Thank you for the opportunity to speak with you tonight about this important issue. When Roland proposed this topic to me, I accepted because it’s an interest of mine. However, as I’ve thought about it, a presentation about end of life, spirituality and death doesn’t offer too many opportunities for jokes! So with the understanding that tonight you’ll probably have to make your own hilarity, let’s begin...

It’s a matter of death

A few weeks ago, some colleagues and I were reflecting on how difficult it seems to be these days to talk about the end of life. We have palliative care, it’s the end of life, you pass away, kick the bucket, are lost... We don’t talk about death, it’s almost as if the word is difficult to say and the concept with all it’s inevitability and finality even harder to grasp. I suppose this isn’t surprising really...

When I think of the “end of life”, I am struck by a phrase that has come to have such a narrow definition and understanding. I know for me, this is influenced by the industry in which I work - aged care. End of life - a person who has lived a long life, the end of their days, maybe alert, maybe drawn into a life space where we can’t follow, suffering Alzheimer's or dementia, at home or in a residential facility.

But end of life is broader than this isn’t it? - it bursts into life in many ways - suicide, a still birth, the termination of a pregnancy, a missing person, a fatal car accident, a prolonged disease...

I wonder if you think that ‘death’ is a topic that is taboo in our society? Our television screens, popular culture and print media scream youth, wholeness, beauty, diet options to correct problems that will lead to health and wellbeing. The virtual gaming industry presents younger generations with a view of death that is not final – if you’re killed, you have two more chances, particularly if you’ve had the opportunity to store some health – and then you just have to wait until the start of the next game or map to use your character, whole and alive, again.
A Chaplain pointed out to me the other day that there’s been a reversal in taboo topics since the Victorian times. Then sex was taboo and death was freely spoken about – cemeteries were in the market square – and young people were chaste and politely spoken about sexuality. Today our cemeteries are on the edge of town, and if you don’t advertise using sex, you’re crazy!

I wonder if you would indulge me for a few minutes and participate in some self-introspection…
(I promise, it won’t hurt!)
We’ve just had dinner (lovely, wasn’t it?) – I want you to imagine that this is your last meal… ever...
Think about your life –
What will you miss?
Who will you miss?
What will you regret?
What do you wish you’d told those you love?
What haven’t you done/achieved that you wish you had?

It’s a sobering thought isn’t it? Considering death when we’re not ready for it...
Death, dying, the end of life – it’s all about the connection between who we are as a person and the inevitability of life. It’s probably also pretty certain that if you had recorded your answers to the questions I asked, and shared them with the person next to you, they’d be quite different. We are each unique human beings, our life journeys have been unique to us – our experiences, our relationships, our values – and so, not surprisingly, our thoughts about how we make meaning of our life when we contemplate death will also be different. As someone said, “there’s no set map for living with dying.”

You’ll have noticed that in the questions I asked when we began that none of them had anything to do with money, financial stability, or economic status. The ending of life clarifies what’s important, doesn’t it? It brings everything into sharper focus. It’s about our humanity, our personal life journey, our spirituality if you like – and these things are much more difficult to grasp hold of than a medical condition that needs to be healed, or a wound that needs to be dressed. Despite the failing of our physiology, it’s our personal, internal, spiritual and philosophical being that often dominates when we consider death. And therefore, it is not as easy to deal with...

In my role as Director of Mission for Blue Care, one of my responsibilities is our Chaplaincy Services. We have 37 Chaplains that work in our services across Queensland and northern New South Wales. One of our Community Care Chaplains told me this story –
A few weeks ago I drove into one of the most exclusive residential areas in South East Queensland. I was greeted at the door by an attractive woman in her early sixties. Her husband, a very distinguished looking man, greeted me from his bed, he was terminally ill and had only a short while to live.

I couldn’t help but feel the comfort of the soft imported leather chair on which I sat. The wealth that surrounded me was awesome. “We have everything that the world could offer,” said the wife, “but I guess now we are really no better off than the person who has nothing. It all means so little now.” My glance met their confused, tearful, searching eyes. “I sense you are now looking for that which the world can’t offer?” I asked, and our faith journey began.

At a symposium on ‘Living Well, Dying Faithfully: The role of Christian practices in end of life care’, it was noted that there was a need to “rediscover the fact that the process of dying is a deeply meaningful and spiritual human experience within which the search for God, meaning, hope, purpose, forgiveness and perhaps even salvation, often rise to the forefront of people’s expectations in new and challenging ways.” These deeper dimensions of death are often hidden behind the medical condition because it seems easier to focus on illness - to explore the aspects of life in the midst of death takes courage.

Tonight I’d like to spend some time thinking with you about spirituality – what is it? How do we understand it? And how it can inform how we care for someone at the end of their life.

Then I’d like to share with you a few examples of programs and thinking that consider the spirituality of a person in the end of life care that is offered.

**Spirituality**

It's important for you to know that when I talk about spirituality, I’m not discussing a particular religion, Christian denomination or faith. How we understand our spirituality can be informed and shaped by these beliefs, of course, but the particularizing of spirituality isn’t what I want to consider with you tonight.

Spirituality is elusive. Defining spirituality can be fuzzy, cloudy, even hazy... As we spoke about death earlier, spirituality is also personal, an individual space, part of who we are. I’d like to consider spirituality tonight using three aspects/elements: making meaning, centering the personal and connection.

**Making meaning**

I wonder if you are the kind of person who likes to understand things or situations or people – how they work, what’s happening, what’s going wrong, what’s going right?? You’re just not satisfied until you work it out!
You know, in some way or other, we do this all the time. We strive to understand life – our life – and everything that makes up that life. Why did I act this way? Why did that happen to me? How can I understand the wonder of the birth of my child? Why do I feel this way? What does that person mean when they say that about me?

Why do I have cancer? Why did they leave me? What the hell is happening?

Key to our own spirituality is how we make meaning of our lives - What means most to me – did I give meaning to others – what values were most important – were there times when I felt hopeless and without meaning – the big questions of life.

### Centring the personal

Spirituality and the search for meaning is part of our humanness; common to all – and yet this commonality is so diverse in nature. It’s like having our own personal rainbow inside ourselves, with our own combination of colours. Everyone else has a rainbow too, but the colour combination is different.

Therefore understanding spirituality is uniquely personal, and our focus for our own spirituality and the spirituality of others has to hold this uniqueness with the utmost respect.

### Connection

Our 21st century world (well, the 21st century world of the supposedly developed nations) holds individuality up as an icon to be worshipped. We ‘develop’ ourselves, we build fences so we can’t see our neighbours, we build our economic security without a thought for others who are bereft of resources. Today we are facing a number of issues globally, eg the environmental threat to our planet, which remind us starkly of our interconnection, and of the impact of our individual actions. How we connect...

In one of my favourite movies, 'Life as a House', George (played by Kevin Kline) learns that he is dying and has only months to live. When a nurse touches his face, he tells her he hasn’t been touched in years. She questions this – ‘not by family, not by friends, not by anyone?’, she questions. When he says ‘no’, she draws the curtain around his bed and puts her hands on his face and slowly runs them down his cheeks. Suddenly she feels self conscious and draws back. 'I'm sorry' she says. 'I'm scared', George says.

We connect in many ways, and physical touch is just one of them. Our relationships with people we care for, we love – our friends, our family, people that are part of our everyday lives – is another important connection. These connections contribute to the meaning in our lives, and how we understand ourselves.
In Psychology Today, one commentator described spirituality as being “like an adventure park waiting to be explored”. I like this description! Though as someone who’ll do anything that doesn’t involve heights or being in a small car that hurtles in many different directions at very fast speeds, I’m not sure how all-encompassing my exploration would be.

However, if spirituality is some “boundary-less dimension of human experience”, we can perhaps only be sure of it for ourselves. And if this is the case, what does that say about how we engage and honour a person’s spirituality as they journey towards death?

## End of life care

### Offering spiritual care

Offering spiritual care to someone who is dying requires both an understanding of spirituality and how integral it is to the person preparing for death; and just as importantly, a self understanding. I think there are three key things that must be remembered for those offering spiritual care:

It’s important to **know yourself** – be aware of how you make meaning in your own, and of your own, life; have some knowledge of your own values and your own thoughts about death. This allows those offering care to focus on the person they are caring for, rather than being caught out by their own reactions to what that person is facing, and dealing with.

**Respect the spirituality of the person receiving care** – as we’ve already discussed, a person’s spirituality is personal and individual. Spiritual care at the end of life is not about imposing our own beliefs on another, but allowing them to make sense of their life’s journey in a way that honours their beliefs.

And finally, **be open to the process** – the process of dying, of making meaning of death, of dealing with the life relationships of a person, can be different with different people; and can change throughout the end of life care. We honour the person who is dying when we are open to their individual process of dying, and can be flexible enough to walk the journey with them.

### Caring for people who are dying

At a conference on Spirituality and Ageing in Auckland in 2009, John Swinton asked the question: “how would I want to be cared for if I had dementia?” His answer was, “I hope I would be loved and cared for just for who I am, even if who I am is difficult for me and for others.” Holding the essence/identity/sense of a person when caring for them acknowledges their individual personhood, and values the wholeness and complexity of who they are.

Last year, I was asked to sit on a team to review the care we were offering to a resident in one of our residential facilities following complaints from the resident. ‘James’ was in his
late 50s. He was suffering from motor-neurone disease. In a matter of months, he had gone from playing golf to lying in an aged care facility, having little movement and being able to speak only between breaths on an oxygen mask. James was angry – it seemed that every part of the care that was offered wasn’t right, wasn’t good enough, wasn’t respectful of his wishes. After interviews with staff, and three hours speaking with James, we didn’t find any concerns with the care that was being given. What I experienced was a man fighting death. He spoke of the future as if it were possible, a reality even; and with this belief, he fought everything he could as if it would prolong his life. There didn’t seem to be any peace, just a fierce determination to live.

One study showed that “illness can cause people to question their lives, their identity and what gives their life meaning.” (Puchalski, C. “Spirituality and End of Life Care”, 2002), and that “illness, facing one’s mortality is an opportunity for new experience, self-awareness, and meaning in life.”

For James, who died a couple of months later, the fight was the way he found meaning at the end of his life.

Puchalski says, “it is through their spirituality that people become unstuck from despair” – this happens in many ways.

Spiritual care at the end of a person’s life is:

Compassionate – as one of our Chaplain’s said, ‘give heaps of compassion – no limits’.

It’s Relational – between the person dying and the person/s offering care – between the person dying and their family/loved ones – having an awareness of what the person wants, even not being there if they and their family have to finish their ‘business’ together.

And be Present – presence for the person who is dying, their family and those who care for them – giving the person opportunity to make their peace, and be at peace.

As part of the Spirit of Caring program developed at a residential care facility in Maleny (a town in the sunshine coast hinterland), staff and volunteers were trained to support people and their families as they journeyed towards death. Volunteers who are trained are part of the Interfaith Pastoral Care Service – they offer companionship to people who are dying, they journey with them and their families in the last weeks and days of life. The Volunteers also attended memorial or funeral services for the people they had cared for.

Caring for staff

Staff were also trained in emotional and spiritual aspects of palliative care. The program found that this training was important as staff also dealt with experiences of death and loss from their own lives as they cared for people who were dying.

One resource says that ‘spiritual care is increasingly seen as everyone’s job’ (Judith Murray, “Spiritual Care in Palliative Care”, 2007), and I agree – but this is where it get’s tricky.
Medical professionals are trained to care for the physical needs of a person. However, they are often one of the stable constants in a person’s life who is dying. An understanding of spirituality and sensitivity to this while caring for someone at the end of their life is important. Similarly, a survey of Australian nurses revealed that although 97 percent of registered nurses believe that they should address patient’s spiritual needs, only 66 percent felt prepared to be able to do so (Barletta & Thompson, 2001).

Helen Dick, a PhD student at the University of Queensland, is currently investigating the spiritual resources that staff in residential aged care facilities use to cope with the death of a person they have been caring for. In her initial study, while only one participant mentioned extrinsic religious practices as a support, all reported being substantially supported by intrinsic spiritual resources such as: meaning; hope; and relationships with others.

**Caring for families and friends who are grieving**

This week you may have seen that people suffering from long-term grief after the death of a loved one will soon have their condition officially labelled a mental disorder. While many psychiatrists have argued grief should not be labelled as a mental condition because it is a natural phenomenon which everyone experiences, the next edition of Diagnostic and Statistical Manual of Mental Disorders, will include a new diagnosis for people still struggling to cope a year or more after a loved one dies. The condition will be officially known as adjustment disorder related to bereavement.

Acknowledging the struggle that family and carers experience, some community services in Blue Care run Grief Recovery programs for family members and carers following the death of a loved one. These programs are usually run by a Chaplain and a member of staff, for 8 weeks. While they focus on moving through grief and loss, they also build networks so that members of the group can provide support to each other once the group finishes its formal component.

The end of life also involves farewelling someone who has died, and this can take many forms. Recognising that spiritual care at the end of a person’s life isn’t only for the person who is dying, but for those offering care and for their families and carers acknowledges the relationship web of life.

I was reminded in a conversation this week that caring for people as they come to the end of their life has changed so much over the past decades – with research, organizations like Palliative Care Australia and care organizations focusing on the needs of a person; many gains have been made.
Conclusion

There are many articles and papers that link spirituality and health; and how spirituality can have a positive response on wellbeing. Did you know that prayer is the most commonly used non-drug method for pain management?

Dying isn’t just a biological occurrence.

Journeying to the end of our lives, or towards death, is something we all do – the inevitability of the lives we live. Medically and physically, we understand parts of this journey. Spiritually, the journey holds mystery as we make meaning of that life, honour the relationships that have enriched it and understand who we have been along the way. The care that we provide to people who face the end of their lives must respect them as whole people, including their spirituality. This will not be a one size fits all approach. It will centre on the person....

The poet, Rainer Maria Rilke wrote:

Ignorant before the heavens of my life,
I stand and gaze in wonder. Oh the vastness
of the stars. Their rising and descent. How still.
As if I didn’t exist. Do I have any
share in this? Have I somehow dispensed with
their pure effect? Does my blood’s ebb and flow
change with their changes? Let me put aside
every desire, every relationship
except this one, so that my heart grows used to
its farthest spaces. Better that it live
fully aware, in the terror of its stars, than
as if protected, soothed by what is near.

My hope is that we will hold the tension of the mystery that is human life and our search for meaning - our spirituality - however that is understood; and that awareness of this mystery for others will inform how we care for them.