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From the cradle - to beyond the grave?
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From the cradle – to beyond the grave?

Peter Gilbert

Abstract

Purpose – This paper aims to describe the content and import of a conference held in partnership between Staffordshire University and The National Spirituality and Mental Health Forum on the importance of considering life in the context of human mortality, and the meaning and purpose of our lives. It was one of a series of conferences on the theme of health and multi-belief systems; other conferences were on mental health and civic regeneration. A fourth conference is planned for 2012 on dementia and beliefs.

Design/methodology/approach – The conference and its format, including case studies is placed within the intense debate concerning the meaning of life in the context of death and what might be beyond “the grave”. With this conversation, and the issue of assisted dying becoming more prevalent, it was felt important to bring into the paper not just philosophical writings but examples from novels and “popular culture” which highlight the intensity of the dialogue.

Findings – Considering the perspectives of a variety of major belief systems assists in relating to and caring for the increasing diversity of older people and their carers when the ultimate challenge of dying is being faced.

Practical implications – As the discourse around assisted dying, belief systems and dignity come more to the fore, staff in health and social care will need time to discuss what are crucial issues for those they serve.

Originality/value – As religion and other belief systems come back into focus, partly through equalities legislation and increased demographic diversity, the Staffordshire University/National Spirituality and Mental Health Forum conference series has been an innovative way of meeting this renewed need.

Keywords Identity, Meaning, Loss, Death, Faith, Rituals, Beliefs

Paper type Conceptual paper

Introduction

Globalisation means patterns of population and issues of ethnicity, identity, culture and belief are changing rapidly. In the UK, there is a mantra that it is a “secular society” and yet, a consideration of Birmingham, the UK’s second largest city to the capital, London demonstrates a high proportion of major religious centres of various belief systems; and one ward with Muslims forming 63 per cent of its population. Research by the University of Leeds indicates that one in five people living in Britain will be from an ethnic minority by 2051 (The Times, 13 July 2010). The recent furore over the proposed mosque and Islamic cultural centre near the site of the 9/11 outrage in New York shows that cultural tensions can be intense even in a cultural “melting pot” such as the USA.

As an increasing number of people wish to discuss spiritual issues, perhaps as a revolt against increasing materialism and mechanistic approaches to healthcare, the National institute for Mental Health in England and the National Spirituality and Mental Health Forum in partnership with Staffordshire University have put on a series of conferences addressing these issues, and this paper considers the second conference (captured on DVD – Gilbert, 2008) on the interrelation between belief systems and attitudes to older age and death.
Death: friendly companion or the final antagonist?

In George Eliot’s (1871-1994, p. 424) *Middlemarch*, the academic churchman, married to the heroine, Dorothea, suddenly finds that his lifetime of writing is interrupted by impending mortality:

> Here, was a man who now, for the first time, found himself looking into the eyes of Death – who was passing through one of those rare moments of experience, when we feel the truth of a commonplace, which is as different from what we call knowing it [. . .] When the commonplace “we must all die” transforms itself suddenly into the acute consciousness “I must die – and soon”, then Death grapples us and his fingers are cruel; afterwards, he may come to hold us in his arms as our mother did and our last moment of dim, earthly, discerning may be like the first.

To Mr Casaubon now, it was as if he suddenly found himself on the dark river-bank and heard the *plash* of the oncoming oars [. . .] Expecting the summons.

In a fascinating paper in the *Oxford Today* journal (Snow, 2009), there is a debate about how much technological improvements should act on humanity. Julian Savulescu, Director of Oxford Uehiro Centre for Practical Ethics favours “procreative beneficence”. He suggests in place of humanism, we should talk about “personism”, as we need to move our perspectives beyond current humanity and bring species forward as far as science can go. Another scientist suggests that we could extend human life by many more decades. But to what end? Already some doctors are concerned that we are adding years to life but not life to years (Brown, 2007).

As Kübler-Ross (1969/2009, p. 6) has written: “The more we are achieving advances in science, the more we seem to fear and deny the reality of death”.

Elsewhere Kübler-Ross suggests that:

> It is the denial of death that is partially responsible for people living empty purposeless lives, for if you live as if you’ll live forever, it becomes too easy to postpone the things you know you must do. You live your life in preparation for tomorrow or in remembrance for yesterday, and meanwhile each today is lost. (From *Death: The Final Stage of Growth*, quoted in McNicholas, 2006).

As a science fiction fan, I am intrigued at how often the problems of extended mortality, or even immortality are featured. In Herbert’s (1970, p. 35) *The Heaven Makers*, the Chems are a race described as prisoners of eternity, gripped by the despair that immortality brought. One Chem, Fraffin, talks of:

> The endlessness of his own personal story appalled him suddenly. He felt himself to be on the brink of frightening discoveries and feared the monsters of awareness that lurked in the eternity before him. Things were there that he didn’t want to see [. . .] To be immortal is to require frequent administrations of moral anaesthesia.

On a lighter, but still cogent note, the fantasy author Terry Pratchett, who recently in a number of television programs disclosed that he was living with Alzheimer’s, published *Reaper Man* in 1992, which describes Death (who is personified in Pratchett’s novel) taking a sabbatical and the chaos that this unleashes in the Pratchett “Discworld”. Sometimes, perhaps we need fantasy and irony to highlight our human pretensions?

In the autumn of 2009, a highly successful young, South Korean model, Daul Kim tragically committed suicide. Writing in her blog, a few weeks before her death, she mused:

> Freedom comes with such a cost. But is it even freedom? One might get numb living like this [. . .] decadent nights to make up for losses. But this endless loneliness, there must be something wrong from the core.

Two weeks later, the model wrote that she was:

> Mad, depressed and overworked [. . .] the more I gain the more lonely it is [. . .] I know I’m like a ghost (Usborne, 2009, pp. 14-15).

Appleyard (2007, p. 4) in his thought-provoking work on “the new immortality” sets out the questions which novels and science fantasy have posed in their own way. If medical science postpones or banishes death, how would human beings adapt? Like the Chems “Perhaps, medical immortals will simply have to resign themselves to amnesia, to becoming serial, forgetful selves”.

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The search for identity

Sociologist and philosopher, Zygmunt Bauman, is one of the most persuasive commentators on modern identity. Bauman acknowledges that in previous times, a person's identity might have been made up considerably from parameters of society, though Thomas (2009), in his masterly exploration of the paths to fulfilment in the sixteenth to eighteenth centuries in England: *The Ends of Life* demonstrates the complexity of this concept. Bauman (2004, p. 29) talks about the: “Longing for identity comes from the desire for security, itself an ambiguous feeling” and that now humans have a project, perhaps the project to create their identity. One can see this, in the tragic story of Daul Kim and perhaps in the fall from grace, in 2009, of the golfer Tiger Woods, who has revealed himself to be all too human, rather than the perfect, iconic figure, which it might be debatable was created by him or for him. Bauman (2004, p. 29) likes to use the motif of humans being small boats sailing on an increasingly tempestuous sea:

And what are the abandoned, desocialised, atomised, lonely individuals likely to dream of and given a chance, do? Once the big harbours have been closed or stripped of the breakwaters that used to make them secure, the hapless will be inclined to carve out and fence off their own small havens where they can anchor and deposit their bereaved, and fragile, identities. No longer trusting the public navigation network, they will jealously guard access to such private havens against and all and any intruders.

One could see Tiger Woods as a partial victim of this isolating and ultra-individualist pursuit of identity. Life becomes an endless, and unrealistic search for perfection and satisfaction. There is an obsession with yesterday and tomorrow but not enough attention to today. This is perhaps why as a counterpoint, there is an increasing attention paid to Buddhist philosophy and various approaches to mindfulness, as a way of focusing our attention on “being” rather than obsessively “becoming” (Gilbert, 2010b; Gilbert et al., 2010).

It is fascinating to see these issues played out on various planes. As the Chief Rabbi, Dr Jonathan Sacks reminds us, human beings are “meaning-seeking animals” (Sacks, 2009). While author Dan Brown (2001, pp. 419-20) is snobbishly scorned, his books and the films of the books are widely perused by the general public. It is interesting, therefore, to see philosophical questions occur. In *Angels and Demons*, one character says:

Science may have alleviated the miseries of disease and drudgery and provided an array of gadgetry for our entertainment and convenience, but it has left us in a world without wonder [. . .]. [. . .] Scepticism has become a virtue. Cynicism and demand for proof has become enlightened thought. Is it any wonder that humans now feel more depressed and defeated than they have at any time in human history? Does science hold anything sacred? [. . .] It shatters God’s world into smaller and smaller pieces in a quest of meaning [. . .] and all it finds is more questions.

The ancient Greeks placed issues of identity and fulfilment within a societal context. Parker (1986, p. 267) points out that Greek religion at the time of Homer was very practical:

There were few expressions of unpractical religion, of concern for a world other than this. After death, according to Homer, a kind of wraith of the dead man vanished to the underworld, there to lead a joyless, eventless, meaningless shadow existence (Hick, 1994),

while Plato began to move the concept from:

The survival of the depleted shades or ghosts to the ardent desire for and belief in an immortality in which the highest possibilities glimpsed in this life may be fulfilled (Hick, 1994, p. 72).

Much of the Greek and Roman world had a fairly undeveloped conception of the afterlife, and thus in Keith Thomas’ words:

The Greeks, and even more the Romans, had laid heavy stress on the importance of posthumous fame as the essential reward and ultimate fulfilment of an honourable and successful life (Thomas, 2009, p. 235).

Whatever the “ends of life”, all the Greek philosophers were strongly of the opinion that there had to be a meaning and structure to one’s activity. Thomas (2009, p. VII) quotes Aristotle’s *Eudemian Ethics* as stating that:
We must enjoin everyone that has the power to life according to his (sic) own choice to set up for himself some object for the good life to aim at (whether honour or reputation or wealth or culture), with reference to which he will then do all his acts, since not to have one's life organised in view of some end is a mark of much folly.

But what should that meaning and structure be? In the twentieth century, human kind reached the apotheosis of group tribalism where an ideology, sometimes attached to racial stereotypes, created a bizarre doppelganger of enlightenment thought. At the time of the Allied invasion of Italy in 1944 Hitler even maintained that it was the Allies who waged:

A ruthless war of annihilation against the German people and who, without any higher ethical aims, strived for the destruction of Germany and European culture [...] (Clark, 2006, p. 176).

In her biography of Robespierre, Ruth Scurr uses the phrase 'fatal purity' to describe the journey of an individual from an apparently ethical horror of the death penalty, to the Terror (Scurr, 2007). Todorov (2009), while holding no torch for religion quotes the late Pope John Paul II (2005, p. 10) in his book, _Memory and Identity_ stating that the search for salvation had been replaced by the pursuit of personal happiness:

Man remained alone: alone as creator of his own history and his own civilization; alone as one who decides what is good and what is bad. It is just a step from here to the gas chambers. If a man can decide by himself, without God, what is good and what is bad, he can also determine that a group of people is to be annihilated.

Todorov (2009, p. 34) reminds us that Alexander Solzhenitsyn looked at both East and West at the time of the cold war, concerned that in the East spiritual life was destroyed by the machinations of the ruling party whereas in the West commercial interests suffocated it.

In 2008/2009, liberal capitalism faced its nadir and stared into the abyss, as governments realised that those respectable pinstriped suited gentlemen (they are mainly men) whom we had all trusted to create wealth in a sensible way, had been engaging in what amounted to a reckless gamble with other people's money.

Aristotle, as we know, did not speak of "happiness" as an individualistic concept, but about "flourishing" as a way of aligning the personal with the civic, rights with responsibilities, personal enjoyment with altruism. The enlightenment thinkers, Rousseau, Diderot, Montesquieu and others, also saw that individuality and liberty had to be placed in a social context. There also needs to be a form of social identity which does not lead back to the gross excesses of tribalism, exemplified by Nazi Germany. Thomas (2009, p. 226) quotes Bishop Gilbert Burnet, who looking back on his life in 1709 affirmed that it was only religion which could afford "true or complete happiness":

In his experience, the pleasures of sense soon became nauseating; public life merely revealed the crookedness of human nature; learning was always imperfect, even friendship "of the best and noblest sort" had yielded him "vanity and vexation of spirit". True religion, however, was an unfailing "joy and delight".

This could be echoed by many Christians, Jews, Muslims, Sikhs, Hindus, Buddhists and members of other faiths today. It is also echoed in another sense by atheists such as the perceptive columnist Matthew Parris (2009, p. 28), who wrote recently that although he has no religion, "the greater appeal of religion" is that people knew that there was a picture, they did know if it had a frame and they did know they had been provided with a means to put it together; and after that if they persisted, the fit might be found.

**Stepping over the threshold**

Margaret Holloway, in her book: _Negotiating Death in Contemporary Health and Social Care_ (Holloway, 2007, 2011) speaks of a change in the "liminal", or threshold period from a time when this was seen primarily as the period following death and is now more often seen in the lead up to an individual's demise, as this is often elongated by dementia or a neurological decline, and the benefits but also the complications of improved technological medicine. For many individuals, their families and carers, dying can be a very attenuated process, which without meaning and purpose, can turn Thomas Hobbes' aphorism that life is "nasty, brutish
and short”, to it being “nasty, brutish and long”. These very practical issues are partly what is driving the intense debate about assisted dying, and the even more specific assisted suicide, in places such as the Dignitas Clinic in Switzerland. BBC Radio 4’s Analysis programme on 28 June 2010 (Storton, 2010) demonstrated the intense debate between religious groups who viewed the debate as a moral “relativism” eroding the sanctity of life; and an alternative philosophy viewing religious belief as eroding individual autonomy.

Perhaps, there are now periods where we stand on the threshold with a liminal perspective? Certainly, one of the thresholds is the often slow process of dying. But there is also still a liminal period after death, as both popular literature and films, as we have seen, and increasing amounts of psychological research from those such as Fenwick and Fenwick (2008) and Fontana (2009) focus on both near-death experiences and our sense that some form of “life” proceeds after physical death. The new guidance on the Spiritual Care of the Dying Person, issued by the Roman Catholic Church (Gleeson et al., 2010, p. 33-5) suggests that we should respect “the mystery of dying”, not that we cease to think, reflect and act to understand the experience, but that there are aspects of the experience which are still hidden from us. As the guidance goes on to say:

If we only see death as a medical failure then we fail to understand the real gift of medicine is not just a science but a wisdom: how to live life to the full of which dying is a part. That requires a sense of the wholeness of a person and the wholeness of a life […] In the process of dying everyone – the person dying and his or her carers – will in someway be touched by the most profound questions of life. What’s it mean? Is death the way in which our lives end in nothingness or is death a movement into something which is unknown? We need both skill and courage to honour and respect these questions, however, they arise.

World religions are all agreed on the value of life, either because life is God-given or has intrinsic human value. But of course, there are radically different concepts of death and some form of continuing existence: reincarnation; absorption into the spirit of the cosmos; a judgement followed by life in another state, either with or without a “glorified body”. The philosophical concept of the integration of mind, body and spirit during life is clearly mirrored in the concepts following physical death (Figure 1). In Figure 1 I attempt to draw an

**Figure 1** The spirit moves

![Image of the spirit moves diagram](image-url)
increasingly complex and exploratory territory, where for some death is a blank wall and end, perhaps a merging with the earth; for others the spirit has no afterlife, but merges with a kind of "Cosmic Spirit", as they feel part of a greater whole; for some religious faiths the soul journeys on in reincarnation; while for other faiths there is a judgement and a specific afterlife. The disillusionment with mere materialism (King, 2009; Gilbert, 2010c) has led many people to explore other realms of being, and neuroscientists like Fenwick (2008, 2009) show that the human brain is wired in ways which look beyond the here and now. The inspirational, and spiritual Debbie Purdy, who has campaigned on issues around assisted suicide simply says, in response to the question: “What do you imagine death to be like?” that “I tend to think that once you’re dead, you’re dead and that’s the end of it” (Campbell, 2010). Personally, I recall talking with an uncle of mine who had been rushed to hospital with a life threatening brain tumour and brought back from the brink of death. He was a gruff, seemingly unemotional man, who had had a hard life. But he described in most moving terms his near death experience of a bright light and warm, welcoming presence. Being brought back by the skilled surgeons was a shock and a not altogether welcome one!

The conference

Perhaps, part of our confusion about dying is partly that, as MacKinlay (2010), in her recent work on Ageing and Spirituality across Faiths and Cultures quotes Erikson as stating that we lack:

[...] a culturally viable ideal of old age, our civilisation does not really harbour a concept of the whole.

Participants from the different faith/belief systems were invited to provide a paper prior to the conference and these evoke human beings innate desire to be, at their best, part of a wider community of human beings and connected to the wider cosmos. For instance, the Baha’i contribution states that:

Baha’i’s (spokesperson: Peter Hulme) believe that the mind is the fruit of the soul. Physical illness and impairment obscure our awareness of the soul but leave the soul unblemished. How we live, though, does affect the soul. Evil deeds performed with intent enfeeble the soul’s physical qualities; good deeds strengthen them. The soul, as it is not composed of atoms or material elements is immortal. This world is the womb of the soul, where it develops according to the conditions we create for it. After death we will become aware of the true value of our actions in this life.

The next world, though as imperceptible to us as we are to plants, is within this world. However, when we die we will meet and recognise those who were known to us in this life. Those souls who have served God in this life are the leaven of the world and will furnish the power to which the arts and wonders of the world are made manifest. These truths are hidden from our plain sight because if we apprehended them directly we would long forget.

The Christian perspective offered by the Venerable Arthur Hawes, speaks of “Christianity” being “an embodied faith”. Christians believe that God was fully revealed in the person of Jesus Christ, but he shared our humanity and expressed himself in space and time. In the words of one of the early Christian theologians: “God became human, so that we might become divine” (Augustine of Hippo).

One can see how different concepts of theology and philosophy appeal to different temperaments and perspectives. For some people, a more ethereal connection may appeal for others the idea of God making him/herself vulnerable by coming down to Earth and redeeming humankind in person, gives a great sense of comradeship with the divine; yet again for other faiths the concept of God becoming human is inconceivable.

The format of the conference was created by a number of keynotes: John Battle MP introduced the conference, while Barbara Pointon (2007, and Pointon and Miller, 2011) spoke on “the ultimate life crisis or a gateway: a personal perspective, and the “post modern life, post modern death” was discussed by Professors Gilbert (2008) and Margaret Holloway (2007, 2011).
There were then a series of case studies, leading into a discussion with faith/belief participants (Box 1) and these were followed by a number of workshops (Box 2). The conference was rounded off by plenary feedback by Professors Bernard Moss and Martin Aaron; with closing remarks by the Vice Chancellor of Staffordshire University, Dr Christine King.

In his introduction, John Battle MP quoted a Carthusian monk as defining contemplation as: “a long, loving look at the real”. And Pointon’s (2007) story of her care for her late husband, Malcolm, who was diagnosed with pre-senile dementia at 51 was a very moving and loving look at the ‘real’. Pointon and Malcolm had been Methodists, in fact Pointon had been a lay preacher, but they had also expanded their thoughts as approaches to Eastern faiths and philosophies. As Pointon put it:

Spirituality is at the core of who we are; and ironically it was caring for Malcolm during his 15 years of Alzheimer’s which revealed to me the nature of spirituality.

### Box 1

**Case Study 1: Dementia**

Mrs Hussein (not real name), is a 70-year-old lady, with diabetes who has increasingly become dependent on her husband due to her forgetfulness and lack of confidence in herself.

Mr and Mrs Hussein came to the UK almost 20 years ago from Indonesia, following political upheavals in that country and settled in Birmingham. Mr Hussein is a qualified accountant and managed to gain some part time work, and learnt English, but his wife stuck close to other refugees and her English is almost non-existent. Mrs Hussein experienced an episode of depression following their arrival in England, but since then seems to have functioned quite well.

Mr and Mrs Hussein’s daughter is married and settled in London, thereby she is not able to spend much time with her parents. The parents do not want to be a burden on their daughter and have tried to keep most of their worries hidden from her. Mr Hussein is happy to continue caring for his wife without wanting to create disruptions in their daughter’s life.

Mr Hussein is a very proud and independent man. They have supported their daughter who is a successful dentist.

Mr Hussein has noticed that for the last approximately four or five years his wife is increasingly forgetting things. Sometimes she will add extra salt in her curries, she may vacuum the living room having just vacuumed it ten minutes ago, she would mention things that are out of context and out of place for her. Mr Hussein currently helps his wife with the cooking, he operates the washing machine, increasingly has to do the weekly grocery shopping himself. Starting to get worried about his wife Mr Hussein made an appointment to see their general practitioner (GP), about a year ago.

Dr Jones’ GP practice is only ten minutes away from their house, Mr and Mrs Hussein do not drive and so walked to the practice discussing why they thought it was important to get to the bottom of this. Having got there, they managed to explain to the English speaking receptionist that they had an appointment with the GP. Upon seeing Dr Jones, Mr Hussein was reassured that there was nothing to worry about and that his wife’s behaviour was normal for her age. The GP felt that her diabetes was being managed (as Mr Hussein administered the medication and helped his wife stick to the appropriate dietary advice), but that he could not give her anything for her dementia.

A year later, things have not got any better. Mr Hussein is extremely worried about why his wife is becoming forgetful to the extent that she sometimes forgets what she was doing just a short time earlier. She has become quite argumentative with her husband and is very repetitive with both her conversations and tasks she does around the house. The situation is making their relationship quite fraught. Mrs Hussein is now not able to go out to see any friends on her own for fear of getting lost or not remembering how to get there or to get home. Mr Hussein has also taken her to accident & emergency at the local hospital after her fall about six months ago.

Increasingly worried, he does not know what to do or who to ask for help as his GP tells him that people of his wife’s age can behave the way that he describes the symptoms. Mr Hussein is also worried that should something happen to him, who will take care of his wife. A friend has suggested to him that perhaps his wife is the victim of ayn nazar (the evil eye) and that some ritual should take place to cleanse her, and then all would be okay again.

What should they do? And what issues can you identify?
As Pointon (2007, p. 119) states in her book chapter:

To stand stripped of everything the world values and to see each other as we really are is a very precious and humbling experience, and one which I would never have encountered were it not for the ravages of dementia. Paradoxically, Malcolm’s “losses” have turned into “gains”.

One of the most impressive aspects of the conference was members’ willingness to share their own personal experience of loss in a whole variety of ways. In a workshop examining different belief systems, one of the social work students at the University shared the following thought of searing pain and spirituality:

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**Case Study 2: End-of-life challenges**

Stephen Gold (not real name) is suffering from terminal cancer and wishes to depart this life in as peaceful, painless and dignified a manner as possible, with his family and friends at his hospice bed side.

Brought up in the Jewish faith, Stephen slipped out of religious practice while studying philosophy at Cambridge University. He now describes himself as “a cultural Jew”. He enjoys many cultural aspects of his erstwhile faith: music, food, etc. but no longer entirely believes in God.

Maureen Gold is a practising Christian. After 22 years of marriage, they are still very much in love and she is distraught about his illness and her impending loss. As a Christian with an evangelical perspective, she believes that a miracle is possible and also desperately wants Stephen to rediscover his faith at this time of crisis.

Their different faith backgrounds and current beliefs have never been a major obstacle for the Golds. They have argued over philosophy and theology at the dinner table for years. Stephen is fond of teasing his wife by saying: “Humanity has outgrown God”, and the Jonathan Miller quip: “I'm not a Jew, just Jewish!”.

The humour is stretched a bit thinner now, though, as Stephen would like to reassure Maureen that he believes they will meet again in an afterlife. Maureen does not wish Steve to suffer, but feels sure there is a miracle, with a medical name to it, waiting around the corner.

The Medical Director at the hospice is attuned to Stephen’s wishes for a release that is not prolonged, and indeed might be eased appropriately. The SHO on the other hand, feels that he should try every treatment possible to fight the cancer and keep Stephen alive.

The hospice chaplain is new and is unsure whether to broach the idea of having a Rabbi visit Stephen.

Steve and Maureen have two daughters in their 20’s. Both dread losing their dad, but Rebecca is quietly urging him to fight the cancer, while Sarah is finding the struggle increasingly painful and, partly because of her own sorrow, she hopes for a quick and peaceful end for him.

Stephen is anxious to die in the hospice. He has a horror of dying in a hospital ward, having visited his father in a geriatric ward with very poor care; and he is also worried that he may be moved to a nursing home, which will be less spiritual than the hospice (NB his Jewish roots are coming through stronger by the day).

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**Box 2**

**Conference workshops**

- The changing nature of hospice care – Mark Jackson and Jane Tiller.
- Multi-faith/belief dialogue – Hifsa Iqbal, Professor Martin Aaron and Professor Bernard Moss.
- Assessing spiritual needs – Dr Sarah Eagger and Melanie Dunn.
- Art and music – Janet Hetherington.
- Positive approaches to the “fourth age” – Dr Susan Benbow and Ben Bano.
- Safeguarding vulnerable adults – Professor Paul Kingston and Malcolm Payne.

As Pointon (2007, p. 119) states in her book chapter:

To stand stripped of everything the world values and to see each other as we really are is a very precious and humbling experience, and one which I would never have encountered were it not for the ravages of dementia. Paradoxically, Malcolm’s “losses” have turned into “gains”.

One of the most impressive aspects of the conference was members’ willingness to share their own personal experience of loss in a whole variety of ways. In a workshop examining different belief systems, one of the social work students at the University shared the following thought of searing pain and spirituality:
On the night my husband died my world fell apart. I worried how I would tell my then 18 month old son, his daddy had died and how does it affect the rest of our lives. It seemed so unfair. I ask the questions everyone asks: Why me? What did I do wrong? We were so young and why should my son have to grow up without a dad? The next few months were extremely tough, nevertheless my first turning point came on Boxing Day of that year. Still raw from my grief and trying to cope with my son’s “terrible two’s” tantrums, a light started to shine in the distance. I refer to this as my first true enlightenment to my personal spirituality, my strength that was then to carry me through the next couple of years and beyond. In front of me on the television was media coverage of the Tsunami. I watched and I can remember, as vividly today as over three years ago, a little blond haired boy sitting on a hospital bed. His eyes told the story and said all I needed to know. His parents were feared dead and he was totally lost, a look I have not experienced before and to this day still has a profound effect on me. I looked at my son, my family around me and all that I held dear and cried. However, this time tears of relief for me and sadness for the little boy. A few days later news came. They had found the boy’s father. Despite the depths of grief there were waves of relief that they were no longer alone. I feel it important to share this experience to truly explain where my belief in the strength of my spirituality originates.

Go gentle into that good night?

Human beings have always wrestled with the questions as to whether to go “gentle into that good night” or to “rage, rage against the dying of the light” (Thomas, 1914-1953). The new Catholic guide, already quoted, starts not with a statement of religious belief, but with the broader aspect of spirituality:

Spirituality can be provided in a range of ways according to an individual’s beliefs. Some people equate it to with explicitly religious values, other see it as a personal search for meaning, seeking to find a purpose to their life and the part that suffering plays in that search. This is not to suggest that those requiring more formal religious care do not need or want to address the wider questions of meaning. Conversely, at such times many people who might not describe themselves as “religious” might wish to return to a faith they were brought up with, finding in that hope and comfort. This is true for both family and visitors as well as the patient (Gleeson et al., 2010, p. 9).

Fictional works, both novels and “science fiction” deal with these issues all the time which shows how close they are to our consciousness. In Herbert’s (1966/1976, p. 160) The Eyes of Heisenberg, the author describes a future where man’s “ultimate goal” has been achieved – immortality. All embryos are tampered with their genes examined and if necessary rearranged. Earth is ruled by the Optimen, but immortality had become a trap. As one of the characters puts it:

They have souls with only one scar […] it was carved on them day-by-day, century by century, eon-by-eon – the increment of panic that their blessed foreverness might be illusion, that it might after all have an ending. He had never before suspected the price the Optimen paid for infinity. The more of it they possessed, the greater its value. The greater the value, the greater the fear of losing it. The pressure went up and up […] forever.

As Appleyard (2007, p. 289) muses: “perhaps the deepest problem of all would be the ultimate refinement of boredom – the loss of meaning”.

In a colloquium at Blackfriars, Oxford in 2009, many of these issues were discussed amongst a range of speakers from medical, legal, philosophical/theological and care backgrounds. A hospice director recalled that one of the hardest cases that he and his staff had had to work with was with a very wealthy family:

[…] who were furious that money had failed to find successful medical treatment for a husband and father and could not put off death – “this time they could not buy the solution; they were not in control”, he said (Pepinster, 2009).

Writers such as MacKinlay (2010, p. 16) suggest that:

With increased individualism in the postmodern society, the significance of symbols and ritual may be in danger of being lost, or weakened. It is hard for individuals to live into, or draw meaning from their symbols in isolation and particularly to engage with the meaning of rituals, as these, in essence, belong to communities, not individuals.

Issues of the importance of rituals in care are also dealt with in the new DVD prepared by Ben Bano for Caritas Social Action Network (CSAN) (2009): It’s Still ME, Lord […].
Jenni Russell, writing in *The Guardian* (Russell, 2009, p. 35) speaks movingly about the death of her father and how, although “intellectually and rationally there should have been nothing startling about his death” “yet I have been as stunned by his death, and the utter absence of him, as if I never knew that human beings had a lifespan”. Without the framework of a traditional religious or social ritual Jenni felt at a loss:

We have gone from the strict and public mourning rituals of the Victorian era with widows in heavy black clothes for a year and a day, and men wearing black armbands to signify loss, to having no mechanisms to signal our sadness at all.

Again, perhaps, it is a combination of our personal experience and popular culture which bring these aspects home. In the popular BBC series of 2010: *Ashes to Ashes (Series 3)*, it transpires that the main character DI Alex Drake (played by actor Keeley Hawes) who was shot and finds herself transported back from 2010 to the 1980s, is actually in some transitory stage of an afterlife. In another BBC programme, the family comedy *Outnumbered*, the seven-year-old child Karen (played by Ramona Marquez) is outraged when her mother kills a mouse. Taking the mouse outside she buries it in a ceremony, which brings together a whole range of religious and secular elements. As Karen puts it:

Brethren, we are gathered in the bosom of Jesus to say goodbye to this mouse, killed before its time.

We have given it cheese and bread for its journey to heaven. At least if it goes to hell it will have cheese.

Dust to dust, for richer or for poorer, in sickness and in health. May the Force be with you – ‘cause you’re worth it. Amen and out”.

For life to have meaning, it must contain the meaning of dying and death; and human beings continually struggle to find the meaning of where we come from, why we are here and where we go to after we die. Despite the welcome advances of science, the story of human beings is still grappling with mystery.

References


Campbell, I. (2010), “In a way I’m grateful I have MS”, “The NS Interview”, *New Statesman*, 6 September, p. 32.


Further reading


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