

# [What theological or ethical principles religion essay](https://assignbuster.com/what-theological-or-ethical-principles-religion-essay/)

As palliative care is specialized comfort care for people who are approaching the end of their lives, it is related to many ethical issues and concerns. Its framework is based on the moral values and principles of the professionals involved, patients concerned, their families and society as a whole. Palliative care is a very sensitive issue and it is important that it is administered in an appropriate manner. The main objective is to achieve the best possible quality of life, both for the person, and for their family. As such, palliative care is more than the provision of medical relief from pain and other distressing symptoms. It encompasses the psychological, social, emotional and spiritual aspects of end of life care.

The palliative care philosophy affirms life and regards dying as a normal process. It neither aims to hasten nor postpone death. It endeavours to provide a team-based support system for the person, enabling them to live as fulfilled a life as possible for the time remaining; and to help their family cope during their loved one’s illness and prepare for their bereavement. Care can be provided at home, in a hospital, an aged care facility or a palliative care unit. Above all, palliative care respects the dignity of the person who is dying, carefully honouring their story, wishes and needs.

A discussion about palliative care doesn’t necessarily mean that death is imminent, in fact, it’s far better to start thinking and talking about your palliative care options before you need them. Palliative care is sometimes required for a person whose death is very near – a matter of hours or days – while others will need care over a longer period of time, sometimes years. In this case their care needs will tend to be less intensive and more episodic. The need for palliative care does not depend on any particular medical diagnosis, but the combination of many factors assessed through the judgement of the person, their family, the palliative care team and other medical professionals, including the person’s GP. Families and carers may also receive assistance from palliative care services in order to help them cope with emotional and social problems; wounded healers also need healing.

To palliate is to cover with a ‘ cloak of care’; to offer protection and provide relief in the last chapter of life. A palliative approach is a type of palliative care and recognizes that death is inevitable for all of us. For me writing, I am reminded of a comment Professor John Swinton made in response to a question at the recent CAPS conference:

‘ Wherever we are in life, there is a storm coming –

preparedness becomes about the solidity of our foundations’.

End of life questions of quality, planning and dignity are ethically and theologically grounded in solidifying our foundation. Clements (1990) wrote of this, explaining that as the person moving through life finds their roles stripped from them, and if they have no spiritual foundation, they may be found naked at the core.

Residential Aged Care Facilities are often the place where people spend the final chapter of their life; people come into care because they are no longer able to look after themselves and most will have chronic illness alongside ageing. The focus of care in aged care facilities is to help people live well with their illness and frailty during their time spent there. This focus on ‘ living well’ is the essence of the ‘ palliative approach to care’. Our goal is always to assess and treat pain and other symptoms thoroughly, in familiar surroundings and in the company of the person’s loved ones.

There’s a Japanese proverb of which I am particularly fond, ‘ A sunset can be just as beautiful as a sunrise’. In my work I’ve seen many beautiful sunsets in people’s lives. Sadly, I’ve also witnessed some that aren’t so beautiful. With forward planning they may have been different. The sudden onset of illness has a way of turning our lives, and the lives of our family and friends, upside down – at any age. Suddenly decisions can be very difficult to make; that’s why planning ahead is important. If we know what a person’s choices and wishes are, we’re able to respect them if something should happen and they’re unable to tell us themselves. Medical treatment to manage symptoms goes alongside comfort care and could include surgery or medications. The focus of a palliative approach is on living. That is why staff will want to set goals and to plan for how the person wants to live the rest of their life.

The end-of-life stage is an extraordinarily profound and emotional time; and a person does not have to be religious to have spiritual considerations. Spirituality is about how we make meaning in our lives and feel connected to other things, people, communities and nature. Spiritual questions, beliefs and rituals are often central to people when they are in the final chapter of their lives. Ensuring that staff are informed about each resident’s unique spiritual considerations will allow them to be properly respected and addressed. Helping the person to tell their story can help them find meaning, affirmation and reassurance.

To effectively palliate would mean that: family and staff communicate openly and with compassion with the person in care and with each other; that pain control and comfort is achieved as far as possible; that the resident has every opportunity to communicate with those who are important to them; and that their physical, emotional, social, cultural and spiritual needs are addressed and as far as possible – met. One size ‘ cloak of care’ does not ‘ fit all’ (Hudson, 2012). When these elements are neglected the ‘ cloak’ becomes an empty ‘ cover up’, leaving the resident exposed rather than protected. When the cloak does not fit it is uncomfortable to wear (Hudson 2012) – but the vulnerable population of people in their fourth age may wear it anyway for fear of seeming ungrateful. An appropriate ‘ cloak of care’ must have a spiritual lining, and provide opportunities to reveal hidden hurt; forgive, reconcile; and find peace in loss through ‘ tasks’ of self-reflection and self-transcendence. Spiritual and pastoral care in this context aims for wholeness and spiritual growth.

Palliative care should not palliate death itself – denying the stark reality of death and dying with false platitudes and consolation can mask existential pain and real needs – and further, make these ‘ taboo’. From a Christian theology, death is recognized as inevitable and necessary. Ageing is an inescapable process that in part defines human existence and experience. From the moment we are born we age. Ageing only ends when we die. Experience of human life tells us that ageing and death are linked. The curse of Adam in Genesis 3 introduces this finitude to our lives.

Our role as pastoral carers is one of empowerment, relationship and human presence. Care of people who are suffering means providing real spiritual care, where a closeness or intimacy is developed between the person who is suffering and the carer. This is often quite alien for health professionals, who, through the culture of residential aged care accreditation, are subscript to activity theory and a ‘ doing’ role that emphasizes action rather than ‘ being with’ (MacKinlay, 2006). This involves not a sense of competence, but a sense of humility in the awareness of our own inability to ‘ fix’ anything, beyond being with that person at their point of need.

The vulnerability of being present to ageing and death constitutes a simple and costly demand to stay. Not to understand or explain – just to stay; ‘ Or else to expire in terrible wilderness, lonely silence’ (Caldwell 1960). In MacKinlay’s (2006) observation that ‘ care of people who are suffering means to walk the journey of suffering with them, to be present with them and authentic in caring’ (p. 167) I am reminded of Jesus’ telling his disciples to ‘ watch and pray’ (Matthew 26: 36-46) to bear witness. We cannot cure the scriptural worst enemy of the fatal sting – but we CAN care sincerely – respecting that the cloak is not ours to fashion and that the chapter will always have an end (Hudson, 2012). Jesus, in becoming human and by his death and resurrection, defeats death and gives resurrection hope of a ‘ body free from ageing’, decline and frailty, providing hope to all people, especially those in the fourth age.

Terminal illnesses do not inhibit people the way they used to; a person burdened with such an illness can live a long and reasonably ‘ well’ life. Consequently terminal disease is tangled in an ethics web concerning limited health resources, contributing to funding and community tensions. These tensions intrinsically present ethical issue in the equity of service provision.

Stemming from this is the sensitive nature of transitioning to palliative care, and further to end-of-life care. ‘ End of life’ can be defined as that part of life where a person is living with, and impaired by, an eventually fatal condition, even if the prognosis is ambiguous, or unknown. The World Health Organisation defines palliative care as ‘ an approach that improves the quality of life of individuals and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and management of pain and other needs, physical, psychological and spiritual.’

There is further tension surrounding communication and generational knowledge. As with Jeffery’s Mrs Davis there can be enormous gaps in generational perspective which may compromise ‘ informed’ decisions. The onus for decision making in a palliative care team lies with the resident themselves – so, ethically, whose responsibility is it to be sure that a decision is well-informed? And further, who can be unbiased in providing information so as not to manipulate a decision? Contradictory beliefs, conflicting principles, and competing duties between the parties involved in end-of-life care can tear the ‘ cloak’.

Beauchamp’s primary principles of health care include: non-maleficence, confidentiality, autonomy, truth telling, informed consent, and justice. Empathy underpins each of the principles above, and in this lies the difficulty. We cannot understand (Okon, 2006 cited by Hudson 2012), we cannot try the cloak on for size – but sometimes just ‘ looking as though’ you could understand (Saunders, 1987 cited by Hudson, 2012) makes a world of difference and goes some way to thwart loneliness. In end-of-life care, our presence as pastoral carers is strengthened in enabling spiritual growth through the sharing of connectedness and ritual.

A palliative approach is built on an understanding of the uniqueness of individuals’ life histories and personalities, and implies commitment to an individual’s developmental tasks of ageing and coming to peace. To be able to reach such goals as personal satisfaction, the individual must have means of expressing themselves. Our role in the care of older people is to support and enable each individual’s sense of meaning and self-expression; to affirm each individual as a person of great value, and loved by God.

Aged care is a delicate balancing act in that functional decline, infirmities and diseases are often inherent in ageing. Because of the nature of chronic illness in the fourth age, a caring response in the face of incurable illness is respect, and commitment to personal autonomy and integrity. That is, our role in promoting overall comfort and wellbeing through positively reinforcing and enabling those with such prognoses, to live to their best quality of life. The goal of palliative care is to provide comfort and care when cure is no longer possible. This paradigm shift entails a shift in the definition of autonomy. People at the end stage of life are not ‘ playing by the same rules’ as you or I who would oblige patient autonomy and nod to expert medical opinion. Health professionals in this context need to be enablers – not decision makers.

Gradual functional decline and loss of control in autonomy are inevitable with age. Loss of control is painful and scary. Perhaps this kind of persona is paralleled only in infancy – leaving our elders feeling a sense of childhood being ‘ forced upon them’ (Jeffery, 2001). Unfortunately admission to aged care often does not help these older adults to feel less like children. The danger and ethical dilemma here is the assumption of impaired autonomy; in that decisions are made and autonomy declared lost even when this is unnecessary, because it is a simpler, easier course of action ‘ we know what is good for you’ (Jeffery, 2001). The basis of this kind of paternalism is beneficence – its motivation is to act in a person’s best interest so that no one gets harmed; making harm or burden the reason for intervention.

Some loss of autonomy is inevitable in later life and steps have to be taken to act in the ‘ incompetent’ person’s best interest, sometimes with their wishes recorded in living wills or advance care plans. Often ‘ autonomy’ presupposes someone, who acts in accordance with such a pre-conceived plan, and who is rational and independent; but autonomy may be better understood in terms of identity and self expression of values (Jeffery, 2001).

A written advance care plan is about ensuring peace of mind. Effective advance care planning can avoid an unwanted transfer to a hospital. But even such counteractions as advance care planning can be problematic as these are based on today’s situation and forecasted futures – i. e. these cannot take into account tomorrow’s medical breakthrough. This being the case, there arise new ethical dilemmas e. g. do we have a right as people acting in someone’s ‘ best interests’ to tweak what they have proclaimed to want for themselves? Would they have wanted what they said they wanted were they deciding now?

When autonomy is understood as a property of action or a capacity of persons (Reich, 1995); impaired autonomy, becomes a hopelessly limiting self fulfilling prophecy in that it diminishes “…the opportunities of those who lack certain abilities or capacities” (Caplan, 1992). Autonomy needs to be seen as a way of valuing the human person, respecting them and recognizing their right to make decisions as the master of themselves.

Personhood is not compromised or incapacitated by end stage life – we are who we remember one another to be – an essential aspect of being human is to care and be cared for; interdependence is a non-accidental feature of the human condition. Being human, we are bearers of the image of God (Gen 1: 26). This image demonstrates our capacity for relationship with God, and with the rest of humanity (Green, 197). This capacity for relationship does not diminish as we age.

If autonomy is taken as valuing one’s uniqueness and the capacity to give gifts, it is a search for meaning in life – authenticity. That is: as Jeffery writes; authentic choice is the autonomy of action that requires meaningful choices to be offered and identified with – which equates to one’s values and essentially what they ‘ stand for’. If this is how we understand autonomy – then this sheds new light on impaired autonomy. In effect we lose the ability to ‘ stand’ for what we stand for. In this case, autonomy becomes less about incompetence and more about advocacy in helping the person to ‘ reconnect their essential values to their choices’ and allowing them to give meaning to their life. By honouring this form of authentic control rather than a control via acquiescent consent or ‘ accept it or leave it’ culture we enable fulfillment and empowerment of the person’s dignity.

Being a resident in a nursing home may conjure conceptions of a twisted and limited self, and is destructive of autonomy. This is partly because the environment is ‘ thick with congruity and thin with community’ (Jeffery 2001); and partly because decision making is made nearly obsolete. The desire to control is moderated by the self-realization of the possibility of not being able to process all the relevant information: as the person psychologically shrinks, so too does their autonomy and self faith. Further, someone faced with a ‘ life shock’ can find their autonomy impaired in that they find themselves in a dramatically different world where previous life plans have no meaning and even stable values disappear (Jeffery 2001). In such settings – autonomy becomes about the ability to make meaningful choices. An older person may not be able to carry out what they decide, but they are able to recognize commitments and to be themselves (Jeffery, 2001).

As partners in end-of-life care, aged care staff must take into account such ethical dilemmas as autonomy and intergenerational tension in the way physical care is given; by focusing on presence, meaningful experience, journeying together, listening, connecting, creating openings, and engaging in reciprocal sharing. Affirmative relationships support residents, enabling them to respond to their spiritual needs. Barriers to appropriate palliative care include lack of time, personal, cultural or institutional factors, and professional educational needs. By addressing these, we may make an important contribution to the improvement of patient care towards the end of life.