

RESEARCH INSIGHTS: END OF LIFE AT HOME

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.



DYING IS MORE THAN
A PHYSICAL EVENT.

IT IS A PROCESS THAT INCLUDES
ONE'S WHOLE BEING: PHYSICAL,
PSYCHOLOGICAL AND SPIRITUAL.

—DAVID KUHL, 2002

THE EXPERIENCE OF CARING FOR SOMEONE WHO WISHES TO DIE AT HOME

The Grattan Report ‘Dying Well’ (2014) confirmed that over 70% of Australians say that they would wish to die at home supported by family, friends and effective services. In reality, less than 15% get to do so.

Across the top 20 OECD countries, Australia performs very poorly in helping people have their end of life wishes met, in their own homes.

Over half of all Australian deaths occur in hospitals. This has significant implications, socially and economically, which will compound as the number of Australians dying each year increases.

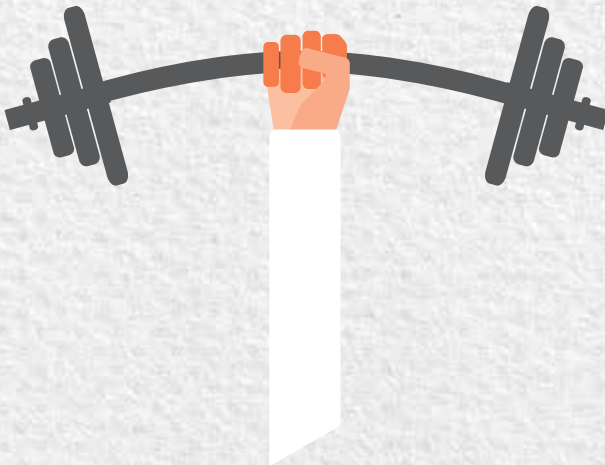
We are working with Bupa to co-design solutions to better support people who are caring for someone dying at home. The role of the person caring is critical in helping that person dying to stay at home. Through our research we identified the key insights of the experience of the people caring and were able to see very clearly exactly what we needed to solve for.

The prioritised solutions are being prototyped and piloted in 2017.

The key five insights that are driving the solutions are detailed here.

INSIGHT ONE:

HARDEST WORK EVER



People who find themselves caring for someone who is dying are about to face the hardest working experience of their lives.

Its a job spec that no-one would willingly apply for..

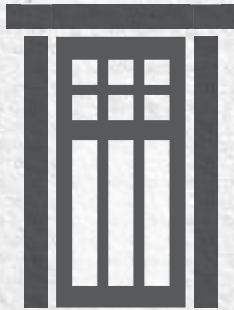
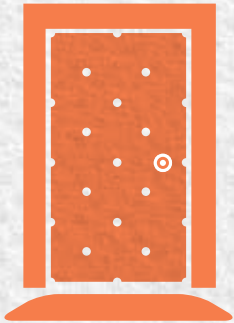
- Managing complex information.
- Managing people and tasks.
- Managing drugs and symptoms.
- Making sense of options.
- Making complex, multi-stakeholder decisions.

Through all of this, the person caring is often experiencing massive emotional and physical fatigue.

However, this work often translates into a transformational and highly rewarding lived experience.

INSIGHT TWO:

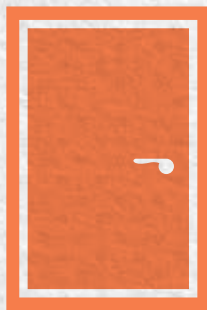
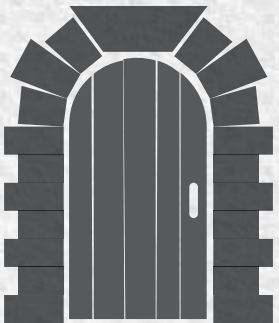
THE WRONG LABELS



The vast majority of resources for people caring for someone dying at home sit behind four doors, labeled 'CARER', 'CANCER', 'PALLIATIVE' AND 'AGED'.

As a result it is very difficult for the person who is caring to locate support and resources that may guide and assist them in their role.

There is no door marked simply 'CARING FOR SOMEONE WHO WISHES TO DIE AT HOME'.



INSIGHT THREE:

FAMILY: A (DIS)UNITED TEAM



The family is the critical unit of caring in the home, and it needs to act as a team.

But the ability of these care teams to operate effectively can be hugely impaired by complexity and conflict around issues such as: ‘what to do’, ‘what does success look like’, ‘who will do the work’ and ‘who’s going to pay’.

But too often the members of the team have no clear sense of their unique role or contribution on the team.

Equally, there is often no single person to guide or (project) manage the team - no coach.

INSIGHT FOUR:

CRISES ARE UNPREDICTABLE



And support timing is everything.

Crisis moments can be highly unpredictable, both in nature and in timing. A crisis moment could be very practical, or highly emotional. It could be in the middle of the day or the middle of the night.

It could be a very natural and expected part of physical health decline. If this is not understood and recognised by the carer, these moments can change the care trajectory and often mean admission to hospital.

Critically, crisis moments can strike the carer in a moment of vulnerability, and at a time when support is not readily available.

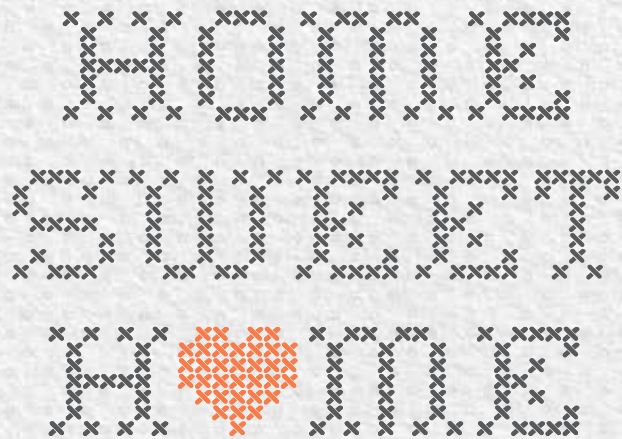
The middle of the night crisis.
The service that comes too late.
The unmanageable pain.

The advice 5 days prior. The support 5 minutes post.

Having the right information, conversation or service at the right time is everything. But it's impossible to plan or predict.

INSIGHT FIVE:

HOME, BUT NOT
AS YOU KNOW IT.



The idea of dying at home is one that can often be idealised, when the reality is that home at the end of life can quickly become unrecognizable.

Routines change, or disappear. Medical visits and interventions are frequent. Machines go “ping”. Familiar rooms feel far more clinical. New roles and challenges become

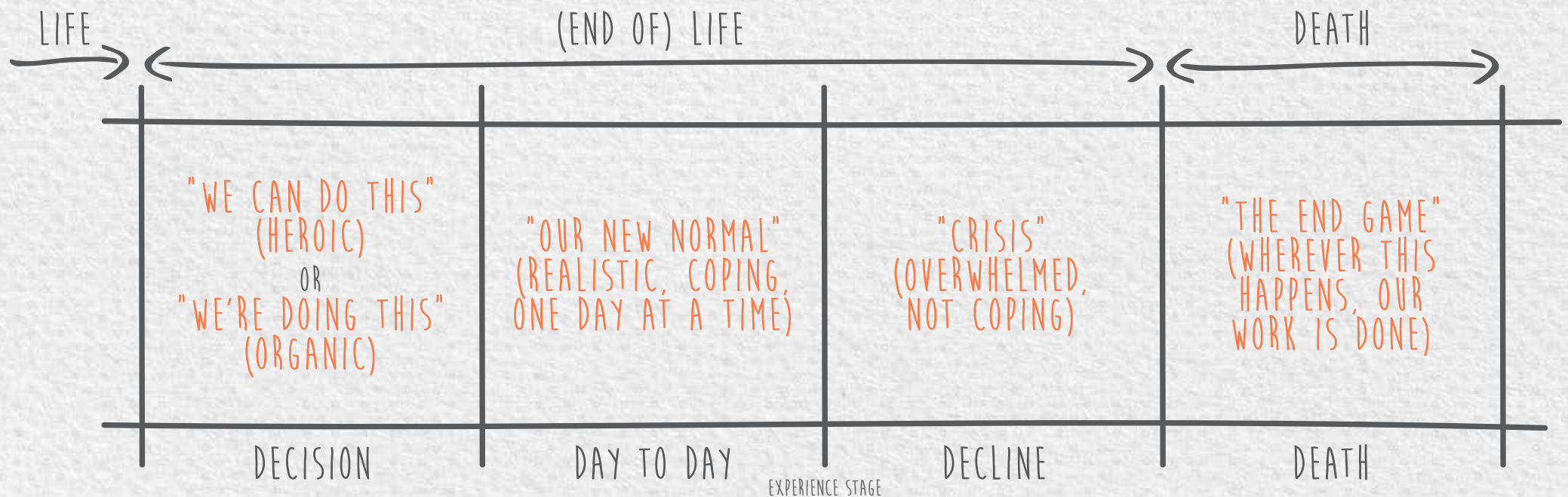
new burdens and sources of stress. Often others are trying to continue life ‘as normal’ (which adds stress and guilt).

Home itself, while desirable, may not be home as it was once known. It’s the idea of home that is key, not the literal place.

'CARING FOR SOMEONE WHO IS DYING AT HOME'

MAKING SENSE OF THE LIVED EXPERIENCE

TYPICAL STAGES AND TRANSITIONS



WHAT DOES SUCCESS LOOK LIKE?

BY CREATING EARLIER
AWARENESS AND
ACCEPTANCE HERE...

