow aged care to be understood as a place of life and death.

The six insights that are driving the solutions are detailed on the following pages.

INSIGHT ONE:

THE AGED CARE INDUSTRY FACES A GROWING AND CHALLENGING FUTURE.



The changing demographics of our ageing population will place significant pressures on the Aged Care sector over the coming decades.

Aged Care providers can expect to care for many more residents, with increasing proportions of older, sicker, and less mentally competent residents.

INSIGHT TWO:

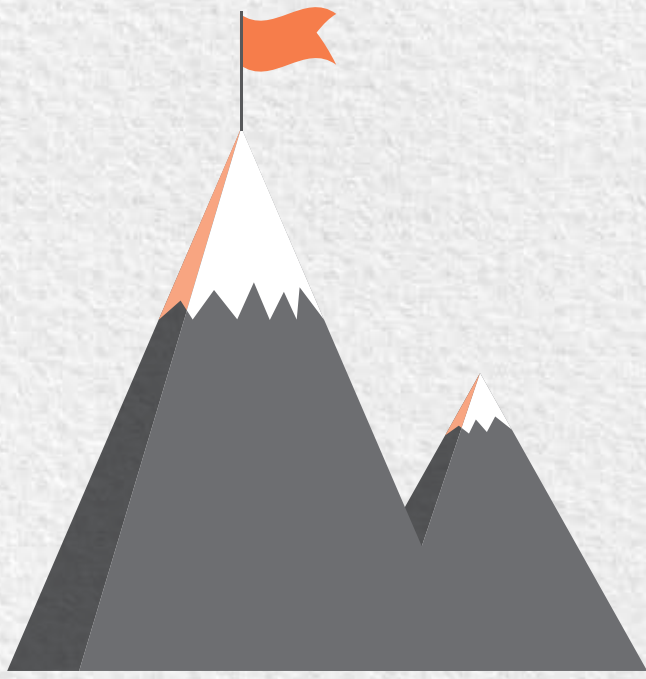
AGED CARE PROVIDERS FACE SIGNIFICANT HUMAN RESOURCE CHALLENGES.

Aged care work is physically and psychologically demanding. Carers often feel their facility is understaffed, and their role overworked. Across the sector, job satisfaction falls with tenure.

By 2022, the industry will need an extra 69,000 aged care workers.

http://mccrindle.com.au/resources/The-Aged-Care-Puzzle_McCrindle_Infographic.pdf

With 62% job satisfaction, there is a need to improve the industry in order to grow job attraction.



INSIGHT THREE:

EMOTIONS RUN HIGH.



Transitioning a loved one into residential aged care is often a very emotional time for families and residents.

For families, feelings of guilt, shame, remorse, anxiety and fear are all common as part of transition. For many family members who have been the primary care-giver to the person entering aged care, the shift back to their family role (wife, husband, daughter) - can be both relieving and unsettling.

For residents, admission and transition into aged care is often often difficult. Feelings of uncertainty and loss are common, and it can be difficult adjusting to the 'new normal'.

INSIGHT FOUR:

AGED CARE NOT IS UNDERSTOOD AS A PLACE OF LIFE AND DEATH.



Once a person enters aged care, it is likely to be the place where they spend their final years.

However in general terms, there is a lack of consistent, open and honest conversations around end of life between staff, families and residents.

It is difficult to sensitively yet openly acknowledge aged care as a place of life and death.

INSIGHT FIVE:

THE SKILLS AGED CARE WORKERS HAVE ARE NOT ALL THE SKILLS THEY NEED.

"SOMETIMES I GET NERVOUS, I GET PALPITATIONS, CAN'T BREATHE — GET ANXIOUS... WHEN I SEE SOMEONE DYING I GET ANXIOUS... I DON'T TELL ANYONE, I KEEP IT TO MYSELF... I DON'T KNOW WHY I FEEL THIS WAY." AIN 10+ YEARS

Facing death regularly does not create death competency among aged care nurses and workers.

End of life training and practice for aged care workers is predominantly clinically focussed. There is a need to develop skills around the social, emotional and human aspects of dying and death.

Nurses working in specialist palliative care units also face death and dying on a regular basis, but typically have much higher levels of competency around the dying experience and conversations.

INSIGHT SIX:

TWO CIRCLES OF CARE SHAPE THE EXPERIENCE.



The experience of dying in aged care is shaped greatly by relations between the Opal circle of (formal) care and the family circle of (informal) care.

The family circle experiences the process of a loved one dying in a linear way, while nurses are at all points of the continuum at once.

Families face significant emotional challenges during the process of adapting to a loved one being in aged care.

Aged care staff will often respond to these heightened emotions by avoiding the wider conversation about death, thereby missing the opportunity to frame life and death in the aged care context.

In both cases, members of these two circles often lack the mental models to imagine and articulate ‘good’ outcomes in the context of the dying of a loved one/resident...both circles can struggle to articulate their purpose and contribution.

'END OF LIFE IN RESIDENTIAL AGED CARE' MAKING SENSE OF THE LIVED EXPERIENCE

THE GREATEST CHALLENGES ARE AT THE END... BUT THE GREATEST OPPORTUNITY FOR IMPACT AND CHANGE MAY BE THROUGH RE-THINKING THE BEGINNING'

