

Ageing with Purpose and Passion
Ageing well and dementia - a spiritual perspective
Edinburgh April 10th, 2019

The title of our roundtable today is - explanatory. It is a goal that I can readily identify with, but is it a real possibility for the majority of people who are growing older in western societies?

It seems there are at least some people in their 60s who are simply waiting to die – and who see no meaning in living any longer. This includes people who seemingly do not have life threatening, or even serious comorbidities.

I see that there is potentially - and even more – a real divide between what the possibilities of ageing well with purpose and passion are, against the realities for numbers of other older people. Yet, quite a lot of this knowledge about well ageing is not new, I remember doing my master's thesis in 1980s on health promotion in ageing. At that point it was the *spiritual* knowledge that wasn't well known; we already had a good level of knowledge on health promotion and illness prevention.

We might like to look at the coming cohort of older people – the baby boomers, and say, but it will be different here. However, I'm still not sure that the knowledge and message about well ageing has been taken up widely in society. In our recent study of baby boomer ageing– Richard Burns and I (2017) found in our focus groups there was some consensus that these people entering into later life expected that they would have pretty much the same life experience as their parents had. (either positive or negative)

New lenses to see new possibilities. Mary Catherine Bateson – new evolutionary life stage, (2011).

So, in her view, the idea of long life as gift is highlighted. New and exciting opportunities open for those who are growing older.

But ***new lenses*** are needed to really see these opportunities. How can we live later life as gift when we don't recognize that it is possible?

And, even further-

Life as gift - what happens when the gift comes wrapped with dementia?

I was recently speaking at a conference on dementia where there were some great papers, and it was good also to see people who have dementia speaking and engaging within the mainstream of the conference. But there were a few things that just slightly jarred for me. The perspective of the person who has dementia as a 'sufferer', as if the whole experience of living is one of suffering. Of the carer who 'carries the burden' of this 'horrific disease.' The inadvertent use of particular and negative language that seems to lock people into states of hopelessness was evident. And further, so often, in secular societies the spiritual is pushed down, and physical and psychological aspects of the disease highlighted, even though individual people who live with dementia may affirm

the importance of their faith in how they live life with dementia.

Another fact we were told, that people who have dementia cannot learn, and so often, the strong focus is on cognition. It reminds me of the work of George (2010) and the importance of the language that we use in relation to dementia, the social context and all people and things associated with it. Further, the work of Sabat, in this same field, and of course, the important theological work of John Swinton on dementia (2012).

In this paper, I want to speak from the heart, not emphasising memory, but acknowledging the whole human being. It was Christine Bryden who challenged me, more than 20 years ago to see dementia and the people who live with it differently.

If we live in a society where there is the potential for older people to live long and fulfilling, meaningful lives. How does this sit with those who have dementia.

How important is it that we look beyond the biomedical paradigm to see all aspects of humanity in the person with dementia, the biomedical, psychosocial, emotional and spiritual, and of course, also the cultural impact of the disease on the person and all those associated with them.

The very fact that people with dementia experience such difference disease trajectories from one another may lead to assumptions about the way the disease is expressed in different people, as one speaker said recently, and I am sure you have heard this said many times, 'if you know one person with dementia, you know one person with dementia'. How do some people seem to quite rapidly succumb to the disease, while others live well for many years.

We are certainly at a stage where I think it can be widely acknowledged that the various types of dementia can be different in their presentation and this is affected by personality, attitudes, education, resilience, culture, spirituality and what the person who has dementia believes about the possibilities of living effectively with the disease - and the characteristics of the people who accompany the person with dementia on the life journey.

Indeed, 'people with dementia have to be understood in terms of relationships, not because this is all that is left to them, but because this is characteristic of all our lives'. Hughes et al. (2006, p.35)

We now know too that a high proportion of cases of dementia can be prevented or at least delayed through adoption of healthy lifestyle. We know also that antipsychotic medications are generally not good news for people who have dementia; they have not been shown to be widely effective and cause numerous side effects. We also know that for moderate dementia meaningful activities and engaging in life to the full is of as much benefit to these people, in many instances as giving medications.

Perhaps it is helpful to remember that ***dementia is not like some physical diseases, for instance, measles*** – which has a high likelihood of prevention though vaccination, readily diagnosed with a great degree of accuracy, runs a

well specified course and resolution with most people recovering without long term effects.

Christine's work on the evolving sense of the self in the journey of dementia is an important contribution for the way that a person may experience living with dementia. It is interesting that back in 2002 wrote of her perception of future loss of her 'self'. In 2017 she completed her doctorate on *Challenging the discourses of loss: A continuing sense of self within the lived experience of dementia*.

Christine's model of self: Will I still be me? JKP 2018

- Embodied self
- Relational self
- Narrative self

Summary p121

Stephen Sabat's work on self and the concept of memory dysfunction – does it help to call it memory dysfunction rather than memory loss? We do focus a great deal on what people with dementia CAN'T remember. But human beings are not only walking memories. We humans are far more, we are embodied beings, connecting in complex interactions between these dimensions of body mind and spirit. Issues of remembering are but one part, and understanding *knowing*, is another, which goes far deeper than being able to recall a person's name.

Seeing life through the prism of dementia

Re-diagnosis? Rementia?

New ways of seeing?

Do we need to wipe the dementia slate clean and start all over again, to ask, what is happening to these people? How much of it really is preventable, and how can we normalise the condition so that, for the most part, people who are diagnosed with dementia can still be regarded as part of society and live with those of us who at this point do not have a diagnosis? How can the gift of longer life be made real for those diagnosed with dementia?

Any one of us may be diagnosed with this condition, and as we are told, this should be done early to help in slowing the progress of the disease. But if we are stigmatised along with the diagnosis, we are immediately removed from the culture that has so labelled us.

At one-point cancer had high levels of stigma, which concerted campaigning has done much to reduce. But dementia seems to carry higher levels of stigma. This especially has marked effects on the person diagnosed with younger onset dementia. Their care partners are also heavily stigmatised.

Conclusion

In the face of all of this, the picture seems grim. And yet, I have inadvertently travelled this journey closely with Christine Bryden for more than 20 years (I never thought about how long it would be) I thank God that I have been led to this journey, and amazing journeys with other people who have dementia and/or their loved ones, that have been entered into at points along the way. The research on finding meaning in the experience of dementia, was something I had never imagined before I met with Christine.

How has that affected me? I realise now that along this journey, I have learnt so much from those who live with this disease; it is they who have been my teachers. I am not sure that I have really been instrumental in any of this journey.

But I know that the stories that I can share and what I have learned, can help bring hope to others who have a diagnosis or are care partners. It is at the core and depth of life that we journey; if things are going well, or otherwise, it is at the spiritual, and it is through the power of the Spirit that we engage with each other and find God already there before us.

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