The Salvation Army

Spiritual Care Needs in Illness, Dying and End of Life Choices

A Theological Response

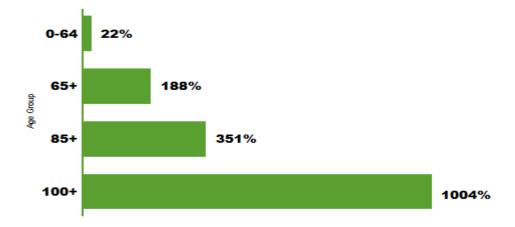
ABSTRACT

In this 21st century, Western society finds itself contending with multiple choices for all of life but often not planning for life itself to end. Despite this non-attention to end of life issues there is now more choice about how and when to end one's life when faced with illness or suffering. As assisted dying is becoming legalised in more countries, medical personnel, families and carers may struggle to cope when someone chooses to follow that path and end their life. Ageing and illness has an impact physically which is uniquely an individual experience. However, recent studies have highlighted that a shared universal experience is in fact a spiritual one and there are spiritual tasks to be worked through towards end of life. This paper is not seeking to outline an ethical response to assisted dying but rather to stimulate thinking around suffering and autonomy. Also older people themselves have shared through a case study how important spiritual care and pastoral support is in their ageing journey. Therefore focusing on spiritual care may support different outcomes within the complexities of end of life care and choices.

SPIRITUAL CARE NEEDS IN ILLNESS, DYING AND END OF LIFE CHOICES

We are living in times of a global ageing population, and increasing years of life for many. This also includes those with disabilities, but, despite longer living, each of us must face death at some point. Technological advancement and treatments are helping sustain longer living but also sets a broader context around dying and death. In this 21st century the dying process takes far longer, often involving several chronic health conditions (McNamara & Rosenwax, 2014). Increasingly people die when they are old. They are also more likely than their forebears to know that they are going to die in the relatively near future. But we are not taking the opportunity to help people plan to die well. In the last year of life, many experience a disconnected, confusing and distressing array of services, interventions and relationships with health professionals. Many do not get enough palliative care.

The following graph reveals the percentage change in the world's population by age from 2010 projected to 2050, (Source UN World Population Prospect).



This paper outlines a context for the church around aspects of the ageing journey, as well as death and dying. Other significant factors are perspectives on autonomy and how a spiritual care response can support addressing existential issues, in particular the importance of preparing for suffering. Suffering impacts all people at some point and can be physical and emotional but importantly a spiritual battle when end of life is faced. At the same time, when misinformed or misunderstood attitudes and language are emphasised regarding death, dying and disabilities a negative impact influences whole communities. However, accurate knowledge and preparedness can support the spiritual task. Also, an added context in the 21st century is the legalisation of assisted dying in some countries. Therefore, a potential response is outlined as carers or staff may have people requesting aid in dying and potential risks for vulnerable people as well as caring for ourselves and scriptural reassurances.

Within populations, there is great diversity of generational age groups, cultural and societal attitudes to ageing, as well as differing expectations and goals for life. There is now a strong culture of individualism and expectation of autonomy, particularly in Western culture. At the same time, there tends to be avoidance even thinking about end of life and certainly death and dying are not talked about easily or planned for, especially so within Western cultures.

The avoidance of dealing with prospective death impacts decision making around illness and dying and these attitudes are also impacting the provision of pastoral care within churches. It is a natural human response to fear the unknown and have concerns about potential suffering which may be involved for us individually, as well as loved ones in the dying process.

Older people, their loved ones and those who would provide pastoral care are dealing with issues which are increasingly complex ethically, emotionally and spiritually due to the impact of longer living with illnesses and ageing. Decisions based on personal value systems can be around treatment, pain control, organ donation, as well as requesting assisted death for example. Although dying is part of the life journey, it often involves suffering, pain, intense aloneness, grief and sometimes hovering for an uncertain time between life and death (Barbato, 2010).

The following graph highlights the impact of institutionalised dying which seems to be a result of not having these important conversations around death and dying.

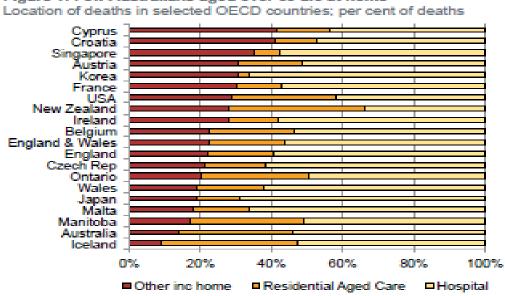


Figure 1: Few Australians aged over 65 die at home

Source: (Broad et al., 2013 (2013))

Another significant factor impacting decision making is the 21st century expectation within hospitals by medical professionals, patients and families, is that all must be done that is medically possible to sustain life. This would seem to be a new ritual where family members seek assurance that they have fulfilled their duties. There are now technological sounds such as heart monitors and other noise, which has replaced the quieter mediative aspects around the dying person within hospitals (Gordon, 2015).

The following statistics regarding dementia, the baby boomer generation and living longer with disabilities are important to highlight in conversations around death and dying too.

Dementia Australian statistics (https://www.dementia.org.au/statistics)

Dementia is the **second leading cause of death** of Australians contributing to 5.4% of all deaths in males and 10.6% of all deaths in females each year. In 2016 dementia became the leading cause of death among Australian females, surpassing heart disease which has been the leading cause of death for both males and females since the early 20th century. Females account for 64.4% of all dementia related deaths. An average of 36 people died per day where dementia was the underlying cause of death in 2016.

In 2018, there is an estimated 425,416 Australians living with dementia

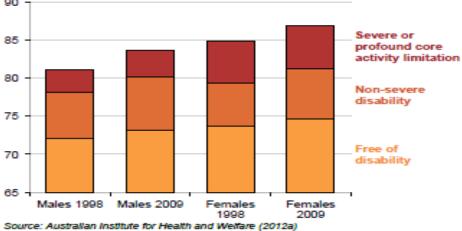
- 191,367 (45%) males
- 234,049 (55%) females

BABY BOOMERS

- Numbers of older people increase faster than population growth
- As a result the number of people who die each year in Australia will almost double in the next quarter of a century.
- As the number of people dying each year increases, pressure to improve the quality of dying is also likely to grow.
- In the near future, increased life expectancy and the transition of the baby boomer generation to older age will see the proportion of older people in the population increase faster than population growth. Those aged over 85 will increase from two to four per cent of the population.

DISABILITY

Figure 3: Years of life with disability have increased faster than years of life without Expected years of life for a 65-year old by disability status



But not all deaths from chronic disease are the same. ⁹ Those who die of cancer commonly experience a period of relatively high function following their diagnosis, followed by a short sharp decline and then death. Others lose functions more slowly, with intermittent periods of serious illness before death. Those who are frail or have dementia are more likely to have a long period of relatively poor quality of life before death. ¹⁰

⁹ Lynne and Adamson (2003) ¹⁰ Ibid.

For this reason, it is vital that a theological and pastoral care response is formulated built on the understanding that when existential spiritual issues are worked through with supportive pastoral care, the physical and emotional experience of dying and death are supported too (Tomer & Eliason, 2008). A foundational Pastoral theological response which addresses existential spiritual issues can support sustaining meaning, achieving peace throughout ageing, disabilities and coming to end of life. Unfortunately, such an intentional response has been lacking generally in care of older people and training of pastoral carers in the church (Gerkin, 1997).

There is theological work and reflection required particularly within the dying journey where a separation process between the earthly life and what might lie beyond is part of the process. There may already be a sense of the divine in the one dying, however, the greater need is reassurance as to whether the person is acceptable or in a loving relationship with that divine being (Bregar, 2013).

In Western society particularly, many people still struggle to talk easily and share feelings about their own death and that of people close to them (Barbato, 2010). In fact the following euphemisms bubble sourced from abc.net.au/news reflects the variety of words used rather than death or died.



This highlights how important our use of language is and the resultant impact and influence. Also, what are realistic expectations around individual perspectives on self-care and of autonomy? We need to understand what we are actually saying when we talk about issues to do with ageing, disability, death, and dying as well as interpretation of autonomy. A dictionary definition of autonomy is that of self-government and acting or freedom to make an independent choice.

This is very well up to a point but our lives and actions have impact on others. Newton's third law in physics states that for every action, there is an equal and opposite reaction with objects but so too do our lives and choices cause reactions for others.

The Health Information and Quality Authority in Dublin (2016, p.10) stress the following points. "Personal autonomy is an understanding of human beings as being worthy of respect. This includes respecting a person's dignity, privacy and his or her choices. Respect for autonomy is important in the context of health and social care, as it is central to person-centred care".

Put this way it seems that this is more a responsibility of those caring rather than a personal battle for an individual. Interestingly it is also stated that "Autonomy does not always involve total independence. Often, decisions are made based on our relationships with another or with the assistance of others. Respect for autonomy does not mean all choices are facilitated". Proponents of self-government fail to recognise that a healthy fully functioning body is required to achieve autonomy and the medical response to illnesses aims to assist a return to autonomy, which is not always possible or best care.

2 Contrasting Stories on Autonomy

Harriet was impacted by developing dementia along with depression and was fiercely endeavouring to remain in independent living. She had some home care visits but she was often neglecting meals and mixing up medication while relying heavily on friends who were also aged, to supplement her support needs, often causing them great distress. She was placed in residential aged care which she bitterly resented and she continued to have a very self-focused viewpoint on her own perceived needs with little understanding of the impact on others.

In contrast, Andrew had as a younger man become heavily dependent on alcohol to the point where he was at risk of early death. He made the choice to try and change his life direction which meant moving into residential care when he was gravely ill. He realised the impact his life choices was having on family as well as himself, and over the final years of his life, chose to focus on not only self-discipline but how to support his community and volunteering to help others.

The stories are not to say one way is right and the other wrong but they help to illustrate that each individual life and choices can have an impact on others. We can never be totally self-sufficient or fully autonomous.

Along with striving for autonomy and individualism is the belief that everyone has 'rights' which of course is correct in fair treatment of all people. However, media writers tend to use legal language of 'rights' in association with dying and death. What is not stressed is that it is not possible to always make a choice which can be categorically 'right' morally and becomes a dilemma in deciding who may have more 'right' than another. Often community opinion or decisions are not based on correct or full information, which can have dangerous outcomes especially around dying and death (Becker, 1986, p.130).

But we should also consider the influence of news headlines that grab attention with bold statements or headings such as: right to die, self-determination, we want choice about when to die. Facing death can reveal our values, assumptions and priorities and commitments. There are always differing viewpoints and moral compasses within society and also the church. For instance, the right to choose any action about personal life versus sanctity of life, autonomy versus physician's responsibility and physician assisted suicide versus refusal of treatment.

We are now living in an era where assisted dying has been legalised in some countries and is gradually expanding to more countries. How do we provide spiritual and compassionate pastoral care to others in our scope of ministry as well as to ourselves in the face of suffering and loss of meaning or hopelessness?

TODAY'S CHALLENGE WITHIN A NEW REALITY

Life goals in Western society tend to focus on the first half of life with emphasis on attaining education, pursuing career, building material possession, extending family while living life at a very fast pace. This has the impact of inhibiting learning some deeper lessons of life particularly if the goals are not realised. The life journey paradoxically involves loss and gain which tends to be more so from midlife.

A valid point raised by Huber (2003) is that of "core identity not being dependent on material possessions, status, relationships, or even own bodies and minds". Discovering the core involves spiritual work.

Nouwen and Gaffney (1990) believe there is hard work involved in order to traverse experiences of loss, grief, pain and suffering. Failure to process the spiritual tasks leads to what Huber interprets as bitterness, stunted spiritual growth of the core self.

The longer we live, the more ongoing impact there is of loss such as deteriorating health, energy levels decreasing, less ability to move around and care for ourselves, loss of loved ones and other relationships through death or relocation, loss of memory.

Kathleen Fischer speaks of needing a spirituality of ageing that holds together both the gains and losses of the ageing processes. Donald Koepke (2016) also sees caregiving as managing loss. A spiritual perspective on loss reflects that loss is a normal part of life and can lead to personal growth and development. Through ministry with older people Koepke has found that, "some persons spiritually decline as they grow older ending in despair as their core beliefs crumble under the weight of age. Others thrive, not because they don't have challenges, but because their spiritual focus reveals other perspectives that are more important and vital for life than the challenges. These people are not defined by the physical, emotional and social perspectives that often are a part of the ageing experience but by the hope, courage and an inner strength that comes from their core beliefs, their 'Essential Spirit'. In order to thrive, the essential spirit is fed and developed".

SPIRITUAL CARE – OUR RESPONSE

Some shared spiritual needs experienced in ageing as well as death and dying can be disempowerment, hopelessness, intense loneliness, disconnectedness from the church community and family, while also trying to process feelings of self-worth, guilt and issues of forgiveness (Anderson, 2008).

Importantly too, in order to provide effective care, pastoral carers must have faced the reality of their own dying and death which can also be challenging for those of the Christian faith despite the gospel of resurrection hope (Becker, 1986). Therefore there is both preparatory work involved for the pastoral carer and then also the spiritual work required by the dying person that includes dealing with grief, fears, possible depression and the unfinished business of life. The pastoral task is to assist in self-acceptance and forgiveness which is necessary for a 'good death' despite the quality of life lived previously (Barbato).

Pastoral care language and the images of a shepherd caring for a flock of sheep come from the theological root of God Incarnate in the person of Jesus caring for those estranged from God the Father. In laying down his life, Jesus is the Good Shepherd. He then asks of his church to also care for each other and discipleship teaching in the New Testament reinforces this aim, such as 1 Peter 5:2 "Care for the flock that God has entrusted to you. Watch over it willingly, not grudgingly-not for what you will get out of it, but because you are eager to serve God" (New Living Translation).

As people are now living longer, some older people calmly wait for death and prepare well, but there are a number of older people and their family members who are not willing to prepare for their eventual death. There is now more choice available across many areas of life however, in particular, medical and surgical treatments which can have both positive and negative outcomes for all age groups depending on need. It must be emphasised that pastoral care provision to the dying must come from the perspective of the dying person and their family and other relationships and the individual's personal beliefs and value system.

Within an ageing context, we understand our spirituality to be that which sustains purpose, gives hope and builds relationship connections and which may also be expressed through religious practice. We must also be alert to meeting the spiritual needs of those who don't practice religion. In fact having Chaplaincy and spiritual care support in residential care is very important as expressed by older people themselves in a case study (2015). The following quotes reflect the contrast in spiritual expression, "I have been supported by the Chaplain in maintaining a stronger religious faith but I think it's also very important having a Chaplain for non-churched people as the spiritual side is important and a big thing when you get old".

Further quotes from the case study, reflect that "for me spiritual or spirituality means an awareness of God and that life is boring without spiritual and religious support, as our spirit needs feeding. I have regular devotions and practise the presence of God". Another older person sees that "my spirituality or faith has developed more depth in ageing and I really appreciate time with God and my relationships with others".

It should also be considered that many older people must have questions within their longer years of life. Understanding spiritual needs and supporting the spiritual quest in ageing has the potential to transform a limited viewpoint of physical earthly life to an eternal perspective and purpose.

We all need encouragement to undertake the hard task of spiritual work in order to support development. Later life can be a time of learning through suffering, gaining spiritual maturity and growing through vulnerability. This is best done through the support of meaningful relationships and community (Stoneking, 2003). Along with the benefits of spiritual direction, is also the simple concept of a spiritual support friend where there is strong connecting and bonding while growing together. We are also reminded of the helpfulness of Lament that can assist expression of pain, rage, sorrow and grief (Evans).

Within the context of death and dying, Hardwig (2000), points out that "spiritual suffering at the end of life may begin well before one is actively dying. Spiritual care is the core of care for the dying: also that of greater personal choice to himself is not whether he wants CPR or artificial feeding and so on but rather how to face his own death, how to bring his life to a close and how best to help his family go on without him". It is also now understood that different sources of suffering if uncontrolled, actually lead to shorter survival as well as impacting quality of life.

Gawande (2014) reiterates this too in his experience of medicine observing that "people with serious illness have priorities besides simply prolonging their lives. Surveys find that their top concerns include avoiding suffering, strengthening relationships with family and friends, being mentally aware, not being a burden on others, and achieving a sense that their life is complete".

We will all suffer at some point in our lives in varying degrees and in order to grow spiritually throughout our lives, we need to be building our resources. The life journey paradoxically involves loss and gain. A valid point raised by Huber (2003), is that of "core identity not being dependent on material possessions, status, relationship and even own bodies and minds".

Discovering the core involves spiritual work. There is hard work involved in order to traverse experiences of loss, grief, pain and suffering. Failure to process the spiritual tasks leads to what Huber interprets as bitterness, stunted spiritual growth of the core self. The benefit of spiritual work is not only for individuals but the greater community too.

Further perspectives particularly in thinking of end of life are quotes from an older person who found that "the meeting of their spiritual needs actually helped them carry on with life when they were contemplating suicide". Other older people recognise that "life can be beautiful and cruel and I am grieving the death of a son as well as my husband, so spiritual support is vital".

Other examples are for one woman who took care of her sister's children when her sister died at the age of 32 years and two other women helped raise grandchildren.

No matter our age, pain which includes physical, psychological and spiritual aspects if untreated heightens the sense of loss of control, and having anything of value to contribute to others.

It is understandable that pain inhibits enjoyment of life and full engagement in life. When pain is uncontrolled we may each relate to the following points made by Evans (2011, p. 223) that "people stay home which then increases loneliness, loss of meaning builds, there is angst, despair and for older people a feeling of simply growing old and useless". In particular, spiritual pain comes to the fore when facing death as the impending loss and separation is felt.

It is vital to understand that pain has a huge influence on our spirituality and religious beliefs which may be either strengthened or even relinquished. As well, it is relevant that technology not only enhances our living but can also lengthen our dying.

Paradoxically though while technology has helped prolong and sustain life, there has been developing alongside that growing ability, less regard for those whom the technology supports such as older people or those with disabilities. There are also perceptions that those with disabilities are 'suffering' and not able to enjoy a fulfilled life. We live in what Wiebe (sourced 2018) refers to as "able-list social conditioning that equates disability with pain, frailty, incapacity and poor quality of life".

It also seems a contradiction that the teaching regarding ageing in Australian vocational training, talks of empowering older people and those with disabilities but a major hindrance to this are external factors not keeping pace with the ideals. Factors such as ease or difficulty accessing buildings, services, transport etc., but also societal attitudes that perceive that a disability needs to be 'fixed'.

Those with disabilities are often not perceived as empowered people who can contribute to society. A further challenge for a person becoming disabled later in life is the able-list perceptions they have absorbed. This can exacerbate loss of meaning and purpose but also their value as people which can greatly influence choices towards end of life.

Further to these important points is clarity around what supports dignity and well-being. Clear teaching on what comprises dignity is vital as a perceived lack of dignity can also influence end of life choices.

Another perspective on suffering is raised by Fowler (2008, cited in Evans, p.235), when she highlights, "What we in America have done is to attempt to use our medical knowledge and medical power to 'tame the terror and eliminate the darkness', which is suffering, from our lives. We have asked medicine to do something that is not its fundamental purpose. In its care of the body, medicine and technology can dull the sword of disease or pain or even death, but it cannot, itself, either tell us where to 'draw the line' or come to grips with the issue of suffering".

This is a vital point. I wonder is there a skewed focus on physical pain to the neglect of addressing other forms of suffering. For example, the experience of ongoing decline, loss, prospective death and beliefs as to whether there is life after death, can all contribute to suffering. In this way, it could be a spiritual crisis rather than fear of physical pain which drives the desire for help to die. Also, spiritual distress occurs for family members.

A commonality we all share would be regret over different aspects of life, for example, personal choices, relationship breakdown, accumulated grief and loss, issues of guilt and forgiveness. These are all spiritual issues.

In an ever changing context in many countries it is now possible to choose how and when to end your life. Euthanasia literally means 'good death' but in a modern understanding is that of ending a person's life where an agent other than the person themselves is involved. Active euthanasia is a physician administering a lethal dose of medication to a patient who is the final agent in events leading to the person's death. It is killing by an act of commission. Evans (2011, p.61) is helpful suggesting that instead the focus can be on euapothenesto, which is good dying and a more helpful moral compass in making decisions.

Passive euthanasia is allowing a person to die or abstaining from treatments to prolong life. In this way it is omission. It is vital to appreciate that it is not dishonourable accepting death as a normal part of life and that choosing to not have life-sustaining treatment while labelled passive euthanasia, is allowing a natural outcome of death in a body unable to sustain life.

Suicide is death by one's own hand as distinct from heroic self-sacrifice is giving up one's life for a cause, principle or another person.

Physician-assisted suicide is arranging death by mutual agreement between the patient and physician. This can be referred to as 'aid in dying' since patients take the lethal dose themselves. In order to clarify the terms around resulting death, focus on who acted last. Also treatment options for people include potential to refuse active treatment, withdrawal of treatment, palliative sedation, reasonable to unreasonable interventions. There is now more potential to negotiate how and when we die (Evans, 2011).

RESPONDING TO REQUESTS

A part of working through a life-limiting illness can be expressing a desire to die but not necessarily acting on that desire. It is also understandable that if there are many uncontrolled symptoms, life seems untenable when there is lack of adequate support and relief from symptoms.

Sometimes, people are not aware of how the palliative care team can help and often palliative support is not commenced early enough. Carpenter as cited in Weir (2017) stresses, "dying is not just a medical event – it's also a psychological and social experience. Palliative care addresses medical, psychological social and spiritual needs of a person with a serious illness and their care partners".

Meador, (2004) sees that "spiritual care should inform the practice of palliative care throughout the course of treatment and that palliative care informed by spiritual attentiveness allows both the patient and the provider to give up illusions of therapeutic entitlement to cure and at the same time honour the privilege of intentional and reverent caring for the dying".

The great pioneer of Palliative Care, Cicely Saunders said, "You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die". This is the challenge within longer living and potential frailty to continue living until death.

It is relevant to point out too, that studies have revealed that pain is not the dominant factor influencing requests for death, but rather clinical depression and hopelessness. Work by Gallagher, Dublin Health and End of Life Essentials Education, all reiterate and outline that a diagnosis and treatment of depression is vital. Despite receiving a life limiting diagnosis, depression is not simply a reaction to the news but an added component for the person which requires treatment. Along the same lines, it is important to also treat any mood or anxiety disorder.

While specifically focusing on training for Physicians, an online module on "End of Life Essentials" makes the following helpful point which is relevant for all health professionals. Any request for assistance to die is an invitation for communication and therapeutic intervention. Sitting behind any request is the individual's unique physical, psychological, social and spiritual concerns. The request is also an indication of potential unrelieved suffering. The importance of reflective listening and asking open- ended questions is stressed. In offering spiritual support, it is possible to rekindle hope and look for meaning making within that situation.

Skanse (2017, p.2) also reiterates this from a Chaplaincy perspective outlining that "People make choices based on their beliefs. Our job is to help people discover what they truly believe, so they won't regret making the decision and we help them to not feel alone". A goal for all those in caring roles is to clarify regarding assistance to die whether there are any misunderstandings about just what is involved. There is great emotional effort as well as consequences to family and friends and staff.

Interestingly, actually talking about assisted death does not increase the risk but may help lessen the risk. Addressing the commonly expressed fears of loss of control, pain, other symptoms, being a burden to others, lack of dignity, and potential desertion by others can clarify outcomes for people.

Some helpful advice is written for nurses but also correlates well for pastoral/spiritual carers. Fowler (2008) recognises that "suffering has a cry and that cry is: be. Be with me. Be, not do. Be, even in silence. Just be. Nurses, however, are good at doing, doing, doing, speaking, speaking, and speaking. Here, suffering brings us back to the necessity of relationship. It is in being-with-another and in hearing that person's lament, that the person who suffers comes to totality or completeness. While most laments are phrased in the language of faith, this need not be the case. Laments can be created with no religious content and can be used as a template for the expression of suffering or a mental template for one working with one who suffers, who needs to express their lament".

Other practical suggestions include assisting with recording life stories. The oral telling of our story and assistance writing the narrative can support finding peace. Not only is there then a recorded history for family, Rayburn recognises that, "reflections on where they have been, what they have accomplished and what they have regarded as most meaningful are vital to establishing a sense of what life has been all about and in what way they have contributed to the flow and essence of life".

In order to achieve peace toward end of life, all people, regardless of religious belief have practical matters, family, spiritual and religious elements to work through. Attempting to resolve unfinished business is important and opportunities for repentance and forgiveness while working through issues of guilt, sorrow and saying farewells. An important goal for pastoral care is to enhance end of life while also supporting greater family interactions. Rayburn highlights four main points for one dying as having opportunity to ask forgiveness, to offer forgiveness, express thanks and love which can contribute to healing. A helpful point for those with no religious belief is perhaps focusing on the cosmos and that they may continue as a part of nature (Rayburn, 2008).

In particular within a Christian perspective, going over our life story within God's narrative and noting what we understand as God at work throughout our timeline is very meaningful. Experienced hospice staff, have found not only the liturgical rituals of worship, prayer and scripture helpful but also, the use of the arts can free up and enable the dying person to express deeper issues. Provision of tools that encourage creativity for painting, sculpting or writing poems and journaling also provides a safe outlet for expressing memories and complex issues. Music is often helpful in different genres but particularly hymns, chants, requiems and laments can be significant. This can be through either live musicians or music via the internet. Literature can also be helpful and looking through photos can stimulate meaningful sharing (Evans, 2011).

RISKS

Wiebe highlights the following points of risk for vulnerable people in choosing to die:

- If anyone is tacitly acknowledged as unworthy, they are at risk, especially when budgeting finances and spending
- At times, full options of health support are not explored or offered to those with disabilities
- All people have dignity because they are human

In parts of the United States, assisted death is an option. One personal story is of a young woman not given the chemotherapy option of treatment for her disease by her health fund but she was covered for the assisted suicide drug which cost less financially. In this way it is understandable that assisted suicide ultimately affects everyone's health care. Within the ageing perspective and particularly dementia, with greater numbers of people impacted, there is risk in the future of potential decisions to end life.

The helpfulness of a heading, Pitfalls reiterates, (End of Life Essentials education) around end of life decisions and request for assisted death, "that prematurely affirming any perspective can propel both parties to stark choices. Delaying inclusion of other skilled members of the health care team and forgetting families and caregivers; they may need to be educated and supported and their need to give care may need to be refocused".

A good death is the correct definition of euthanasia and the aim is to give people dignity, choice and support to address their physical, personal, social and spiritual needs. The Grattan Institute (2014) suggests 3 specific reforms required within Australia:

- More public discussion about the limits of health care as death approaches, and what we want for the end of life
- Plan better to ensure that our preferences for the end of life are met
- Services for those dying of chronic illness need to focus less on institutional care and more on people's wishes to die at home and in homelike settings

The report published in 2014 sees that the voluntary euthanasia debate often clouds this issue. The writers recognise that voluntary euthanasia and assisted suicide are rare, even in jurisdictions that permit them. Instead, this report is about ensuring that when death inevitably comes for each of us, we die comfortably, in surroundings we would choose. We need the courage to promote mature discussions about a topic that many dislike, but that we cannot avoid.

SELF CARE

It is important to understand our own values and responses to end of life choices. We need to prepare and continue supporting others who may think and choose different options to us.

When someone chooses to die, both staff and residents in care need opportunities of sharing how they are feeling and are coping, while at the same time being supported to work through their grief. It is important for everyone impacted to take time to reflect and express how they are feeling. Within residential aged care there are already some good practices regarding grief and loss. However, there may need to be extra focus on different debriefing opportunities and supervision for staff and Chaplains in a future where people seek assistance to die.

Finally, as we recognise that suffering is universal, that we cannot prevent or control it necessarily, Fowler puts it succinctly saying, "When I am present for the suffering and lament of another, truly present, I am reminded that suffering is also my lot, even if not right here, right now. As I share in another's suffering and lament I am present to them, I allow the terror and darkness that cannot be controlled to confront me in my own frailty. This presence is a presence in vulnerability-the vulnerability of the shared human condition-that, while it still retains identity boundaries, is open to an ontological change in both persons by virtue of human connectedness".

There are also many scripture reassurances that remind us we are not alone in the complexities of life and as our life journey reaches its end. One Old Testament selection is from Psalm 84:5-8 is helpful,

"Blessed are those whose strength is in you, who have set their hearts on pilgrimage. As they pass through the Valley of Baca (a place of weeping), they make it a place of springs; the autumn rains also cover it with pools. They go from strength to strength till each appears before God in Zion. Hear my prayer, O Lord God Almighty; listen to me, O God of Jacob".

A New Testament selection, Jesus, our suffering Saviour promises in Matthew 11:28-30, "Come to me, all you who are weary and burdened and I will give you rest. Take my yoke upon you and learn from me, for I am gentle and humble in heart and you will find rest for your souls. For my yoke is easy and my burden is light".

In conclusion, Arnold (2013) reminds us "that dying is the final hardest test of courage".

The Apostle Paul writing from personal experience encourages us to not lose heart. Our body may waste away but there is an inward spiritual renewal possible. There is an eternal life and perspective from our earthly life and it is in our weakness that God's love can be evident and glorified. The provision of spiritual and pastoral care can assist older people and their families from all cultures and religious expressions, facilitate the complexities around ageing, illness, dying and death.

REFERENCES

- Anderson, L. (2008). Pastoral Care and the Spiritual Formation of Older Persons. *Journal of Religion, Spirituality & Aging, 21*(1-2), 104-118. doi: 10. 1080/15528030802265395
- Arnold, J. C. (2013). *Rich in Years: Finding Peace and Purpose in Long Life*. Elsmore, Australia: The Plough Publishing House.
- Barbato, M. (2010). Caring for Living and the Dying. Adelaide: Griffin Press, Adelaide.
- Becker, A. H. (1986). Ministry with Older Persons. Minneapolis: Augsburg Publishing House.
- Bregar, J. (2013). Acquiring Wisdom: A Metaphor for the Theory and Praxis of the End Stages of Life. Journal of Religion, Spirituality & Aging, 25(1), 52-64.
- End of Life Essentials: Education for Acute Hospitals, mm.Learn.org: Self-Study Module 14: Physician-Assisted Suicide
- Evans, A. R. (2011). *Is God Still at the Bedside?* Grand Rapids, Michigan: Wm. B. Eerdmans Publishing Co.
- Fischer, K. (1995). <u>Autumn Gospel Women in the Second Half of Life</u>. Paulist Press, New Jersey.
- Fowler, M. (2008). Suffering and spirituality: Nursing and Health Care Ethics: A Legacy and a Vision cited in *American Nurse Today*, Volume 4, Number 5: Accessed Jan. 2018
- Gawande, A. (2014). Being Mortal. Bevin Way London: Profile Books Ltd.
- Gerkin, C. V. (1997). An Introduction to Pastoral Care. Nashville: Abingdon Press.
- Gordon, M. (2015). Rituals in Death and Dying: Modern Medical Technologies Enter the Fray. *Rambam Maimonides Med J, 6*(1), 1-7.
- Grattan Institue Report No. 2014-10, Septebmer 2014.
- Hardwig, J. (2000). Spiritual Issues at the End of Life: A Call for Discussion. Hastings Center Report 30, no. 2: 28-30
- Health Information and Quality Authority in Dublin (2016, p.10)
- Huber, L. W. (2003). Aging as Pilgrimage; Spiritual Potentials of Late Life. In M. A. M. S. H. Kimble (Ed.), *Aging, Spirituality, and Religion* (Vol. 2, pp. 7-22). Minneapolis: Augsburg Fortress.
- Kimble, M. A. (2002). Beyond the biomedical paradigm. Generating a spiritual vision of ageing. *Journal of Religious Gerontology, 12(3/4),* 31-41.
- Koepke, D. R. (2004). Challenges in Aging: Managing Loss, complaining and Spirituality. Professional Development resources and Care2Learn Pages 1-38, at www.pdrsources.org. Accessed in 2016
- Koepke, D. R. (2016). The Essential Spirit. Eugene, USA: Wipf and Stock Publishers.

Meador, K. (2004). Spiritual care at the End of Life: 2004, NC Med J July/August, Volume 65, Number 4.

McNamara, B. & Rosenwax, L. (2007). The mismanagement of dying. *Health Sociology Review, 16*(5), 373-383.

Mottram, K. P. (2007). Caring for those in Crisis. Grand Rapids: Baker Publishing Group.

Nouwen, H., & Gaffney, W. (1990). *Aging, The fulfillment of Life* (2nd ed.). New York: Bantam Doubleday Dell Publishing Group, Inc.

Rayburn, C. (2008). Clinical and Pastoral Issues and Challenges in Working With the Dying and Their Families. *ADULTSPAN*, 7(2), 94-108.

Salt, M. (2015). Effectiveness of a Spiritual Care Assessment and Planning Tool in Residential Aged Care: A Case Study

Skanse, J. (2017), *Plainviews.healthcarechaplaincy* Volume 14 No. 12 (2017). https://plainviews.healthcarechaplaincy.org/articles/Who Decides When to Pull the Plug and What is the Chaplains Responsibility

Stoneking, C. B. (2003). Modernity: The Social Construction of Aging. In S. Hauerwas, Stoneking, C. B., Meador, K. G. & Cloutier, D. (Ed.), *Growing Old in Christ* (pp. 63-89). Grand Rapids, Michigan: Wm. B. Eerdmans Publishing Co.

Tomer, A. E., Grafton T. (2008). Existentialism and Death Attitudes. In A. Tomer, & Eliason, G. T., & Wong, T. P. (Ed.), *Existential and Spiritual Issues in Death Attitudes* (pp. 7-37). United States of America: Taylor & Francis Group.

United Nations World Population Prospect Graph on Ageing.

Weir, K. (2017). *How psychologists can bring their expertise to end-of-life care*: American Psychological Association, November 2017, Vol 48, No. 10

Wiebe, R; https://www.second-thoughts.org/home/files/better-dead-than-disabled.pdf

http://www.abc.net.au/news/2017-05-23/why-we-dont-speak-openly-about-death-and-dying/8547824

https://www.dementia.org.au/statistics