

RESEARCH INSIGHTS: END OF LIFE

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.



WE NEED THE COURAGE TO
PROMOTE MATURE DISCUSSIONS
ABOUT A TOPIC WE MAY
DISLIKE BUT CANNOT AVOID
IF WE ARE TO HAVE BETTER
DEATHS IN AUSTRALIA.

— GRATTAN REPORT 'DYING WELL' 2014

OVER THE NEXT FEW PAGES WE
WILL SHARE THE KEY INSIGHTS
THAT HAVE BEEN GATHERED OVER
OUR 40 YEARS OF EXPERIENCE,
AND HAVE BEEN VALIDATED
THROUGH OUR WORK IN 2016.

INSIGHT ONE:

A 'TABOO' TOPIC



Talking about death and dying can be very difficult.

In our society today, this is a taboo subject, full of fear. We don't talk about it. We'd prefer to avoid it – as if that can somehow delay the inevitable.

When in truth, this topic, more than any other, knows no boundaries.

This will affect each of us, at multiple points in our lives, and ultimately through our own death.

LifeCircle are curious to know what impact this 'taboo', this avoidance, has on the social and emotional experience of death and dying in Australia?

INSIGHT TWO:

A LANGUAGE OF AVOIDANCE



Death's finality makes us uncomfortable, so we use euphemisms and 'avoid-isms' to give us a sense of safety and distance.

Terms like 'passed away', 'no longer with us', 'lost his life' are used to indirectly reference the inevitable end of the human condition.

Terminal conditions are describes as a 'battle' or a 'fight'.

Language is often softened in an effort to help us cope with reality - but in this case, it inflates our ability to avoid the honest and courageous conversations around death and dying that can be so transformative.

LifeCircle wonders what might be needed to help each of us, within our families, and across our communities, to be able to talk about death more openly?

INSIGHT THREE:

THE ROLE THAT ISN'T



We don't tend to self-identify with the label of 'carer'. We don't see ourselves in that way.

We stay in our role of husband, wife, child, sibling, or friend.

There is often no clear-cut defining point that shifts us into the carer role, so we don't acknowledge it (and perhaps don't want to).

Society doesn't legitimise the role or the label (at least not around end of life).

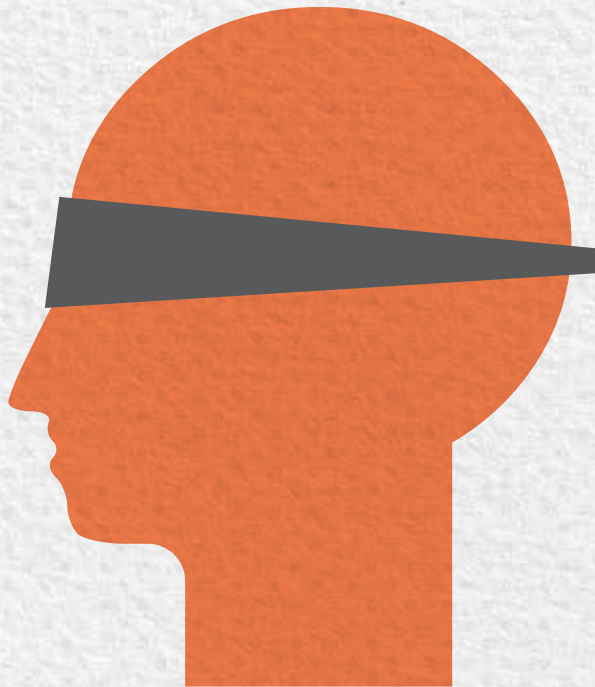
Few seek out, or find succor in the label.

As a result we don't use it to access or navigate the system to seek out what might be available to us.

What might help people better self-identify as someone who is caring?

INSIGHT FOUR:

UNCERTAIN & UNPREPARED



The practical challenges of caring for someone who is dying would be significant enough even if you were forewarned and prepared (and not in such a raw emotional state). And if the work stayed constant.

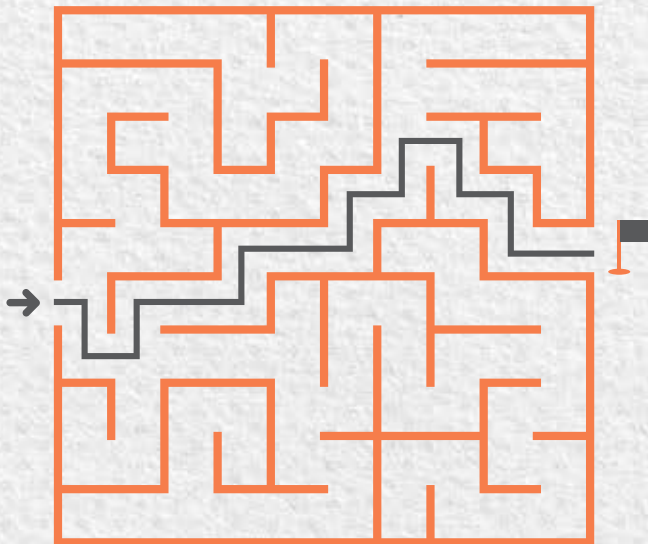
But many enter into the decision ‘by accident’, and are never prepared for the practical (strength, time, money, commitment) challenges that follow.

This sense of uncertainty and unpreparedness is further driven by a combination of lack of authoritative information and a willingness/desire to avoid the subject (and find out what’s next).

How could we help people be better prepared and informed about the role they were taking on?

INSIGHT FIVE:

FRAGMENTED SERVICES



Navigating and accessing the end of life services that are available can be incredibly difficult.

Services are often not co-ordinated, and are delivered through different systems: some through the Commonwealth Government, some through State and Local Governments, some through private services.

This is hard enough to navigate at the best of times: but particularly difficult when the person caring is likely to be emotionally and physically exhausted.

Often people just don't know what services and supports are available to them, and therefore don't access them.

How might we help people caring better navigate and access the system to that they can make better use of the service and supports that already exist?

How might we design to fill the gaps?

INSIGHT SIX:

'YOU CAN'T ASK THAT'



In such an emotionally charged time, when both the person dying, and those caring for them feel so vulnerable, it is often difficult to know the right questions to ask, let alone have the courage to ask them.

Sometimes the people that we turn to for guidance at end of life – often our doctor, or our priest, aren't able to talk openly about end of life.

There is no safe and private place to ask the really complex, frightening, even existential questions.

There is no one place that gathers all of the wisdom of our where real lived experience, our empathy, and our willingness to provide helpful answers can be captured.

Often people just 'muddle through'.

How might we design a place where people could express their deepest fears and ask their darkest questions?

INSIGHT SEVEN:

WHO CAN WE LEAN ON?



Life is full of complex experiences. During these times we often need the support of others for guidance, reassurance, perhaps a shoulder to cry on.

Generally, we are quite good at connecting to others who are living a similar experience, and then supporting each other through the process - for example parenting groups, school communities, work social groups or online communities.

There is very little evidence of peer support organically forming around the end of life, for the person caring for someone who is dying.

LifeCircle wants to explore how better peer support might help to change the experience of death and dying.

INSIGHT EIGHT:

MISSING MENTAL MODELS



Our societal disinclination to discuss the topic of death, and the absence of a clear decision point, makes it difficult have a strong mental model of what the journey ahead might look like.

Both the positive and the negative parts of the journey.

People who have this lived experience often feel fulfilled and enriched, and value their life differently as a result. But they can struggle to find ways to share their story. It's almost awkward to talk

positively with most people about the death of a loved one.

So we lose the story of the experience.

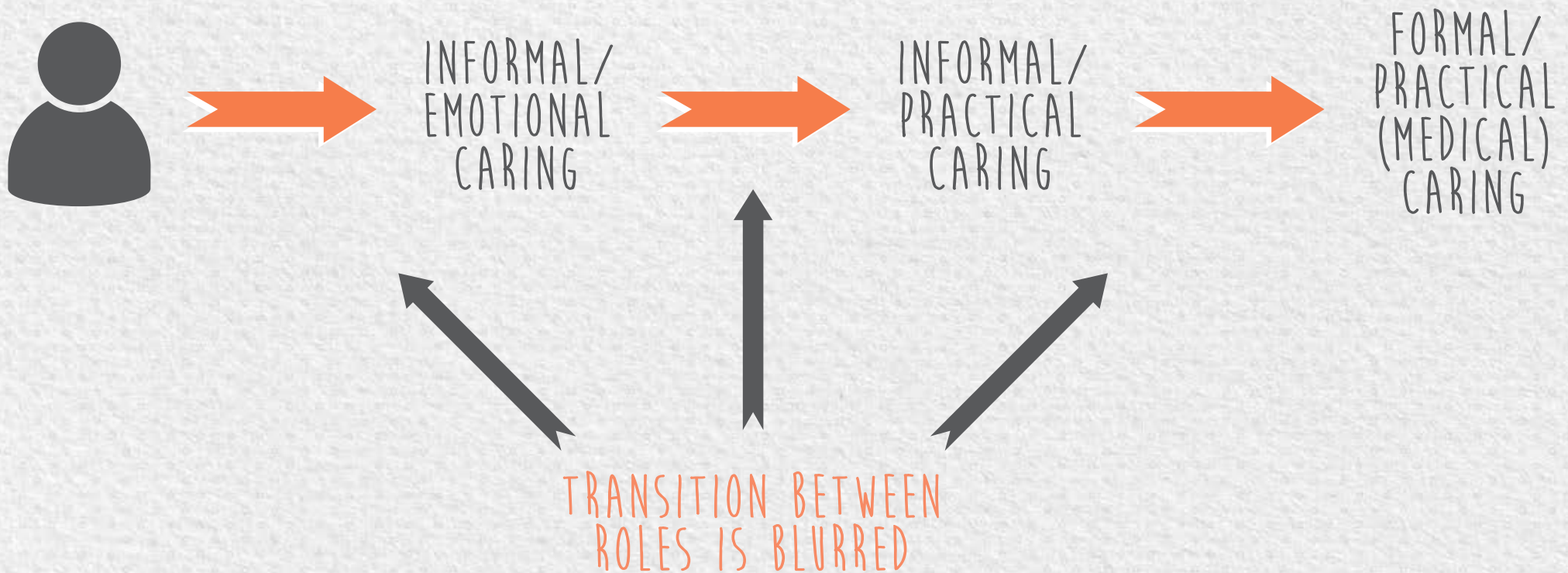
It isn't shared. It isn't accessed by those who need to hear it. We lose the IP. We lose the sense of achievement.

LifeCircle would like to find ways to help people share their stories and lived experiences of caring for someone who is dying, to prepare and support others embarking on the same journey.

'CARING FOR SOMEONE WHO IS DYING'

MAKING SENSE OF THE LIVED EXPERIENCE

TWO SHIFTS HAPPEN ORGANICALLY: #1 THE CARING ROLE (PRACTICAL).



'CARING FOR SOMEONE WHO IS DYING' MAKING SENSE OF THE LIVED EXPERIENCE

TWO SHIFTS HAPPEN ORGANICALLY: #2 THE CARING MINDSET (EMOTIONAL)



'CARING FOR SOMEONE WHO IS DYING'

MAKING SENSE OF THE LIVED EXPERIENCE

TWO SHIFTS HAPPEN ORGANICALLY: #2 THE CARING MINDSET (EMOTIONAL)

