The Art of Dying Well

The Doctrine Committee of the Scottish Episcopal Church
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GROSVENOR ESSAY No. 9

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Introduction

The notion of the art of dying (ars moriendi) may sound strange to us, but it has a strong Christian heritage and counterparts in all the world faiths. A fundamental role of religious and philosophical ways of life is to teach people how to die well. For this reason, it is a part of spiritual practice to contemplate our mortality and to loosen our attachments to the world, so that through processes of spiritual or metaphorical deaths we become more and more able to live this life with freedom, and to leave it in peace.

Christian processes of letting go find some parallels in Hindu and Buddhist disciplines of detachment. In Hinduism, for example, there is an ideal of four stages of life (ashramas), the last two of which involve preparing for, and awaiting freedom through, death. The four stages are, respectively:

i. for study;
ii. for work and house-holding;
iii. for loosening worldly ties and attachments;
iv. for total devotion to God, having renounced all fears, hopes, desires, duties and responsibilities.

While these stages represent an ideal rather than common practice, they convey a need to spend time letting go (stage 3), and to turn one’s attention wholly to God, in anticipation of death (stage 4). Buddhism teaches a different discipline of detachment, based on the Buddha’s teaching that suffering is caused by craving, and therefore that to end suffering we must stop craving. Buddhist meditation promotes a heightening awareness of the spirit, where physical realities matter less and less, attachment to the self falls away, and there ceases to be awareness of one’s own separate identity.

All religious traditions that help us to live with our mortality, teach spiritual themes and practices to aid our saying goodbye to this life. There are also important differences between the traditions, including different attitudes towards embodiment, different understandings of selfhood and selflessness, and different ideas about where the passage of death takes us.
The Christian tradition is sometimes criticised for being too focused on death and afterlife, to the detriment of birth, generation, and flourishing in the here and now. The feminist philosopher, Grace Jantzen, recently developed a philosophy of religion based on natality, in reaction against what she saw as a western religion’s preoccupation with mortality; its ‘necrophilia’, she called it, in which the senses, sexuality, and sensuality are all denigrated.\(^2\) The premise of this Essay, however, is that the art of dying well is learned for the sake of life: life in the present, life in our dying, life beyond our dying, and life for those we leave behind. Realism about our mortality should never eclipse natality and life. However, if we cannot come to terms with our mortality, we may also become afraid of birth and life.

Christians and post-Christians in the West are less familiar with death than our recent ancestors, and than our cousins of other faiths. We have medicalised and hospitalised death to such an extent that we have removed death from every day life. The increasing professionalisation of the funeral industry also means that the bodies of the deceased are taken from us early on; no longer kept in homes, washed and dressed by family members or local women, or visited by neighbours. We now carry little sense of the normality of death, or of death in the midst of life. ‘Everything in town goes on as if nobody died anymore’, says Philippe Ariès of contemporary Western attitudes: ‘Except for the death of a statesman, society has banished death…the old black and silver hearse has become an ordinary grey limousine, indistinguishable from the flow of traffic. Society no longer observes a pause; the disappearance of an individual no longer affects its continuity.’\(^3\)

It is not that we avert our eyes from death. We are intellectually and artistically fascinated by it, producing university courses, book series, conferences and cultural festivals on the theme. We follow anxiously the shifting thought on the causes of mortality (and thereby learn that dying is something that we should not do), and we debate the rationality of suicide, even beyond the bounds of terminal or life-limiting conditions. Sometimes we are public in our mourning, creating shrines of flowers, for example, whereas a generation ago we might have visited the family instead. We are more conversant about death than our parents and grandparents, and less inclined to shroud it from children, and we have become specialists in bereavement, developing bereavement support tailored, for example, to children, young people, parents, lesbian and gay people, teachers and others in professional roles.\(^4\) We have a popular
phrase, ‘in denial’, which derives from Elisabeth Kübler-Ross’ famous model of the stages of dying and grieving.\(^5\)

Yet, for all our interest in death, dying, and bereavement, we do our utmost to maintain continuity, as though nobody dies. Perhaps it is the finality of death that challenges us the most, which would explain the popularity at funerals of Henry Scott Holland’s words, ‘Death is nothing at all. I have only slipped away into the next room’ (we will say more about these words in a moment). Sometimes we do not even hold funerals; the deceased have asked us not to. In Scotland, a practice is developing whereby families hold a private committal at a Crematorium first, and follow it not with a funeral, but with a Memorial or Thanksgiving service. Undertakers encourage this practice because it is straightforward for arranging timings and transport, but they would not encourage it if clients found it insensitive. Mourners opt for short and private committals, which move them quickly on from the fact of death, back to a focus on life. This affects the nature of church provision for them and for the deceased. Funerals help us to receive the dead, send them on their way, and then take our leave; for we must begin the task of adjusting to life without them. Memorials and Thanksgivings keep the dead alive. They tend to be more celebratory than mournful. How far they confront the reality of death will depend on those designing and taking the service. Culturally, this way of saying goodbye is akin to the grey limousine replacing the black hearse; if we have not seen the coffin we could almost pretend that no-one had died.

In the USA, the desire for continuity gives rise to other trends: an increased belief in Heaven despite a decrease in most other religious beliefs,\(^6\) and therefore, presumably, a Heaven that floats free from the trauma and trials of getting there; and a growing belief in the Rapture amongst evangelical Christians, which is the hope, based on I Thessalonians 4.17, that Christians who are alive today will not die but will be caught up in the clouds, with the dead who have been raised, when Jesus returns.

These trends reflect and affect how we are around death. If we do not face death, death becomes more frightening to us, and we become still less able to face it, and less able, thereby, to embrace life.

The art of dying is also, therefore, the art of living. By bringing dying in to our living, we also grow in freedom to live our lives fully, whatever our physical health, and eventually to live our dying well.
In a famous sermon preached in 1907, Albert Schweitzer, the German theologian and medical missionary, provokes us to overcome death by becoming familiar with it. He tells us to regard ‘our lives and those who are part of our lives as though we have already lost them in death, only to receive them back for a little while.’ He encourages us with insights into the benefits that follow: ‘true, inward freedom from material things’; feeling ‘purified and delivered’ from our baser selves; a deepened appreciation of the preciousness of life, and of our loved ones so that we ‘become sacred to the other because of death.’

Schweitzer recalls us (as Christians) to our baptism because, in our baptism we have already died, and our ‘lives are hidden with Christ in God’ (Colossians 3.3). Those ‘who belong to the Lord in spirit’, he says, ‘have shared with him in spiritual experience his death and resurrection to a new life. They now live in this world as men who are inwardly freed from the world by death.’

Three years later, in 1910, Henry Scott Holland preaches in St. Paul’s Cathedral on the occasion of the death of King Edward VII. It is a sermon intended to comfort and encourage a nation: ‘Death is nothing at all. I have only slipped away into the next room’. Today we usually hear these words out of context. In his sermon, Scott Holland acknowledges death’s reign over us; indeed he calls it the ‘King of Terrors’, ‘cruel’, ‘irrational’ and ‘the pit of destruction’. He can say death ‘is nothing at all’ because, by our baptism, death is now behind us, not in front. So ‘Let the dead things go, and lay hold on life’, Scott Holland exhorts us. ‘Then the old will drop away from you, and the new wonder will begin. You will find yourself already passed from death to life, and far ahead strange possibilities will open up beyond the power of your heart to conceive.’

Schweitzer and Scott Holland believe that we can pass through death to life because Christ conquered death. They do not teach that we can have on-going life without passing through death, which is the wishful thinking of our own time. But they do suggest that by practising our passage through death, we can already benefit from some of the fullness of life that death can yield, and be somewhat prepared for the losses that our physical death will bring. So they articulate something of the art of dying.

How we learn to approach our death is of course influenced by our beliefs and uncertainties about afterlife, by what views prevail culturally, and also by what we may have been taught by religious figures, particularly in our youth. Questions about the nature of afterlife have been
addressed more substantially in Grosvenor Essay No. 6, *Death and Resurrection: New Life in Christ*. They appear here insofar as they affect the ways in which we prepare to die, and in which we care for the dying, dead and bereaved. For example, today we tend to view a sudden or quick death as in many ways a blessing because the deceased has not lingered unhappy, in pain, disabled, bedridden and dependent, a burden to family or community. ‘At least x didn’t suffer’, we tend to say, whereas in centuries past a quick death was not regarded as good because it afforded the deceased no time for the amendment of life, for repairing of relationships or the bringing of affairs to a conclusion. Whether we view a quick death as a blessing or a curse, depends in part on our views of what happens to us after we die. The focus of this Essay, however, is not death and afterlife, but death and dying. We face death in order to learn to face it, and so learn the art of dying and of living.

This Essay falls into three Parts. Part 1, ‘Recovering the art of dying’, traces aspects of the art of dying through Scripture, tradition, and prayerful practice. We consider views on death and dying in Scripture; Augustinian and Lutheran perspectives on the relationship between death and sin; and changing ways of dying within Christian practice, especially in Scotland. We hear something of the art of dying through Jeremy Taylor’s classic text, *Holy Dying*, and we consider how we learn the art of dying through the regular rhythm of Christian prayer.

In Part 2, ‘Living with Dying’, we discuss medical and palliative developments that affect our dying. Inspired by the Hospice movement, we look for ways of bringing physical, spiritual, emotional and social factors together in the art of dying well. We also visit some of the issues around calls for Assisted Suicide. We take a look at some of the medical processes and care processes involved in dying, and consider experiences of those who are dying in old age, those in their youth, and those for whom terminal diagnoses have turned into chronic conditions. How do people manage who have expected to die, but who now receive treatment that keeps them alive? On this complex reality, we hear from the Chaplain to those living with HIV in Edinburgh, Marion Chatterley.

We could have focussed on any number of conditions with which people contend, and there is not room to be at all comprehensive. Alongside the prolonged circumstances of living with HIV/AIDS, we have wanted to give some specific attention to dementia, because of its increasing prevalence, and because of the challenges it poses to dying well when one’s mind is fading.
Throughout Part 2, we bear in mind that over the last 150 years, dying has become an increasingly medical matter, and that insofar as it is in our hands to facilitate a good death, we tend to focus on the period of a person’s final stages of life, and the quality of care available. The perspective of this Essay is that if we see dying as an art, we begin to think more broadly. As Jeremy Taylor encouraged us: dying is an art best learned in good health, so that we can be better prepared for whatever we may face in our final weeks and days.

In Part 3, ‘How care for the dead affects the dying and the living’, we look at current and changing ways of caring for the deceased and the bereaved. We consider some contemporary and cross-cultural patterns of provision, and raise questions about best practice. Not surprisingly, some discussion of these themes also appears in Parts 1 and 2. Post-mortem care cannot be separated from our pre-mortem preparation: our knowledge or anticipation of what will happen to our bodies, what sort of funerals are possible, and the nature of bereavement support for those we will leave behind, all inform how we prepare for death.
Part 1

Recovering the Art of Dying

Views of death in Scripture, and a Biblical ars moriendi

Death represents one of the topics on which the testaments contrast with one another most sharply. The Old Testament generally regards death as an undesirable necessity, with no particularly vivid ethical implications. Some passages entertain a figurative sense of continuing existence, but without an understanding of that existence constituting 'life'. Only in a very few OT texts, perhaps only one, does the expectation of a resurrection of the dead emerge.

On the other hand, entire the New Testament is saturated with the anticipation of a resurrection from death to continuing life. This is, of course, associated principally with Jesus’ resurrection, though by the first century CE, the Pharisees and some other groups within Judaism had come to regard resurrection as theological axiom. The specific contours of Christian teaching on life after death do not take on definitive shape within the New Testament, as Paul’s difficulties in Thessalonica and Corinth amply illustrate, but one can discern a broad affirmation that Jesus’ resurrection inaugurates a state of affairs in which death’s universal scope has been broken, the promise of well-being for God’s people is being fulfilled, and all will eventually be raised from death to a divine discernment of reward or punishment.

Given the differences between the testaments, and the inchoate doctrinal directions manifest in the NT, the notion of a biblical perspective on the art of dying must be approached with a certain reticence. Still, the framework on which subsequent generations of wisdom will build is visible in the mist. It recognises the inevitability of death for all human beings (and all living things, bearing in mind that the life/death binary itself constitutes a tautological affirmation that life must yield to death), a death that temporal intelligence cannot fathom.

Death is, in that sense, very much like what the Old Testament envisions: an endless duration of shadowy subsistence (in familial heritage, in memory, in record-keeping, in the enduring effects of temporal actions) about which we may know little other than that the dead no longer participate visibly in the cosmos of cause and effect, of interaction and community.
The condition of the dead is not, therefore, indifferent; the subsistent traces of the dead persist as a treasury of honour or shame, a legacy of story, allotment, and precedent, so that our behaviour toward the dead reflects on both them and us. As sharers in the New Testament, we affirm that mortality is not the last word relative to life, and that in Jesus and in the anticipatory visions and inferences of the apostles, we understand that by the conduct of our mortal life (as distinct from our lives under supernatural conditions) we store up consequences that we must anticipate affecting our eventual eternal identities. As such, we ought to live always in the light of our inevitable deaths, not blithely assuming that our behaviour will not matter coram Deo, but willingly, joyously, offering to the world a testimony of trusting (and penitent) humility. Remembering that we are dust, and that at any moment we will return to dust, we devote our interval of enfleshed vitality to the cause of freely pursuing what is good, what is peaceable, what is joyous; what expresses our dedication to the God of hope and redemption from death.

Setting aside, for the time being, the Genesis story of the incursion of death into existence, the Old Testament expresses a near-unanimous sense of death as simply a given condition of worldly existence. The inevitability of death functions in some contexts as axiomatic: 'As for mortals, their days are like grass; they flourish like a flower of the field; for the wind passes over it, and it is gone, and its place knows it no more' (Ps 130:15f); 'The days of our life are seventy years, or perhaps eighty, if we are strong; even then their span is only toil and trouble; they are soon gone, and we fly away' (Ps 90:10).

Human mortality corresponds, in some accounts, to our dependence on God's spirit (or 'breath'). We received life, in the beginning from the in-breathing of God's spirit: 'the LORD God formed man from the dust of the ground, and breathed into his nostrils the breath of life; and the man became a living being' (Gen 2:7). Apart from God's animating presence, we are as lifeless as the earth from which we were made; '…the dust returns to the earth as it was, and the breath returns to God who gave it' (Eccles 12:7), and 'When you take away their breath, they die and return to their dust. When you send forth your spirit, they are created' (Ps104:29-30).

The Old Testament characterises the disembodied dead as rephaim (NRSV 'shades'; the Hebrew is an obscure term which also functions as the identifier for a lost giant race of Canaanites). These spirits are eternally consigned to a realm below the earth’s surface. The
domain of the dead is variously identified as Sheol, Abaddon, the Pit, the deep, and so on; it is located below the surface of the earth, and one typically reaches Sheol by verbs of descent.

Likewise, in the rare occasions in which the OT calls attention to somebody making a way from Sheol to the land of the living, it does so with verbs of ascent or rising. While it is tempting to ascribe this spiritual stratigraphy to naiveté about geology, figures of 'descent' and subterranean realms correspond to the location of graves, and to the dying sun's setting in the west (apparently going down into the deeps of the sea), so that these expressions may not indicate so much a literal expectation that excavation would lead to Sheol, but that the most obvious ways of talking about an elusive experience draws on visual cues.

The inhabitants of Sheol, the *rephaim*, constitute a sort of negative reflection of the community of the living. Their realm has gates (Ps 9:13, Job 38:17); its inhabitants dwell in dust, darkness, and shadow (Job 10:21f, Is 26:9) where one's ancestors sleep (cf. The stereotyped concluding idiom 'he went to sleep with his fathers' in 1 & 2 Kings, and 2 Chronicles). The land of the dead seems even to have a monarch: 'By disease their skin is consumed, the firstborn of Death consumes their limbs. They are torn from the tent in which they trusted, and are brought to the king of terrors' (Job 18:13f).

The principle characteristic of protracted existence in Sheol is its futility. 'Whatever your hand finds to do, do with your might; for there is no work or thought or knowledge or wisdom in Sheol, to which you are going' (Eccl 9:10). The shades cannot engage with mortals or God - their future offers no change or activity to which they might look forward, not even worship. 'For Sheol cannot thank you, death cannot praise you; those who go down to the Pit cannot hope for your faithfulness' (Is 38:18); '[I]n death there is no remembrance of you; in Sheol who can give you praise?' (Ps 6:5); 'Do you work wonders for the dead? Do the shades rise up to praise you? Is your steadfast love declared in the grave, or your faithfulness in Abaddon? Are your wonders known in the darkness, or your saving help in the land of forgetfulness?' (Ps 88:10-12).

The dead were thus unable to protect their own interests; we read of no haunting in the Old Testament (with the possible exception of Rachel's lamenting over her children in Ramah). On the other hand, the danger that one's legacy be dishonoured or annihilated by the living
frequently troubles OT writers. Psalm 109 adds curses that arise even after death to the predictable prayers for the enemy's afflictions: 'May his posterity be cut off; may his name be blotted out in the second generation…. Let them be before the LORD continually, and may his memory be cut off from the earth' (109:13, 15). In a similar way, Isaiah warns the king of Babylon that in contrast to the glorious tombs of other kings, his corpse will be unburied, trampled underfoot (Is 14:18ff). (Christopher Hays has challenged the premise that the Old Testament regards the dead as powerless by pointing to passages, specifically in the Isaiah Apocalypse, that bespeak anxiety about the status of the dead - anxiety that would make no sense if one simply knew that the dead were powerless.)

The prospect of endless futility (compounded by the risk that one's shade be vulnerable to dishonour and disturbance), combined with the experience that righteousness constituted no protection against death, engendered theological conflict in the Old Testament. On one hand, many currents in Old Testament thinking affirm that God will not allow the righteous to suffer, nor permit the wicked to prosper - but the evidence of centuries forced many other sources to conclude that rectitude and turpitude were accorded the same life span. Thus, according to Ezekiel: 'The person who sins shall die. A child shall not suffer for the iniquity of a parent, nor a parent suffer for the iniquity of a child; the righteousness of the righteous shall be his own, and the wickedness of the wicked shall be his own.

But if the wicked turn away from all their sins that they have committed and keep all my statutes and do what is lawful and right, they shall surely live; they shall not die. None of the transgressions that they have committed shall be remembered against them; for the righteousness that they have done they shall live' (Ezek 18:20-22).

But Ecclesiastes remarks that: 'In my vain life I have seen everything; there are righteous people who perish in their righteousness, and there are wicked people who prolong their life in their evil-doing' (7:15); 'Everything that confronts [the righteous and the wise] is vanity, since the same fate comes to all, to the righteous and the wicked, to the good and the evil, to the clean and the unclean, to those who sacrifice and those who do not sacrifice. As are the good, so are the sinners; those who swear are like those who shun an oath. This is an evil in all that happens under the sun, that the same fate comes to everyone' (9:1-3). The Psalmist may advise that we not fret ourselves because of evil-doers,
but observation shows that too often, the wicked persist like dandelions rather than withering like the grass.

In a thin thread of the Old Testament, we can observe first the intuition, then the confident affirmation that God will, post mortem, rectify apparent injustices. The Psalmist trusts that 'Such is the fate of the foolhardy, the end of those who are pleased with their lot. Like sheep they are appointed for Sheol; Death shall be their shepherd; straight to the grave they descend, and their form shall waste away; Sheol shall be their home. But God will ransom my soul from the power of Sheol, for he will receive me (49:13-15); and even more confidently Isaiah exults 'Your dead shall live, their corpses shall rise. O dwellers in the dust, awake and sing for joy! For your dew is a radiant dew, and the earth will give birth to those long dead' (26:19). Ezekiel prophesies — perhaps in a figure, but in a bold figure nonetheless — that the bones of the whole house of Israel will be brought up from their graves, that God will put flesh on their bones and put God's spirit in them, and they will live.

At length, among the latest writings, the Book of Daniel asserts an eventual resurrection of the dead for judgment — that a time will come when 'Michael, the great prince, the protector of your people, shall arise. There shall be a time of anguish, such as has never occurred since nations first came into existence. But at that time your people shall be delivered, everyone who is found written in the book. Many of those who sleep in the dust of the earth shall awake, some to everlasting life, and some to shame and everlasting contempt. Those who are wise shall shine like the brightness of the sky, and those who lead many to righteousness, like the stars forever and ever' (Dan 12.1-3). 2 Maccabees echoes this hope with the promise that the martyred brothers and their mother would drink of ever-flowing life, under God's covenant; but that the tyrannical oppressor, by the judgment of God, would receive just punishment for your arrogance (7:36).

It is in the broad context of this conspectus of the Old Testament's view of death that we will return to the Genesis story of how death entered the world (Gen 3:1-19). The tale is so familiar that it is often difficult to see just how disjointedly the narrative proceeds. The talking serpent (nowhere here identified as Satan, a devil, or even particularly malicious — but simply as 'more clever' than other animals) asks the woman whether God had indeed forbidden her to eat of all the trees in the garden; she responds that she and her man had been warned against eating, or even touching, the fruit of the one tree in middle of the garden,
'or you shall die' (3:3). The serpent rightly observes that she will not die; so she takes, eats, and shares the fruit, and neither she nor her man die.

Only after God calls out to them while taking an evening constitutional, and after the two humans both try to assign responsibility for their disobedience to someone else, does the curse of death fall on the humans: 'you are dust, and to dust you shall return' (3:19). And even then, the turn to mortality seems to require that the humans not eat from the tree of life (of whose existence the reader will not have known until this point) in order that they not enjoy divine immortality — so God banishes them from the garden in which the tree of life grows.

In the context of the wider Old Testament portrayal of death, the Genesis story seems more like a Just-So story that explains why it is that people die, than as the first act of a cosmic tragedy. Adam and Eve practically disappear from the Old Testament after the Cain and Abel story; only later would the fateful 'first disobedience' take on paradigmatic significance as a pivotal moment for the nature of humanity. As the Old Testament simply accepts the inevitability of death, so it seems to regard Genesis 3 with resignation, as though it would have happened sooner or later.

Between the later parts of the Old Testament and the New Testament, some schools of thought in Judaism came to the firm conclusion that God would not simply allow death to end the ethical/political/theological significance of human life. As the Wisdom of Solomon says, 'The souls of the righteous are in the hand of God, and no torment will ever touch them' (3:1); 'But the ungodly will be punished as their reasoning deserves, those who disregarded the righteous and rebelled against the Lord' (3:10). Within the Old Testament, this sentiment emerges clearly only at Daniel 12:2-4: 'Many of those who sleep in the dust of the earth shall awake, some to everlasting life, and some to shame and everlasting contempt....' The theological reasoning that ultimately issued in Pharisaic, then in rabbinic, Judaism held that God's justice could not be realised if the last word for the pious died in misery, or the wicked died in prosperous comfort; hence, there must be a further dimension to life, in which God redressed the imbalances that temporal life tolerated.

This conclusion was not by any means universal among the people of God before the cataclysmic destruction of the Temple. Several stories in the New Testament hinge on the dissent between Pharisees and
Sadducees on this point. The anecdote in Matt 22:23ff//Mk 12:18ff//Lk 20:27ff explicitly identifies the Sadducees as ‘those who say there is no resurrection’, and in Acts 23, Paul escapes by instigating a fracas between Sadducees and Pharisees, saying ‘Brothers, I am a Pharisee, a son of Pharisees. I am on trial concerning the hope of the resurrection of the dead.’ While the dubiety of the Sadducees on this point is attested, we have clues that bespeak other perspectives as well. Philo of Alexandria treats life after death as a strictly spiritual matter, in keeping with his Platonic/Stoicising tendencies, and Josephus’s presentations of the topic do not provide any coherent picture of the topic. The Pharisaic position ultimately prevailed, and may have been dominant at the time of Jesus, but the matter of life beyond death was undeniably contested in Jesus’ day.

On this topic, as on very many others, Jesus seems to have held a generally Pharisaic position. He offered few instructions on the character of death itself; Jesus in several sayings relativises the importance of death: ‘Do not fear those who kill the body but cannot kill the soul; rather fear him who can destroy both soul and body in hell’ (Matt 10:28), and the several occasions in John’s Gospel when Jesus indicates that death itself matters less than the glorious power of God to which it points (11:4, 12:33, 21:19; indeed, John associates ‘death’ and ‘glorification’ so forcefully that they almost become synonyms in his usage). The gospels present Jesus as affirming a general resurrection at a time of judgment, at which God would redress the injustices that mortality had permitted. Jesus, however, asserted a unique role for himself (or ‘the Son of Man’/‘Human Son’, which role ought not be simply conflated into Jesus’ own identity); those who join themselves to Jesus might be considered differently from those who were good or evil apart from Jesus. John’s Gospel characterises this salvific relation between Jesus’ followers and Jesus as ‘believing in him’, ‘believing in his name’. The synoptic gospels treat the effectual characteristic that joins believers to Jesus as ‘following’ or ‘being disciples’, which entails taking up the cross, and not being ashamed of Jesus. Whatever the specifics of how one attains this condition, Jesus promises that his followers/believers/family will be rescued from the danger of judgment. They will be treated as though they were righteous by virtue of their association with him, and thus need not fear death.

Jesus’ specific teachings about death, though, figure less forcefully than his bodily resurrection from death. The gospels present this as a fait accompli with little interpretive elaboration. The fact of Jesus’ victory over
death moves to centre stage in the apostolic exposition of the gospel, and particularly in Paul’s letters. Paul identifies Jesus’ resurrection as the pivotal theological datum in creation, the hinge of human existence. Paul locates Jesus’ resurrection as the ‘coming attractions’ anticipation of the general resurrection (‘Christ has been raised from the dead, the first fruits of those who have died’ 1 Cor 15:20), confirming and foreshadowing the premise that all will be raised to judgment. The resurrection to exalted life vindicates Jesus as righteous; then (Paul reasons) all who unite themselves by baptism with Jesus in his death, are assured that they will share in his resurrection.

Paul’s association of resurrection with vindication and righteousness entails his understanding that death is antithetical to righteousness; death becomes a manifestation of the spiritual effects of alienation from God, a sort of anti-sacrament (an outward and visible sign of an inward and spiritual lack of grace). Paul describes death as ‘the wages of sin’ (6:23), and James submits that ‘when desire has conceived, it gives birth to sin, and sin, when it is fully grown, gives birth to death’ (1:15). Once death is firmly associated with the power of misdirected desire, of unrighteousness, Paul can connect the dots that also associate death with Adam and disobedience. Moreover, as the specific ‘natural’-theological effect whose undoing demonstrates Jesus’ vindication and salvific power, Death sometimes figures as the consummate adversary, the harsh taskmaster who punishes the slaves of sin. In all these ways (and more), death symptomatises the underlying condition of alienation from God and God’s ways — and Paul understands Christ ultimately to have undone their power over the children of God (so also Hebrews 2:14f).

The Book of Revelation stands somewhat apart, since it discusses death in a comprehensively eschatological and (in many cases) post-mortal context, more concerned with a sort of poetic apocalyptic than with spelling out a schematic account of death’s relation to sin, resurrection, and so on. Still, the Revelation takes it for granted that human identity survives death, that the life after temporal death will entail judgment, and that Death is an adversary of God (though here it is only one among several opponents). In the concluding resolution of the book, John cites Isaiah 25:7f, ‘[God] will swallow up death forever. Then the Lord GOD will wipe away the tears from all faces’, repeating the refrain of God’s final annihilation of death.
To summarise the New Testament understanding of death, then: Death constitutes both an inevitable element of temporal life (life according to the flesh), and a representative figure for all the characteristics of temporal, physical life. Thus Death bears a defining connection to sin, not necessarily because sin causes death, but because both sin and death are universally manifest in temporal life. Everybody dies, and nobody’s perfect.

At this point it is worth commenting upon Scripture as read through the Augustinian and Lutheran doctrines of ‘original sin’ and ‘justification by faith’.

Whatever one may think of the Augustinian tradition of binding ‘original sin’ to biology, and to Adam’s primal transgression, Augustine must be correct to insist that it is futile and a distraction to look for some point in time at which an infant first becomes subject to sin. While in one sense, cute li’l babies do not belong to the same category as remorseless self-serving financiers, all are mortal, and all babies will sin sooner or later. Hence we may say with justification that all humans are subject to sin. Slice the problem some other way if you want to avoid the bugaboo of original sin, but arguably there is no intelligible way to parse temporal human-ness apart from mortality and sin.

The topic of ‘justification by faith’ matters so much for the Apostle Paul because it touches on the magnitude of God’s merciful grace; that for which an even-steven exchange is made, that which we can claim as our due, has nothing to do with grace. And by this logic, any effort we make to shore up our standing before God amounts to a repudiation of God’s forgiveness, God’s grace, and even Christ’s self-giving on the cross. Thus, necessarily, self-justification collaborates with Death. All share in lives coloured by sin; none of us can lay claim to attainments that would suffice to exculpate ourselves, and the persistent temptation to immunise ourselves to any possible criticism enmeshes us, once again, in the snares of Death.

As such, Death is both integral to the fullness of (temporal) humanity, and is an adversary, since it represents an unnecessary limitation. Death ‘wants’ to finalise our separation from God; it has never been able to do so, and in laying claim to the life of Jesus, Death overreached itself and its power was broken by the inextinguishable life of Jesus. Death’s power has not vanished, but from the Mount of the
Resurrection we can see Death’s brittleness. Strengthened by Christ’s encouragement and sustained by the Holy Spirit, we can wait-out death.

To what does all this add up, with regard to a biblical practice of the *ars moriendi*?

First, that although the Christian hope affirms that Death has been broken, Death persists as an element in every human life. Death is not a failure of discipleship, nor an unjust imposi**to**n. We rightly grieve at death, for we who remain are the poorer without our brothers’ and sisters’ presence among us. This grief, however, takes its place within a broader frame in which death does not bring our relationships to a terminus, but interrupts what will be rewoven. (Consider below, Jeremy Taylor’s words on appropriate attitudes in mourning.) Indeed, unwelcome as a person’s death itself may be, it marks the hinge which opens onto the fullness of life in God’s presence, which we confidently hope to share. We live in Death’s shadow with mindfulness, but without fretfulness; with earnestness, but not without joy.

Second, the inevitability of death does not justify carelessness in how one lives. We will be held accountable for the use to which we put our days and nights, as for our wealth, strength, intelligence, and other resources. A biblical *ars moriendi* rejoices in the on-going opportunity to shape lives that bespeak Christ’s grace, and accepts the limitation on this opportunity.

Third, while the Bible offers various characterisations of what will ensue after death, we have good reason not to take any of them as precise specifications of Heaven, or Hell, or any other state. The sheer diversity of those accounts militates against supposing any one of them is more concretely applicable than others. We are promised that resurrection life is in some sense bodily, but ‘bodily’ in a sense we cannot yet ascertain. We have been taught that those who have understood and sought God’s approval will flourish, and that those who defy the ways of life, truth, grace and hope will subsist in their alienation from divine blessings. Whatever pictures one associates with those assurances, they suffice to underscore the worth of directing our lives toward a death congruent with our affirmations and our hope.

We may sum up a biblical *ars moriendi* as the enacted acceptance of unearned justification. We practice hopeful generosity, and renounce the fearfulness that withholds trust from God; we practice humility, and
renounce the presumption that we have escaped the effects of mortal limitations on our understanding; we practise solidarity with the breadth of our sisters and brothers, and renounce the enmity that strives to separate us from one another. In harmonious unity, disinterested respect for others, and confident grace we adorn lives given for God's glory, and accept death as a completion of that offering.
Continuity and change across the ages in Christian approaches to death

In one obvious sense there is a strong continuity to be observed in Christian approaches to death that is captured well in the familiar hymn of the American poet, John Greenleaf Whittier (d. 1892), *Immortal Love for ever full*. For the Christian life must begin and end in Christ:

Through him the first fond prayers are said  
Our lips of childhood frame;  
The last low whispers of our dead  
Are burdened with his name.

In actual practice, though, there have been huge changes in approach over the course of the centuries, not least in Scotland itself. Thus in late medieval Scotland, as in the rest of Europe, one might almost speak of a culture obsessed with death and its consequences. Not only was anointing of the body in preparation for death the norm, so too was the ritual confession that went with it: the desire to be shriven of one’s sins, not least those deemed ‘mortal,’ that is carrying the consequences of dispatch to hell unless repented of in time. Even then, the so-called ‘temporal’ consequences remained; the need to purge the punishment due to such sins, to be suffered in Purgatory unless steps were already afoot to ameliorate such consequences. Masses could be said on one’s behalf or, even better, churches or other charitable institutions founded that would undertake such intercession as part of their wider role. Many a collegiate church, hospital or alms house had its origins in this way.

All that went with the Reformation but, it may be suggested, something equally lopsided took its place. Instead of the social interdependency that characterized the medieval view (one needed to rely of others’ prayers and actions), sole emphasis was now placed on individuals themselves and their own personal certainty of salvation. Justified by faith alone, they needed no further actions prior to or in death itself. So funerals were abolished, and no prayers said as the body was laid in the grave. Prayers could be said at home but even here there was no requirement that this should be done and in any case they must make no reference to the individual who has just died, as though their salvation were somehow in doubt.

Gradually from the mid nineteenth century onwards Presbyterian practice in Scotland began to change, partly under the influence of the
now more prominent Episcopalians. Not that the influence was all one way. No less than three Scots were to become Archbishop of Canterbury during the past two centuries, among them Thomas Randall Davidson (d. 1930) and Cosmo Gordon Lang (d.1945). The third may be used to illustrate the rather different practices of the nineteenth century. Archibald Campbell Tait (d. 1882) was to lose five of his children to scarlet fever while he was Dean of Carlisle. Lang, as his biographer, records how each of the children prepared for death by expectantly dressing in the robes of heaven, making for themselves angel-like robes and garlands, and so easing for their parents their sense of future loss.

In the latter part of the twentieth century patterns changed again. Cremation only slowly displaced burial but by the late twentieth century it had become the norm and with it more secular funerals that in turn had a major impact even on those still conducted in church. Increasingly, addresses on such occasions took the pattern of eulogies of the dead, with the earlier emphasis on the more awesome aspects of a sinner encountering his Creator now largely forgotten. Not that this was the only change. Perhaps the most obvious was the way in which most now reached the ‘threescore and ten’ of which the Bible had spoken (Psalm 90.10). In previous generations the loss of one or more children in their early years had been certain, while the death of women in pregnancy was also all too common. While men escaped the latter hazard, long hours of labour, poor working conditions, and war often achieved a similar result.

In trying to decide the most appropriate approach in our own day, we have of course the Bible and the Christian tradition upon which to draw but this needs to be nuanced even in respect of the Bible in terms of the different circumstances of our own day. Thus, for example, while it is probably because of his arduous present circumstances that Paul speaks of welcoming death (Phil. 1.21-4) – a pattern repeated in the lives of numerous subsequent generations - in the modern western world that longing for death is likely only to be found in the very old or seriously ill. Again, probably because of expectation of imminence of the end, Scripture has little to say about the nature of the after-life. Indeed, for some contemporary scholars, the Bible enjoins us to think exclusively of resurrection at the end of time. But the hints to the contrary eventually led the Church along different lines – to a purgatory, heaven and hell running alongside our own world, and, if (as indicated above) not all the proposed details would win assent from us today, the questions they posed are still pertinent in determining how best to approach our own death and that of those we love. Do we face judgment at death? If so, however much we
are supported by the grace of Christ, are we still fundamentally alone or also aided by the whole community of faith and its prayers? How should we view the body we have left, as integral to the new person that we shall then be or not? Or is it more a case of the history that it enshrined now being taken up into a more glorious identity? Grosvenor Essay 6, *Death and Resurrection: New Life in Christ*, offers reflection on these issues.

Here our concern is rather with how faith can help us approach the inevitability of our own death, the dying among us and those who mourn. It is a commonplace to observe that death has now replaced sex as the great unmentionable. These days many Christians appear reluctant to talk about death, even with those who are now approaching their end. This is not to say that the other extreme is correct, like some in the early Church who actively sought their own martyrdom, or Christians who counsel mourners that they must rejoice because their beloved is now with Christ. Christian teaching about death and afterlife does not strongly prevail culturally. Belief in reincarnation has gained strength in the West, as have views that no soul, mind or spirit survives death, and that only the body has continued existence through the decomposing and regenerating processes of nature. It is hard to imagine children of today’s generation having quite the confidence of those of Archbishop Tait. Significantly, the contemporary poet and priest, David Scott, suggests, for the parents at least, a more tortured reality:

... and at their prayers each day  
in a borrowed house, they tested  
the Bible texts against a silent nursery.  
(concluding lines of *Dean Tait*)

The proportion of those who die intestate suggests that little thought is given to our own deaths in our own society, perhaps due to fearful evasion: government estimates suggest that sixty per cent of Scots die without having made a will.

Yet Christianity has a great tradition of living in the light of death upon which we can still draw. Throughout the medieval period individuals were buried in the robes of their office, not as a symbol of pride (who could see them thus?) but as a reminder that as they lived, so must they enter eternity, as good or bad priest, good or bad king, or whatever. In the later middle ages, this then took a more public form in what are known as cadaver, transi- or *memento mori* tombs. A particularly splendid example is that of Archbishop Chichele (d. 1443) in Canterbury Cathedral. Erected
well before his death in 1426, above he is made to recline in the stately robes of his office as an erstwhile archbishop of Canterbury while below he is reduced to a mere skeleton, a reminder to all who pass by of the fate that awaits them also. In case the sculpted message proved insufficient, words were added: ‘I was a pauper-born, then to primate raised. Now I am cut down, and served up for worms. Behold my grave.’

As part of Counter-Reformation piety the practice then arose of some, including kings, having skulls on their desk as a permanent reminder of their ultimate destiny, of sitting under judgment on how their lives had been conducted. Even today a visit to any major art collection and we will see paintings inspired by that same practice, as it was projected back into the lives of saints such as Mary Magdalene and Jerome. Too extreme by any modern standard, nonetheless the same essential truth is found in the art of dying’s reflective literature that was produced over several centuries by both Catholic and Protestant, and can be seen to culminate in the more balanced writings of a near contemporary of the extreme practices just mentioned: in the work of the seventeenth century Anglican divine, Jeremy Taylor who balanced reflections on *The Rule and Exercise of Holy Living* with the following year *The Rule and Exercise of Holy Dying*, like Chichele a full sixteen years before his own death. It is to the content of these writings that we now turn.
Bishop Jeremy Taylor, *The Rule and Exercises of Holy Dying* (1651)

While the art of dying is ancient and far-reaching, the term ‘The Art of Dying’ is also the title of two Latin texts, the *Ars moriendi*, which date from the early fifteenth century. These texts were written to provide advice on how to die well according to the teachings of the medieval Church. They contain images of demons preying upon a person’s soul at the time of death, and encouragement on how to resist them and hold on to faith. The first of these texts was written in 1415 by an anonymous Dominican friar, probably at the request of the Council of Constance (1414-1418), and in the aftermath of the horrors of the Black Death.

Art of dying literature became immensely popular throughout Western Europe. It offered counsel and consolation for the dying, including on how to resist despair, impatience, spiritual pride or avarice, and encouragement to remember the redemptive power of Christ’s love. It also offered guidance to those present at the deathbed, and prayers that could be said for the dying.

Jeremy Taylor’s work, *The Rule and Exercises of Holy Dying*, is a development, and indeed is often regarded as the climax, of this tradition of consolatory death literature.

For almost four centuries, Taylor’s *Holy Dying*, has been loved and admired by people as diverse as John Wesley, S. T. Coleridge and Edmund Gosse. It remains, perhaps, the quintessential statement on holy dying and the pastoral of the dying and the bereaved within the Anglican tradition. More even than that, with its slightly earlier companion piece on *Holy Living* (1650), *Holy Dying* remains a Christian classic of both literature and devotional theology. Jeremy Taylor, who eventually became Bishop of Down and Connor in Ireland after the Restoration, acquired in his life-time a reputation as a writer and preacher, though not, perhaps as a great theologian. Throughout his book on the ‘art’ of dying, and in gentle and lucid prose which is scattered throughout with classical and biblical allusions and which has earned him the title of ‘Shakespeare of Divines’, Taylor exercises a rule of reason and moderation in all things that remains persuasive even to the modern reader. Deserving still to be read, he bids us follow a ‘quiet and disentangled life’ which is governed by patience and charity and without fear of death.

Though learned, Taylor was neither speculative nor scientific in his thinking. Yet in *Holy Dying* he gently seeks, with poetic insight, to answer
the question ‘what is death?’. Adam in the Garden of Eden, Taylor writes, ‘when he fell then he began to die’, which is not to suggest that even in Paradise his term of life was unlimited. Rather, as life is known within a quality of living, so ‘death is not an action, but a whole state and a condition’, and thus, for Adam: ‘his first state was, and should have been (so long as it lasted) a happy duration; his second, was a daily and miserable change; and this was the dying properly.’ The final moment when the soul and body separate, the moment of physical death is, for Taylor, ‘but accidental’, while during a life well lived and which endures whatever suffering may be sent to us, ‘God dresses us for heaven.’ In short, if our life, after the Fall, is a series of ‘little deaths’, then finally we should have no fear as God in Christ has overcome death.

And so if holy living is characterized by patience through sorrows as well as joys, then holy dying is the preparation for the life of the resurrection lived with the four great qualities of patience, contentedness, truth and diligence. There is not a hint of morbidity in Taylor’s prose, but rather he is realistic, balanced and always moderate without false piety. His many examples drawn from literature are taken as easily from Greek and Latin literature as from the Bible – and indeed, with particular reference to King David, he remarks that often the ‘actions of holy persons in Scripture are not always good precedents’ for our own mode of behaviour. It is better, sometimes and in the spirit of Taylor’s late Renaissance humanism, to refer to Socrates or Virgil in his poetry even in preference to the Bible.

The latter part of his book is addressed particularly not to all of us who live our earthly lives under the shadow of mortality, but to those who care for the dying, the great task and privilege of the minister or priest being to ‘dress a soul for funeral.’ For Taylor, the funeral liturgy is clearly concerned, above all, with the passage of a soul from this life to the next, and those of us who are left to mourn are bidden, as always in our conduct of life, to do so with moderation and within the bounds of reason. For, after all, he reminds us with gentle charity and understanding, for the Christian despair is unreasonable, and therefore there should neither be ‘grief that is immoderate and unreasonable’, but rather, ‘when thou hast wept awhile, compose the body to burial.’ The focus is given entirely to the one who is dying and to the soul on its journey from this world to the next, and any other preoccupation is, in the end, for Taylor, a sign of immoderate self-concern. Furthermore, once the body is laid in the grave, then Taylor is ready to turn back to life with a gentle and simple image that denies the ostentation of grandiose monuments: ‘some flowers
sprinkled on my grave would do well and comely…. and a soft shower to turn those flowers into a springing memory or a fair rehearsal.’

Before death occurs, the clergy are to be ‘ministers of reconciliation’, ready to offer communion to the dying, but only within the ‘use of reason’. There are, clearly, circumstances when the sacrament is physically inappropriate, and these are to be recognized and accepted within the love of God. Rather, if there is a pastoral concern for repentance and to ‘provoke a drowsy conscience to scrutiny’ before death, at the same time those who wait at the death-bed should never be judgemental – a clear reference to insistent demands for death-bed repentance after a life that has been, it may be, ill spent. Rather, says Taylor, ‘let us lay our hand upon our mouth, and adore the mysteries of the Divine Wisdom and providence,’ praying for rest and pardon for the departing spirit.

In his style, as in his theology, Jeremy Taylor, breathes a spirit of Anglicanism at its purest. As a disciple of Archbishop Laud, his was a spirituality centred upon the Eucharist, the sacraments and the discipline of prayer. At the same time his demands are always governed by moderation and reason, and a genuine sense of the richness and joy of life. Quoting Antisthenes, he remarks that ‘it is not the happy death, but the happy life, that makes man happy.’ Death is something that is more to be found in the life of ‘idleness and vice’ than in the passage from one condition to another that is made easy by Christ. And as we reflect upon our own liturgical provision for the dying, for death and for those who mourn, we would do well to return to Taylor’s far from unsympathetic call for moderation in grief, and his concentration upon those who are moving through death and upon the state of their souls. And when all is said and done, a few spring flowers on the grave, watered by rain and a sign of the life that endures, will be a better monument than any great tomb or elaborate memorial stone.
Beginning to learn the art of dying

The Medieval tradition of the art of dying focused most strongly on the time of a person’s death; on the death-bed fears and needs of those who are dying and of their friends and families. In the Christian West, in the centuries following the Reformation, people were instructed to learn the art of dying whilst they were still in good health, and not to leave it to the hour of their death. As Taylor wrote:

it is a great art to die well, and to be learned by men in health, by them that can discourse and consider, by those whose understanding and acts of reason are not abated with fear or pains - and as the greatest part of death is passed by the preceding years of our life, so also in those years are the greatest preparations to it; and he that prepares not for death before his last sickness, is like him that begins to study philosophy when he is going to dispute publicly in the faculty. All that a sick and dying man can do is but to exercise those virtues which he liefore acquired, and to perfect that repentance which was begun more early.\(^{10}\)

Or, as Amy Hardie, film-maker in residence to Strathcarron hospice, has put it, ‘it’s great if, before you get to that stage, you’ve done a lot of work on yourself’.\(^{11}\)

Since the nineteenth century, we have increasingly medicalised the concept of dying well, and have confined it again to a person’s last illness and perhaps even to their very final moments. We have retained perhaps little awareness that dying may be considered an art to be learned throughout life.

Nevertheless, dying and receiving life are central motifs of Christian worship and discipleship, and something of this pattern rubs off on us. In baptism we die and rise in Christ, put off the old and take on the new. We are taught to take up our cross daily. At the Eucharist, we remember the passion and death of Christ, and partake of his body so that we are made into his body, our life established by his death.\(^{12}\) Regular daily prayers, though we may not be regular in saying them, treat every sleep as a dying, and every waking as a rising. At evening and night prayer we pray that God would let us depart in peace, and commend our spirit in to God’s hands. In the morning we give God thanks ‘for bringing us out of the
shadow of night into the light of morning’,\textsuperscript{13} or use similar words to rise to the dawning of the new day. Our major annual observances also lead us to reflect upon mortality and life-giving death: particularly Lent, Holy Week and Easter, when we remember Christ’s passion, death and resurrection - but also All Saints, All Souls, Remembrance Sunday, and saints days, when we remember those who have died before us.

Moreover, Christianity casts most spiritual practice as a kind of dying. We die to pride when we ask for forgiveness, we die to grievances when we forgive others, we die to security when we take risks, we die to fear when we love, we die to possessiveness over people we love when we let them go, and so on.

All these mini-deaths are echoes of our baptism. If we continually die in Christian discipleship, we approach our physical deaths as people who are continually being transformed. This is why we ask God to ‘grant us to die daily to sin, that we may evermore live with [Christ] in the joy of his risen life.’\textsuperscript{14} And this is why we might say at home before a funeral ‘We shall not die, but we shall be changed…The perishable shall be clothed with the imperishable, and the mortal must be clothed with immortality.’\textsuperscript{15} Even if our death is not good physically, we hope that it will be the passage to our final transformation.\textsuperscript{16}

However, the process of clothing our mortal bodies with immortality is not seamless. We fear the unknown on this side of death, whatever hope we might attach to the hereafter. While the central pattern of dying and rising filters through our liturgies and spiritual practices, it does not follow that most Christians find a strong connection between spiritually and physically dying, so as to feel prepared for the latter.

In Part 2 we turn to consider the realities of facing our physical death, and the challenges of finding healing or ‘wholeness’ of body, soul and spirit as we die.
Part 2

Living with Dying

Lessons from the Hospice Movement

When her mother was slowly dying in hospital, it seemed to Karen Armstrong that death was ‘taboo’ even there: ‘when we go to hospital we are meant to get better and meet government targets’, she writes, ‘we are not supposed to die there anymore’. We have ‘banished death’ from modern society, she says, pushing it ‘off-stage in hospices and nursing homes’.  

Armstrong is right that Western healthcare too often conveys a sense that death must be resisted, postponed, or avoided. However, hospices try to remedy this problem.

Hospice care extends to homes, hospitals and nursing homes, and involves an explicit philosophy that death is neither to be postponed nor hastened. Hospices are proactive in learning about dying, and they take educational programmes to schools and elsewhere. Where churches are developing their understanding of ‘dying well’, they are doing so most extensively in conjunction with hospices and palliative research.

The concept of hospice has been evolving since the 11th century CE, when, at the time of the Crusades, hospices were founded as places of hospitality for the sick, wounded, or dying, as well as for travellers and pilgrims. An emphasis on hospitality remains central to the modern hospice movement, which owes much of its vision and impetus to Dame Cicely Saunders and her founding of St Christopher’s Hospice in London in 1967. Saunders describes the hospice as: ‘a place of meeting. Physical and spiritual, doing and accepting, giving and receiving, all have to be brought together….The dying need the community, its help and fellowship….The community needs the dying to make it think of eternal issues and to make it listen’.

By listening attentively - she tape-recorded conversations with hundreds of patients at the end of their lives - Saunders developed the notion of ‘total pain’ to convey pain’s physical, emotional, social and spiritual components. Palliative care treats pain on all of these levels, and aims at healing rather than cure (which is the removal of disease). Healing is seen as possible even in death, in a way that is wholly
consonant with the Christian hope of transformation. As a writer on palliative care, ageing and spirituality puts it: ‘Christians believe that even in death there is healing. ... Healing...can occur in the presence of disease, as the person grows into wholeness of body, mind and spirit’.  

Contemporaries of Saunders who developed similar work in the 1960s and 70s included Florence Wald and Elisabeth Kübler-Ross, both operating in the United States. There are now more than 8000 hospices and palliative care units around the world in over 100 countries, and also a drive to bring palliative care increasingly in to primary care, that is, into people’s homes, community nursing and GP practice. An extensive review of palliative care services in Scotland was undertaken by Audit Scotland in Aug 2008. There are thirteen voluntary hospices, two national hospices and eleven NHS specialist units in Scotland.

Saunders’ Christian faith was a fundamental motivating factor in her care for the dying. At the same time, she was clear that a hospice is for people of all faiths and none, and that people’s spiritual needs are not necessarily to be defined by religion. In hospice settings (speaking in very general terms), ‘religion’ is understood in terms of a set of beliefs or the following of liturgical practice and use of ritual; ‘spirituality’ is understood in terms of an integrated inner life. ‘Some people are religious and not spiritual’, says a Christian hospice chaplain in the US. ‘Some are spiritual and not religious: some are both. Intellectual assent to a codified set of doctrines does not provide one with the spiritual resources needed to cope with many of the challenges of life and death.’ Religion can also be a ‘double-edged sword’, he adds: ‘For those who believe that if they keep praying they will get well and then do not, their faith can be shattered because it was not deeply grounded in the first place.’

Hospice care is ‘person-centered’: patients define what they mean by a ‘good death’, and the care-team help them to achieve it. Religious frameworks are therefore not imposed upon patients who are not religious. Hospice chaplaincy teams are increasingly multi-faith, but chaplains recognize that they may not be asked to share the teachings and practices of their own faith. It is also the duty of the whole team, and not only of Chaplains, to offer spiritual care. But chaplains are called upon to provide particular expertise, such as conducting a ceremony (for example a marriage, or a naming, blessing or baptism for a dying baby), listening to a final confession or testimony of faith, or creating a space for family and personal reconciliation.
Palliative care teams recognise that un-addressed spiritual distress can lead to poorly controlled symptoms, an increased need for pain relief, and an unquiet death. One of the many fruits of hospice work is the wealth of research into the nature of spiritual health, which helps to convey what it is like to be dying, what are the lowest points, and what brings healing.

**Spiritual health and meaning**

Hospice care teams gauge a patient’s spiritual health by her ability to find meaning. They take the view that people ‘can suffer almost anything if there is meaning attached to it’, and will often quote Viktor Frankl: ‘Man is not destroyed by suffering, he is destroyed by suffering without meaning’. They also observe that when patients are able to tell stories about their lives, or to express themselves creatively, this can reduce the need for pain relief. For this reason, hospices place great value on art and music therapies, ethnography and film.

It is worth exploring what is of value in this creative work, for it may be that something less elusive than meaning is at stake.

When people tell stories, meaning-making is involved. Arthur Frank explains, in his seminal work on illness, *The Wounded Storyteller*, that: ‘Stories have to repair the damage that illness has done to the ill person’s sense of where she is in life, and where she may be going. Stories are a way of redrawing maps and finding new destinations’. Stories are also a way of summing up one’s life and so of finding it, sometimes for the first time, or with sufficient completeness to then be able to let it go. Marie de Hennezel, a psychologist in a palliative care unit in Paris, describes an encounter with Dominique, who cannot bear being ‘pinned in bed and waiting to die’ (p. 34). Marie asks her if she has ‘finished living’, or if anything is ‘tethering’ her to life (p. 35). Dominique replies that ‘there are so many things still unsettled’. Marie invites her to tell her about them, and she responds with her life-story. She ends by saying ‘So this is all me...This is my life’. ‘It’s your life’, Marie reiterates, with the emphasis on *your*. Marie later writes that ‘the silence that follows holds neither lament nor discomfort. Dominique has fallen asleep, and on her face there is a tiny smile of triumph’.

Was ‘meaning’ the crucial quality in Dominique’s story? It depends what we mean by ‘meaning’ which will vary according to context. What does Abigail Rian Evans have in mind when she observes that: ‘When
pain is under control, there is more acceptance of the diagnosis, and thus one can find meaning in one’s death’ (p. 274)? The pattern seems to be that when pain is controlled, people are able to participate in what is happening to them. Feeling engaged, and empowered, and able to connect with people again, may well be more important than the anyway usually impossible task of establishing meaning. For example, François Mitterrand, when dying from cancer, wrote of Maria de Hennezel’s work: ‘The mystery of existence and death is not solved, but it is fully experienced’.  

The healing power of stories to re-plot connections may have less to do with finding meaning, and more to do with shifting the ill person from passivity to activity, and out of isolation. To quote Arthur Frank again: ‘The ill person who turns illness into story transforms fate into experience; the disease that sets the body apart from others becomes, in the story, the common bond of suffering that joins bodies in their shared vulnerability’. This insight fits with Cicely Saunders’ insight that those who are dying bring gifts which we receive through listening. It also fits with patients’ own accounts of good spiritual care, viz., the practice of being listened to, which engages ‘their essential ‘inner self’ rather than their weakening physical ‘outer self’.  

Reference to an ‘inner self’ echoes Pauline language, and returns us to the pattern of on-going transformation, and the art of dying. We ‘do not lose heart’, wrote Paul. ‘Though our outer nature is wasting away, our inner nature is being renewed day by day’ (II Corinthians 4.16). Paul looked forward to the completion of this transformation on the other side of death. Not everyone, and not all Christians, take a post-mortem view of inner growth. Some regard spiritual development when dying as pertinent only for the here and now, and for what can be passed on to others. Either way, an emphasis on the inner person is empowering when one’s outer person is fading, and furthermore, people come to feel that the most important part of them is growing. In this way, they may feel accomplished in their dying. ‘Death can cause a human being to become what he or she was called to become’, writes Mitterrand; ‘it can be, in the fullest sense of the word, an accomplishment’ (de Hennezel, p. ix).
Dementia

The possibilities for participation and empowerment may seem hard to envisage where people have dementia. However, person-centred care approaches show that opportunities to participate in decisions, to re-narrate one’s story, to take risks (where risk is seen as something to be facilitated rather than ‘managed’ in a restricting sense), to remain in touch socially, and take part in community life, are key in enhancing well-being for people who have a diagnosis of dementia. When we restrict the activities and opportunities of people living with dementia, from fear that they may come to harm, we can compromise other aspects of their wellbeing, and cause them ‘silent harms’ that ‘weaken their sense of self’. For example, if we stop someone from going shopping by doing the shopping for them, or if we move a bed downstairs, and likely therefore introduce a commode, and so inhibit the opportunity for social gatherings at home, we undermine rather than help to enhance a person’s sense of self.

Christine Bryden writes about living with dementia, while she is between stages 1 and 2 of Alzheimer’s. She refers to her ‘inner self’ as an entity that will continue as the disease progresses. While explaining that people in stage 2 ‘need even more patience as well as subtle help’, she says ‘please don’t take over.’ She anticipates stage 3: ‘Thankfully I’m not here yet, and I’m not sure how I’ll communicate with you from an “insider’s perspective”, but I’ll try.’

Dementia does, as it progresses, take away many (not all) opportunities to make decisions or to communicate, but we are learning more about ways of maintaining contact with people as dementia takes them further away from us. For example, we are aware of the benefits of music, and also of touch, including of treatments that mirror how we care for youngsters and infants, given the ways in which dementia returns people to infant-like states. However, we cannot know what is going on internally for people. We cannot fully know this of anyone, still less of people with dementia. ‘But am I really still me?’, Christine Bryden asks, as her Alzheimer’s deepens. She does not say that the disease wipes out her mind. Rather she says that is ‘unwraps me, opens up the treasures of what lies within my multifold personality’. ‘As I unfold before God’, she writes, ‘I can feel safe as each layer is gently opened out’. Bryden gives us one answer to the question of whether our inner selves can grow if we have a form of dementia. She sees her Alzheimer’s as enabling a kind of
flowering: ‘The fullness of who I once was will be seen in the simplicity of who I am within’.  

‘A person with Alzheimer’s disease/dementia has spiritual depths as all people do and may grow closer to the divine as s/he becomes less attached to the reality defined in this world,’ writes Elizabeth Cochran, who has developed a person-centred approach to caring for people with Alzheimer’s. She offers the following advice: ‘Do not be put off by the loss of memory; effects can be created in the moment that may add to your person’s inner peace in ways no outsider will ever know. Spiritual feeling can continue even after communication is marred. Church, spiritual rituals and prayers can sometimes be helpful in sustaining these feelings.’ Indeed, those living with dementia find that habits, rituals, and prayers learned in youth, remain in the memory far longer than do resources that have been acquired in later life. Carers and clergy find that people with dementia often remember prayers, and even take on the saying of prayers they would not have uttered when in full health, such as the prayer of consecration!

Cochran goes on to say that for others, ‘ritual is meaningless and a simple expression of feelings by someone who cares can be enough. Verbal and non-verbal communication of love is a powerful tool.’ People with dementia ‘rise to love’, as a Church of Scotland minister has put it, speaking from her experience of working with Faith in Older People, and of caring for her father who had Alzheimer’s. The tough demands of dementia recall us to community, and to our power and responsibility to keep faith with, in and for one another.
Assisted Dying

Loss of autonomy, and loss of control in relation to our end-of-life care, alongside fear of intolerable suffering, are major points of concern in debates over assisted suicide and other forms of assisted dying.

In assisted suicide, the patient is the last causal actor; in euthanasia the doctor or other agent is. Euthanasia has been legalized in the Netherlands, Belgium (since 2002) and Luxembourg (since 2009); assisted Suicide in Switzerland (since 1942) and in the US states of Washington, Oregon (in the 1990s). A court decision in Montana in 2009 created a defence for a physician who may be prosecuted for assisting a suicide.

An Assisted Suicide (Scotland) Bill comes before the Scottish Parliament in 2013. The proposal is for new legislation to permit assisted suicide for those who voluntarily request it, and who have either a ‘terminal illness’ or a ‘terminal condition’ and find their life intolerable. To qualify, a person must be aged over 16, and have the mental capacity to make an informed decision (using the definition in the Adults with Incapacity (Scotland) Act, 2001. A proposal for consultation was published by Margo MacDonald MSP on 23 January 2012 http://www.scottish.parliament.uk/parliamentarybusiness/Bills/46127.aspx, and it is this that has now secured sufficient support for a bill to be produced.

A previous bill, which included provision for voluntary euthanasia, was defeated in 2010, although a poll conducted at the time suggested that 77% of adult Scots backed the proposal. The Assisted Suicide (Scotland) Bill (2013) Bill differs from the End of Life Assistance (Scotland) Bill (2010) in some significant ways. The 2013 Bill:

1. does not include voluntary euthanasia
2. has seemingly narrower eligibility criteria: a person’s disability and inability to live independently are not sufficient to qualify for assisted suicide
3. does not require the presence or assistance of medical staff at the suicide
4. does not stipulate the need for assessment by a psychiatrist
5. does not require that written requests be witnessed.
In England and Wales, within the same time-frame, a consultation is being run by the All Parliamentary Group (APPG) on Choice at the End of Life, in partnership with a non-profit campaigning organisation, Dignity in Dying. This group of MPs and Peers aim to promote greater patient choice at the end of life, particularly over where, when and how one dies: ‘The group believes that provided sufficient legal safeguards are in place, mentally competent terminally ill adults should have the right to an assisted death’.  

Christian responses to assisted suicide and assisted dying proposals are divided. Age Scotland conducted a survey amongst members in which 89% of respondents who opposed legalising assisted suicide did so on religious grounds, whilst 50% of all respondents who said they were religious supported legalising assisted suicide for people with a terminal illness.

Compassion is a paramount factor in Christian support for assisted dying. Church of Scotland minister Scott McKenna argues that compassion trumps tradition; that if intolerable suffering is avoidable and the sufferer wishes to die, it is inhumane not to enable in law that such wishes be granted. He is concerned that churches come across as cold and paternalistic, and portray God as immune to human suffering, when they would deny a compassionate death to those crying out for a change in the law. While palliative care practitioners say that they can control 85-90% of pain, this does not offer reassurance, McKenna argues, regarding the 10-15% of pain that may be intolerable and unable to be relieved.

Alongside the compassionate concern to relieve suffering, is the recognition that those who seek and are granted the right to an assisted death, regain some of their life and are able to live their last days with greater peace and optimism. Therefore, enabling assisted deaths for those who are eligible and desire them, would seem to be a way of granting as good a death as possible in some individual cases. Since the 1990s, the Swiss Roman Catholic priest and theologian Hans Küng has argued that there should be no compulsion either to die or to live. Sitting at his brother’s bedside as organ after organ failed, he asked himself if his brother’s slow and painful death was really the will of God. He concluded that the all-merciful God, who gives men and women freedom and responsibility for their lives, also gives dying people the responsibility for making a conscientious decision about the manner and time of their deaths.
The cost of not legalising assisted death is clear, from the distressing nature of particular cases. The cost of legalisation is harder to measure or predict, in terms of the elderly, sick, mentally and physically disabled feeling or actually being vulnerable to pressures to choose to die, or not to be resuscitated. As Baroness Jane Campbell argues, following her own experience of medics assuming that she would not wish to be resuscitated, ‘We want help to live – not help to die’. Therefore, ranged against compassionate and autonomy-enhancing arguments in favour of assisted dying, are concerns for the most vulnerable members of society, and acknowledgement that disability organisations are against legalising assisted deaths.

Hence, Christian arguments against assisted dying include concern to protect people at their most vulnerable. They also incorporate concern for potential facilitators of assisted deaths, and the effect that a facilitator-role may have upon them. This is a particular issue in Scotland, where facilitators may not be trained physicians; The Assisted Suicide (Scotland) Bill is not a Physician-Assisted Suicide Bill, given the resistance by physicians in Scotland to become facilitators. These two concerns, for facilitators and for those who may feel pressured to die, were highlighted by Rowan Williams when he was Archbishop of Canterbury, and Williams’ arguments were incorporated into the ‘Submission to the End of Life Assistance (Scotland) Committee by the College of Bishops of the Scottish Episcopal Church’, when that Bill was proposed in 2010:

in talking about legislation guaranteeing to people a right to die, we can quite soon move to finding ourselves in the position where others are thereby deemed to have a responsibility to enable the person concerned to exercise that right. In addition, we might add that in talking of someone having a right to end their life, this can also swiftly move to talk of a person having a duty to end their life under particular circumstances. We are well aware of this move in other areas of legislation. ‘Your fathers fought for the right to vote in elections, you therefore have duty to exercise that right!’ Rights, responsibilities and duties intertwine in our consciousness in many ways, and important as it is to articulate rights, once these have been enshrined in legislation, and put formally into the public domain, the language of responsibility, and the language of duty can come swiftly in its wake.
Traditional religious attitudes about death underpin these arguments about protection. Religious people receiving end-of-life care sometimes say that God has a time for them to die,\textsuperscript{48} entailing that they will accept death but will not hasten it. At least two strains of thought inform such an attitude amongst Christians:

(i) that life is sacred and it is God who gives life and takes it away;
(ii) that we should not come in to God’s presence unsummoned, which is a Thomist argument against suicide.\textsuperscript{49}

In Christian thinking, we participate in our dying by giving up our spirit. This maps our dying on to the pattern of Jesus’ death. Jesus did not befriend death but surrendered to it when his time came, waiting until the conditions were fully ripe for death to yield life.

There is a significant corollary to this Christian acceptance of death, viz., that death is not viewed as a failure, as it often is within the medical profession. Chaplains or accompaniers help people to give up their spirit by helping them to resolve any concerns that are ‘tethering them to life’. They do not, like doctors, have a duty to preserve life. They accept the irretrievable process of dying, and, like midwives, help a person through this process when the right time comes.

From this acceptance of death it is possible to develop a theological argument in favour of assisted dying; for if we believe in life beyond this life, why insist on clinging on to this life through intolerable suffering? Scott McKenna holds that ‘it is an act of the deepest faith to let go and let go of pain, suffering and indignity in the sure knowledge that we live in God’.\textsuperscript{50}

The Bible expresses no explicit deprecation of suicide, and there is no straightforward way of inferring guidance from Scripture on suicide, let alone on assisted suicide in relation to medical care and intolerable suffering.

When the Bible narrates the deaths of Abimelech (an ‘assisted death’, since the wounded leader demanded that his armour-bearer kill him), Saul, Saul’s armour-bearer, Ahitophel, Zimri, and (arguably) Samson die, the narrator betrays no sign that their self-determined deaths warrant criticism. Judas’s suicide (in Matthew’s version of the story - Luke
simply has him stumble and explode) likewise receives no criticism, although the context in which his death is narrated could be seen as one of condemnation. These biblical characters, it should be noted, kill themselves under circumstances when they can not take life after death (and judgment) as given aspects of their faith in the God of Israel; they are hastening their departure to Sheol, but they do not seem to be transgressing the Torah. On the other hand, it should be noted that despite the abundance of crimes and misdemeanours set forth in the Old Testament, only rarely does anyone invoke the Torah explicitly as a criterion for distinguishing good from bad, mitzvah from averah. Hence, an argument from silence is not enough to propose that the Torah tolerates suicide; such a proposal would also require positive evidence.

When Paul ponders his ‘desire to depart and be with Christ’, he stops not because suicide would be a sin, but because he may still do some good for the Philippians. Paul’s case stands out because of his invocation of the topics of resurrection and judgment; were he to have known that suicide would bar him from entering the kingdom of heaven, it might seem peculiar that he not acknowledge it. To this extent, then, the evidence of the Bible suggests no opprobrium to suicide or to assisted suicide.

On the one hand, a ‘desire to depart’ is not equivalent to a desire to die by suicide; it can be consistent with awaiting death and eschewing suicide. On the other hand, consideration of Paul’s ‘desire to depart’ helps us to realise that Christian attitudes towards death are at least two-fold: death is not only our foe, but works on our side. This ambivalence renders our deliberations around assisted dying highly complex. Death is the enemy that negates life, but death has been met, its sting removed, and when the time is right we embrace death, or submit to it, and it becomes the gateway to new life.

We rightly keep such personifications of death out of medical and legal debate, where anyway intolerable suffering rather than death is seen as the ‘enemy’. More pertinent for public debate is another attitude towards death, which is also available to Christians: death as a natural process. This natural attitude sits well with environmental emphases, and is expressed in the growing trend for woodland burials, and in Celtic Christianity which emphasizes our bodies being enfolded by the earth. A natural view is also present in the palliative perspective of letting death run its course, and is apparent in some instances of hospice after-care, for example, in the case of a toddler being allowed to crawl over the body
and coffin of her deceased mother. But a natural view is complex in end-of-life debates because medical science has made new things possible. Our ability to prolong the most limited of lives obscures a sense of a natural end, and may also affect religious discernment of just when God is ‘calling us home’. In the meantime, where people’s hopes for euthanasia or assisted suicide are dashed, they live out prolonged suffering. In this unhappy state of affairs, it is some relief to find statistics showing that increase in the quality of palliative care correlates with decreases in the numbers of people opting for euthanasia or assisted suicide (in parts of the world where these are an option).
The time of death: Some pastoral considerations

The stories that need to be told

Everyone who reads this booklet will have their own perspective on dying and death. It is quite likely that the particular experience one has of dying and death will impact upon the viewpoint one holds regarding both.

As these words are being written three sad stories of death are in the national news. One is of Tony Nicklinson. He is a man who, following from a major stroke, developed what is called 'locked-in syndrome'. He became a household name in the summer of 2012 because he petitioned the Supreme Court to rule that any doctor who assisted his dying would not be liable to prosecution. He lost his case. Within twenty four hours he had communicated to his wife that he had lost his will to fight and to live on. He developed pneumonia and within a further week died.

Here was a situation where death was desired but where it could not be found except as the outcome of courtroom drama and the debates of law.

The second story is of a canoeing accident on Loch Gairloch in the Scottish north west highlands. Two men and four children were in a boat that capsized. One man was not found in the days following and was presumed drowned, his two children aged five and two though alive when found died very shortly afterwards, and another girl aged five died later.

It takes little imagination to recognize the utter grief of the relatives and friends of these two families, and the prospect that those closely concerned may find eventual recovery impossible.

The third story is of the murder of Keith Bennett murdered by Ian Brady, the moors murderer. Brady has never revealed where Keith's body was left. Keith’s mother went to her grave in August 2012 asking that a space be left near to her so that her son’s body might one day be placed close to hers.

The grief of the mother faced with a brutal murder was never requited, though others testified to the bravery of the life she lived.
Whatever principles one holds with regard to dying and death it is the personal experience one has that will largely determine the position one holds in respect of dying. This is inevitable, natural and is to be welcomed. The stories need to be told, retold and listened to.

What is a good death?

The above stories may lead us to say that there rarely is such a thing as a good death. This seems, at first sight, an easy and obvious thing to say. And yet there are clear exceptions to this statement.

In private correspondence with one of the authors of this Grosvenor Essay the pastoral theologian, Stephen Pattison, has written, ‘Deaths are all different and it is their unpredictability, universality yet particularity in the moment that is so disconcerting. Some people almost slip away, others go with enormous distress. We mostly don’t have the choice.’ Pattison’s comment encapsulates the enigma of death perfectly. What happens, just happens and elements of choice in it are often overtaken by events even if every attempt is made to honour an individual’s personal wishes.

One situation that can be spoken of is that of a widower who wished to die at home. He was very poorly. In his life he had been a very correct man; dignified, courteous and finely mannered. He had honoured his wife’s wish that she die at home and had faithfully nursed her in conjunction with the statutory services who offered excellent assistance along with friends and neighbours who also helped greatly. There were no children.

In hospital he indicated his wish, and the hospital concurred with his desire, to go home. He was helped to dress (yes, shirt, tie cufflinks and so on) and went home in a taxi. Within hours however his condition deteriorated and there was no choice for the authorities but to have to hospitalize him once more. To do otherwise would have resulted in the charge (implicit even if not actual) of neglect and of a ‘lack of care’. He died in hospital. His choice, his desire, could not be honoured.

Medical technology in the form of attached machines, and medical intervention in terms of pharmaceuticals and chemicals, coupled with an increasingly professional medical élite risk ambushing the ill person into a form of clinical – technological capture. In such a setting the person is no longer the person they were but becomes an annexe of wire
and tube sprouting machinery; a victim of chart and record analyses and memoranda; and a dispatch vehicle for liquid, powder and pill potions.

Many reading this booklet will have been at the bedside of dying relatives or friends. When the person who is dying is lucid and has a mind not affected either by his or her condition, or by pharmaceuticals, the conversation that takes place is generally mature, accepting and measured.

Honesty surrounds the situation and can be rendered ever more real not least when there are tears, distress or anxiety. Silence too can envelope the encounter between the one who is visiting and the person being visited. Silence is good when it is a part of the relationship between those present. It is unlikely to be good if either is fidgety, uncertain of what to say or do next, or embarrassed by the lack of words or noise.

In conversation with one of the authors of this essay a cleric has spoken of his father, firstly, and later his mother. He said that they had had a 'good death'. How had this come about? It seems that each had been secure Christian believers with well established faith. The two of them, along with other members of the family, were part of a tradition that regularly prayed for 'a holy and happy death, rest in paradise and peace at the last'. These are words from the Book of Common Prayer and are part of the normal vox populi of those in the high church or Anglo-catholic traditions of the Anglican Church. This theme was the subject of their own prayers. It was the subject of the prayers of others in the family. Both husband and wife seemed to have good deaths, in that there was calm, peace, honesty and silence around the bed as each of them in their own time, came to death. And for them, mercifully, they could have their last wishes honoured.

For there to be a good dying and a good death there must be genuine honesty spoken in a context of affection and concern. With honesty comes about the greater likelihood (one can never claim certainty) of personal accommodation with what is happening or has happened and from it find a personal peace in the dying or the death, whether of oneself or of another. It may well indeed be a peace that passes all understanding; most especially if it becomes a sharing in the loving heart of God for his people in the complexities of their lives and their dying.
But we have the enigma that there are some deaths and some dyings that simply are not good, and no amount of amelioration can make them so. The three stories from August 2012 at the start of this section each belong, in their different ways, in this category. At the very least, honesty demands that we must accept this inevitability.
Medical Angles on dying and giving care

Our bodies have an almost miraculous ability to counter disease and repair themselves, but eventually they all decline. Death faces us all eventually, and so how can we have a 'good death' and what do we mean by that term? For many it would mean living healthily for as long as possible and dying with dignity in a caring environment rather than dying alone, in pain and in impersonal surroundings.

Medical science has the potential either to help or to hinder the process. It is important, however, that technology does not take over and that medicine be viewed as one part of the general approach of caring for the person as a whole. In the past, medical practitioners were sometimes aloof, in control and uncommunicative and medicine was occasionally used to prolong life unnecessarily. Increasingly, however, many patients desire to be well informed about the causes and prognosis for their condition and to die at home if possible. They also often wish to have more control in their treatment and families often want to accompany them in their last journey and to be present at the end.

With a rapidly aging population, medicine has a huge potential to enhance the quality of life of the elderly in the many years leading up to death.

Several aspects of medical science are relevant here, namely:

(i) gerontology – the study of aging, which includes life extension science (the study of the slowing or reversing of the aging process in order to extend life span),
(ii) geriatrics – the health care of elderly people,
(iii) palliative care in a variety of locations such as a hospice – the relieving and preventing of suffering, including pain management and life support.

The Science of Aging

Gerontology includes the study of changes in people as they age, the biological causes and effects of aging, the interface between normal aging and age-related disease and the effects of an aging population on society (Macieira-Coelho, 2003).
A hundred years ago, life expectancy was shorter than now by about twenty-five years in the West: for instance, a quarter of children died of infection before the age of 5. Now, due to sanitation and medical care, life expectancy continues to increase at about two years per decade. The main cause of death is the aging process itself and the various associated diseases such as cancer or Alzheimer’s. At present we face a rapidly aging population: for instance, those over the age of 85 in USA are projected to rise from 5.3 million to 21 million by 2050.

Until about 1990 it was believed that aging was a fixed biological process with a built-in time of death and that the historical trend of increasing life expectancy would soon cease. But it is now clear that aging is not fixed and average life spans have not peaked; many gerontologists expect a maximum lifespan of 120 years, while others wonder whether it will continue indefinitely. A key aim of gerontology research, however, is to improve health near the end of life rather than achieve Methuselean ages.

Aging of our mortal body (or soma) is highly complicated with no simple cause. It affects cells, tissues and organs and involves multiple kinds of molecular and cellular damage, such as DNA mutation, protein damage, disruption of membranes by highly reactive molecules called free radicals, and imperfections in copying and translating genetic data. Aging thus represents the gradual accumulation of diverse forms of damage.

At the moment when the last breath is taken, most of the body’s cells are still alive and continue to carry out their metabolic functions, procuring nutrients and generating the energy to power the activities of proteins and other components. It is only a little later that the cells themselves die when they are starved of oxygen.

So how long can we and other complex organisms live and why do different species have different longevity? According to the Disposable Soma Theory (Kirkwood, 2008, 2010) our cell maintenance and repair systems evolved when life expectancy was half of today’s value and were balanced by environmental threats faced by our ancestors. Most animals die relatively young due to predation, infection or starvation: wild mice, for example, rarely live longer than a year, whereas bats are safer because they can fly, and freshwater hydra show no signs of aging at all.
The energy intake by an organism is used for a variety of purposes, such as maintaining the body in good order and at the appropriate temperature, growing, physical work and movement, reproduction, proof-reading the genetic code involved in synthesizing new proteins, powering the waste-disposal mechanisms that clear away molecular debris. The Disposable Soma Theory suggests that evolving species make a balance between investing in growth, reproduction and repair mechanisms, and so longer-lived animals have evolved better maintenance and repair systems. Furthermore, women live typically five or six years longer than men perhaps because their bodies evolved to repair damage more effectively since their health was more important for the success of reproduction.

The genes that extend life mostly govern the organism’s metabolism as it uses energy for various functions, but hundreds of genes are responsible for controlling the complex processes of cell maintenance and repair. The evidence is that our genes contribute about 25% to our individual life expectancy while other factors, such as life-style, nutrition, exercise and environment contribute 75%.

In future it is hoped to understand better many complex cell processes, so that we can try to limit or reverse the build-up of cell and organ damage that ultimately leads to disability and disease in the elderly. It may be possible to alter mechanisms (such as apoptosis or cell suicide) that cells use to counteract damage accumulation. For instance, in diseases such as stroke, suppressing apoptosis in less damaged tissue may reduce cell loss and aid recovery. Also, often cells stop dividing (senescence) when the caps (or telomeres) at the ends of chromosomes erode too much: the cells then lock themselves into a state where they can perform useful functions but not divide. Understanding the complex molecular circuitry involved in future may enable the locks to be unpicked and cell division to be safely restored to aging cells.

Many reputed anti-aging products are currently on the market, representing $50 billion of revenue per year in the USA, including skin care, hormone replacements, vitamins, dietary supplements and herbs, but none of them have been shown to be effective and many claims of anti-aging medicines have been strongly criticized by medical experts. For example, the life-span of worms, flies and mice have indeed been increased by reducing their calorie intake, but this has not been shown to work in humans, since we have a much longer-lived slow-burn biology without the same flexibility to alter our metabolism.
At present, an increase in life-span can often be produced by improving medical care, having a healthy diet, exercising and avoiding hazards such as smoking, overeating or over drinking. In future, it is expected that further lifespan increases will come from reducing the rate of aging damage in the body, replacing damaged tissues and organs by cloning, repairing or rejuvenating damaged cells and tissues with stem cells, and enhancing telomerase enzyme activity.

Health Care of the Elderly

Geriatrics focuses on the special needs of the elderly, since their bodies are different from those of younger adults (Isaacs, 1965). The decline of various organ systems shows up and the aim is to decrease the effects of normal aging and to treat any diseases that appear.

Typical examples of decline include: memory and reaction time begin to decline around age 70; for eyes, difficulty in focusing close objects begins in the 40s, susceptibility to glare increases and ability to see in dim light and detect moving targets decreases in the 50s, the ability to see fine detail decreases in the 70s; the maximum breathing capacity of the lungs decreases by 40% between age 20 and 80; the heart rate during strenuous exercise falls by 25% between ages 20 and 75; spinal discs separating vertebrae can slip, rupture or bulge; mineral loss in bones exceeds replacement at age 35, making them more brittle, and speeds up in women at menopause; the coatings of joints become thinner and allow bones to grind against one another causing pain that can be made worse by osteoarthritis; veins in legs can become enlarged when valves malfunction leading to swelling, pain or even blood clots.

Complications can arise from mild problems and multiple problems can compound the difficulties. Particular attention often needs to be taken with multiple medications and their interactions. Also the presentation of disease can often be vague or non-specific.

The major categories of impairment in the elderly include immobility, instability, incontinence and impaired intellect or memory. Impaired vision and hearing are also common and can lead to other problems such as depression, social isolation or difficulties in dealing with everyday issues.

Use of drugs can be more difficult with the elderly (Gidal, 2006). Changes in physiology such as dryness of mouth or gastrointestinal
absorption can be an issue, as can psychological problems such as memory loss impeding the reliable regulation of drug usage (Hutchison, 2006).

One of the most pressing issues is how to treat and prevent delirium, in which hospitalized patients become confused and disoriented by the uncertainty and confusion of a hospital stay. It can lead to a decline in health and other health complications. Treatment involves keeping the elderly patient mentally stimulated and providing specialized care.

Ethical issues arise when the elderly cannot make decisions due to long-term dementia or short-term delirium. Respecting a patient’s privacy while ensuring they receive the appropriate services and help needs sensitivity. Important too is ensuring that abuse does not occur, be it physical, financial, emotional or sexual.

Young People’s Care

The causes of death in children are substantially different from those in adults, and palliative care guidelines also differ. In 2010 in Scotland, there were 59,000 live births, and the deaths included 336 neonatal and post-neonatal, 218 infants, 42 ages 1-4 yrs, 24 ages 5-9 yrs, and 24 ages 10-14. The leading causes of death among young children in the UK (55% in newborn babies) are: premature birth complications (36%), congenital abnormalities (26%), birth asphyxia (7%), injuries (4%) and pneumonia (3%). More children under the age of five die in the UK than in any other country in Western Europe.

Several groups have worked to coordinate services better:

(i) Children and Young People’s Services MKN
(a Managed Clinical Network is a new way of delivering services to patients, focusing on services and patients, involving clinical staff working across boundaries)
(ii) CATSCAN – Children and Teenagers Scottish Cancer Network was set up in November 2007 to improve quality of cancer services to children and their families.
(iii) SCYPPCN – Scottish Children and Young People’s Care Network – has a vision of well coordinated services and well informed families able to exercise real choice in place of care (home, hospital or hospice), place of death and bereavement care. The aim is for every
child or young person in Scotland to have access to sustainable, holistic, family-centred and high quality palliative care and support.

(iii) ACT (Association for Children’s Palliative Care) views palliative care as an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancing the quality of life for the child or young person and supporting the family - it includes management of distressing symptoms, providing short breaks and care through death and bereavement. Short breaks provide the child or young person with an opportunity to enjoy social interaction and leisure; they also support the family in the care of their child and provide opportunities for siblings to have fun and receive support.

‘Living and Dying Well (L&DW)’ was launched in Sept 2008 as a national action plan for palliative and end of life care in Scotland. It aims for a comprehensive approach to palliative care and to improve the quality of care. One of its seven groups (Group 6) focused on adolescents and young adults between 15 and 25 and produced a report in June 2010 making the following points.

Children’s palliative care is significantly different from adult care and their needs are particular to their age and stage of life.

Palliative care for young people is an active and total approach to care that focuses on enhancing the quality of life for the young person and support for the family. Their physical, psychological and developmental needs are significantly different from both children and adults, and a number have learning disability and impaired communications.

Clear arrangements are needed for continuity of transition between children and adolescents and between young people and adults. Adolescents and young people make up 13% of the population in Scotland but less than 1% of the number of deaths. In 2008 of the 56,000 people who died, only 403 were in this group and 356 were under 15. Thus the number of young people needing palliative or end of life care is between 500 and 800. This small number poses a challenge to local services who may rarely encounter a young person with these needs.

Young people often have conditions that are rare so that the appropriate dedicated facilities are few. The conditions may be
unpredictable in their trajectory, with care needed for times ranging from hours to 20 years (with a mean of 5.5 years).

Other points particular to children are as follows.

Respect for the child-parent relationship is crucial and both children and parents need to be acknowledged as a vital part of the decision-making process, including preferences in testing, monitoring and treatment.

In addition to alleviating pain and other physical symptoms, the child’s quality of life can be improved by appropriate education, counselling, peer support, music therapy and spiritual support for both the patient and family. The goal is to add life to the child’s years and not simply years to the child’s life.

Support may be needed in dealing with a range of deep emotions, arising from anger, grief, guilt, suffering, disappointment, fear of abandonment and isolation, and the difficulty of accepting the impending death. The child should be reassured that they are not responsible for their illness and should be encouraged to talk about their feelings and to express themselves, such as through art or music. Open and honest communication may help relieve a child’s distress, allowing for mutual support and personal growth during the final phases of a child’s life.

The psychological, emotional and spiritual needs depend upon a child’s development stage and their relations with family and friends. Parents of children with life-limiting illnesses can face many challenges such as social isolation, fears about the future, stresses around making difficult decisions and the practical concerns of daily life. Infants with no concept of death may obtain support from being held, comforted and soothed. Pre-school children may believe death is reversible and may not be able to conceptualize their own death, but they may benefit from clear explanations about what is happening to them. Primary school children begin to understand their own mortality, and so helping them understand the situation and allowing them to participate in medical decisions where appropriate is important. Teenagers may have a more sophisticated concept of death, and so reinforcing self-esteem, respecting privacy and allowing participation in medical decisions are all important aspects of care.
A specialist children’s hospice is specifically designed to help children and young people with emotional and physical challenges and to provide respite care for families. It provides flexible and practical support to the whole family, often over many years, so that families and friends approach death with dignity and peace.

CHAS (Children’s Hospice Association Scotland) was established in 1992 to provide children’s hospice support. It offers themed teenage weekends to raise self esteem, provide peer support, give opportunities for discussion, establish friendships, introduce end of life care planning and support young people to realize their potential. It works in local communities to reduce isolation. The first children’s hospice in Scotland, Rachel House, opened in March 1996.

Conclusion

Modern medicine offers enormous help to those near the end of life, but it has to be seen within the greater range of care offered by others. Many would prefer not to die alone and in hospital, especially if it transpires that the dying person is more aware of their surrounds than we would at first imagine. In addition, it has recently been reported that a majority of terminally ill people would like an opportunity to exercise more control in order to enhance the quality of their dying process (Schoepfer et al, 2009).
Living with terminal diagnoses and chronic conditions: experiences from communities living with HIV

As Chaplain to communities in Edinburgh who are living with HIV, Marion Chatterley accompanies people who have been forced to address their own mortality. In what follows, she reflects on how individuals and communities respond to diagnoses that affect the young, that may be shared by family members and friends, and, perhaps most challenging of all, that have been terminal and are now chronic. She begins by reflecting upon the shocking impact of a new deadly virus, upon a society that was learning to look away from death. Socially we have remained on the trajectory she describes, with the funeral business becoming increasingly professionalised, death becoming correspondingly more discrete, and our emphasis upon the continuity of life, as opposed to the disruption of death, ever greater.

Here are Marion’s reflections:

Post war improvements in health and health care transformed life expectation for the majority of people in the developed world. Even in Scotland, where poverty has been linked with high rates of some diseases, general life expectancy was increased. Death moved from home to hospital settings and became distanced from most people’s day-to-day lives. The ‘swinging 60s’ convinced people that life was for living; the consumer society was born and hedonism became an acceptable societal norm.

Death became something that happened elsewhere and was no longer managed within a community. Bereavement support services were needed (Cruse was established in 1959) because, with death tucked away, bereaved people had fewer opportunities to talk about their experiences. People were encouraged to ‘get over it’ and ‘move on’, and found that friends and neighbours did not know what to say to them and so avoided conversation completely. The post-war years in Britain were a time for looking forward and rebuilding communities. Many families had been directly affected by the war and the new focus was on peace time and the opportunities it gave for living.

The practical aspects of death were also moved from the family situation. Gone were the days when local women laid out bodies in the parlour. Funeral directors dealt with the dead, clergy conducted funerals, and life went on.
The impact of HIV on communities that had learned to live in this way cannot be underestimated. In the mid 1980s it became apparent that a new virus was affecting and killing young men and women. The first identified cases were among gay men and globally they were the most affected group at that time. However, in Edinburgh there was a particular story unfolding.

A local GP, working in an area of urban deprivation, began to see a pattern of illness among his drug using patients. By 1986 it was apparent that a significant percentage of injecting drug users in the City (more than 60%) were infected with HIV. This was a group of young people who were struggling to manage their drug dependence and who were now forced to deal with a life threatening illness. There was no treatment and little hope was offered to those who were diagnosed. For instance, a woman I know was diagnosed during pregnancy. She was told that she would not live long enough to see her child go to school.

There have been dramatic changes in the intervening years and HIV is now a manageable but chronic condition. However, the impact on individuals continues to be significant. My ministry amongst people who are living with HIV often takes the form of conversations about death and dying. I work with a relatively young cohort of people who have been forced, by virtue of an HIV diagnosis, to face their own mortality. Many have been multiply bereaved and, for them, the boundary between life and death is very thin.

The history of HIV in Scotland means that there are three distinctive groups of people who are directly affected by the HIV virus. As noted above, injecting drug users were significantly affected in the 1980s; those who have survived are now in their 40s and 50s, have seen many of their peers die and usually live with multiple and complex health issues. Men who have sex with men (MSM) have been affected by HIV from the earliest days and now form a significant percentage of those who are newly infected in Scotland. People from sub Saharan Africa, many of whom acquired their infection abroad, comprise the third substantial group.

When we consider the concerns for those who are living with a life limiting illness, some are universally experienced and some are particular to specific client groups. People who were infected with HIV through injecting drug use are of particular interest in Scotland and will form the focus for these reflections.
Sharing injecting equipment is a very high risk activity for the transmission of a blood borne virus. The ideal conditions are created for transfusion of blood from one person to another and, not surprisingly, those who share equipment have very high rates of infection. In Scotland, a highly successful public health intervention was the introduction of needle exchange and substitute prescribing (non injectable opiates) and this has had a significant impact on the rates of transmission of blood borne viruses in our country. The cohort of people who live with HIV were infected early in the 1980s, at a time when there was little anxiety about infection.

The nature of drug using, which tends to be a sociable activity, a way to spend time with friends and acquaintances, means that infection usually affects groups of people who have other connections with one another. I have worked with families where siblings, cousins and sometimes parents have all been infected. This is significant when there is a death. The bereavement is complicated by the complex relationships within the social group and the fear of what might happen to other members of that group. Those who survive can also experience feelings of guilt – there is no apparent reason for some people to have died from their HIV infection and others to be living 25 years later. ‘Why not me?’ is a regular refrain.

In the past 18 months, there have been a number of sudden and unexplained deaths among people who were infected through injecting drug use in the 1980s. The impact has been significant and complicated. Sudden death brings its own particular challenges, but these are exacerbated by the return for some people to a ‘looking over the shoulder’ state of being. None of us knows who might be next and that is very frightening. I have noticed an increase in the number of people who want to update their funeral plans; people who want to talk about existential matters, to consider what happens when people die; to address concerns about whether those who have behaved badly during their lifetimes might be treated differently at the moment of death from those who led more exemplary lives. Fear can be overwhelming and disabling. In turn, people who are attempting to deal with their fears but who have limited personal coping strategies are more likely to revert to former and unhealthy attempts to cope. For instance, to turn again to drugs or perhaps to abuse alcohol or gambling.

The conversations that I have with people in this situation are usually very straightforward and without any religious sophistication.
People want to believe that they will go to heaven, a place that offers unlimited delights for body and mind. When we begin to explore these ideas, people usually begin to think about the decisions they have made in life. I hear a significant number of confessions, often made as people begin to reflect on the reality of their life experience and begin to face the fear of their own demise. The traditional language of the church can be unhelpful in these situations, but there appears to be a universal compulsion to share the burden of guilt that may have been carried for many years. In some ways this has many parallels with pastoral care within a parish, but the order of gravity is often considerably greater. Many of the people I see in these situations have spent some time in prison and have committed crimes for which they have been punished. The burden often comes from the crimes that were never successfully prosecuted or the harm that was caused to others. This is simply part of a universal acknowledgement that we have all behaved badly at times, that we have caused harm to other people and that the burden of that (as described in the 1662 Prayer Book) is intolerable.

The dramatic change in the prognosis for people living with HIV in Scotland has, paradoxically, brought new problems. In the early days when there was no hope, people prepared to die. Their focus was on taking control of their dying process, in recognition of the fact that there was little else that was within one’s control. Coffin painting workshops were popular for a brief period of time and people spent a lot of energy thinking about the music they would like for their funerals and the legacy they would want to leave for loved ones. Many people made videos for their children in an attempt to leave some kind of heritage. Others created art work to express something of their own reality and to allow them to feel that something semi-permanent would be left behind.

Pastoral work focused on supporting people to take as much control as they could. They were encouraged to make detailed funeral plans: burial or cremation; what to wear; choices of music and readings; where to scatter their ashes. This work was important for two reasons. Obviously, it gave clear guidance at the time of death but, perhaps more importantly, it forced people to face the reality of their situations. In doing so, it enabled a whole generation to talk very openly about death. It would not be uncommon to stumble into a conversation about funeral music or for people to ask the Chaplain how they might be described at their funeral. This reality check was taken a stage further. When people died in the HIV hospice, other patients would often go to see them. People’s faces were not covered when they were moved from their
rooms to the mortuary. It became normalized to see and to touch dead bodies. One woman even asked to climb inside the mortuary fridge in order to experience how that would feel.

This very immediate sense of one’s own mortality had the effect of making the situation easier to manage. People did not welcome the fact that they were dying but the blunt reality gave a focus. We know, for instance, that people bereaved by violent death are almost always helped by knowing the full facts – the imagination can cause far more distress than the truth. Similarly, people who were preparing to die were able to focus on the facts as they understood them and the very clear consequences of those facts.

When it became apparent that treatment for HIV was effective and that life expectancy could be revised, many people found themselves unable to cope. There was no longer a focus on dying, but it had not been replaced by a focus on living. There are parallels with the experience of bereaved people who have spent many years caring for a loved one. Evidence suggests that such people can find it very difficult to establish a routine and a lifestyle. They may have forgotten what they would choose to do for themselves as their entire focus has been on the needs and quality of life of another. For people diagnosed with HIV more than 20 years ago, life has been about survival and has often focused on medication and its side effects. This new world that includes effective treatments and the promise of a future can be confusing and frightening. In some ways the certainty that death was just around the corner offered a comforting reality. Yet again, people are living with uncertainty. This is the first generation of people to use effective treatment for their HIV. We do not yet know enough about the long-term effects of living on medication or, indeed, the long-term effects of living with HIV. People are beginning to wonder how they will die – if not HIV then what?

There is not always much comfort to be found in the reality of living long-term with HIV. The situation for people who have been diagnosed in the past 10 years is very different, but for those who have been living with HIV for more than 25 years there will always be challenges. This is a generation of people whose entire adult lives have been dominated by their HIV. The impact on mental health has been documented and most manage to live independently only because they are able to access specialist support services.
As people have begun to trust that they have a future ahead of them, many have begun to experience the impact of the bereavements that they have lived through. Some have lost partners or children, others have lost siblings, cousins, close friends and drug using acquaintances. Each death has its own meaning and story. Amongst this cohort of people, a number have reduced or stopped their use of street drugs. One result of this is a new awareness of the pain they are dealing with; it can sometimes feel worse than it did in the predictable days of drug use and a poor prognosis.

Inevitably, these thoughts lead to discussions about life after death. People often initiate conversations about angels and the connection between heaven and earth. A number have described profound experiences when they have made a connection with a loved one who is long deceased. This can, of course, cause deep distress to those who long for a comforting sign and do not find any. This can lead to an interest in spiritualism which, in turn, regularly disappoints.

Opportunities can be created for conversations about Christian love and hope. An appreciation of God’s love can be extremely difficult for someone who has never experienced human love. The ministrations of the church are not always welcome. Many people have experienced prejudice and discrimination within church settings and are very suspicious of organised religion. My challenge as a Pastor with this community is to offer a glimpse of Divine love in order that people might begin to trust that they are indeed loved and precious in the sight of God.

The building bricks for those relationships are unconditional care and support. Other professionals have, of necessity, clear and distinct boundaries. Unacceptable behaviour is challenged and there is often a punitive response (for example, exclusion from a service for a period of time). As ‘God’s hands and feet’ I would argue that we do not have the luxury of walking away from difficult situations. It is still possible to challenge, to make sure that the person understands that their behaviour (usually verbal insults and/or threats) is not acceptable but that the Chaplain will not walk away. Our task, I believe, is to offer unlimited chances, to encourage people to come back and try again. For many of the people I see, second chances have been few and far between. An opportunity to repent and heal can be the first step on a journey towards a different understanding of self and of God.
In my experience, transformation comes when people are enabled to find an inner peace and to trust that they are indeed children of God. This is, of course, universally true but learning from this distinctive cohort of people has sharpened my thinking and has encouraged me to remember that there is no limit to the love of God. God’s love for us is boundless but at the same time it is not without boundaries – we each recognise on a daily basis the mistakes we make and the wrongs we do. As members of worshipping communities we are regularly reminded that we can be forgiven and we are given opportunities to confess our sins and to start afresh. My aim is to offer nothing more or less to my flock of souls – each one loved and known by God whether they are yet able to recognise that fact or not.
Part 3

How care for the dead affects the dying and the living

It is always a question for Christians how far we aim to shape cultural trends, and how far we aim to listen and respond to such trends. This is a very live question at present in relation to care of the dead. For example, does the Church, with experience and theological understanding of the care of souls, set the tone for pastoral and funeral provision; or does the Church behave most pastorally by adhering to what the dying and bereaved request? The different discussions in Part 3 canvas a range of attitudes in response to this question.

In the Scottish context, this question bites where traditional funerals are replaced by celebratory memorials. A survey of current religious trends in Britain suggests that the ‘long-standing ecclesiastical near-monopoly, over death, may…be eroding, partly in the face of a shift of focus in funerals away from an act of mourning mediated by a religious professional to a more participatory time of celebration and commemoration’. Funeral statistics are not collected by the Office of National Statistics, nor by the General Registrar for Scotland, so we do not have official figures for the numbers of religious, humanist or other funerals. Coop Funeralcare has conducted what it believes to be the largest survey of current funeral trends in the UK. Its findings, published in the on-line document, ‘The Way we say goodbye’ (2011), is not specific about Scottish statistics, but it reports that 2/3 of the funerals it organizes in the UK are still ‘traditional’ in following ‘the established rites of a particular religion’, whilst roughly 10% are ‘humanist’. It also reports a growing trend of ‘contemporary’ funerals, which are neither traditional religious nor humanist, but are personalized, may contain a hymn or other religious elements, and focus more on celebration than on mourning.

This growing preference for celebratory remembrance is at the same time a preference for focusing upon the individual who has died, rather than upon any larger reality. Dr Matthew Engelke at the London School of Economics, observes that many who describe themselves as “non-religious”, which cover[s] the entire spectrum from absolute atheist to a more general lack of commitment or belief, especially when it comes to organised religion,’ choose funerals conducted by the British Humanist Association (BHÂ). He further notes that one of the most striking aspects of BHA funeral ceremonies is that they strive to be true to the individual: to reflect as best as possible the character, world views and the
sensibilities of the person who has died. ‘The focus is almost exclusively on the person, which is often not the case with the more traditional religious ceremonies’.  

Engelke goes on to say: ‘This gives an intriguing glimpse into the extent to which modern citizens feel it important to express their uniqueness and individuality’.

Questions of best practice arise not only at the interface with Western individualist culture, but also where particular church cultures meet indigenous religious cultures, or diverse Christian cultures. We consider some challenges for particular communities in Malaysia, Borneo and Australia.

Indisputably, the Church should always properly hear and respond to people’s concerns and desires. The question is: what is the most pastorally fitting manner of response.
Current Liturgy and the End of Life

As the Scottish Episcopal Church (SEC) begins to ask what liturgical provision we need both to provide pastoral support and ministry to the dying, and to form in all worshippers positive and trusting attitudes to dying firmly rooted in Christian faith, here is a very brief survey by the Convenor of the Liturgy Committee, of what the SEC currently provides, and of some examples from the wider Church that may inform our thinking.

Death and Daily Prayer

Despite the fact that we find death such a hard subject to talk about openly and sensitively, Christian liturgy places both the reality of death and a Christian approach to death and dying regularly before us every day. It is present in our regular Eucharistic worship, in the rite of Baptism, and in the Daily Prayer of the Church, as well as in the liturgies that deal with death more directly, such as funerals and ministry to the dying.

To take just a few examples from the SEC’s contemporary liturgies (and to make no mention of everything the Prayer Book continues to offer about this), here are examples of the way in which Jesus’ acceptance of his death is used as a positive image of dying,

Obedient, even to accepting death,
He opened the gate of glory
and calls us now to share the life of heaven.
  *Scottish Liturgy 1982, Eucharistic Prayer II*

Recalling the night of Israel's release,
the night in which the sons of Egypt died,
your Chosen One, himself the First-Born,
freely offered his life.
  *SL82, Eucharistic Prayer IIi*

As children of your redeeming purpose ... who are called to share Christ's suffering and be made like him in his death ...
  *SL 1982, Preface of Lent*
At every Baptism the candidate is ‘immersed’ in the death and resurrection of Christ, but in Emergency Baptism this is often done in a situation in which death or the threat of it is a present reality for the candidate,

In the company of all those
who with Jesus have faced their death,
and with him have discovered through death
the endless love of the God of life.
*Holy Baptism 2006, Emergency Baptism*

In the offices of Daily Prayer, the Psalms reflect most of our human fear and anger about death, as well as trust in God in the face of death. But it is in Compline or Night Prayer that we are invited, as night falls, to entrust ourselves to God in the darkness,

The Lord almighty grant us a quiet night and a perfect end.

Into your hands, O Lord, I commend my spirit.

Now, Lord, you let your servant go in peace;* your word has been fulfilled.

Almighty God, whose most dear Son
lay at this hour in the sepulchre in obedience to your will;
may we by your grace be so buried with him
that with him we may rise to life everlasting;
*Daily Prayer, Night Prayer*

*Contemporary Funeral Liturgies*

Naturally, the funeral liturgy addresses death more directly, expressing both the faith of the Church in the face of death and also the care of the Church for the dead and the bereaved.

Contemporary liturgies emphasize Christian hope based in the Resurrection, and invite the mourners to place their grief alongside this faith. Certainty about the destination of the journey through death, into the hands of God, is a frequent theme.
Though now taken from us, let him/her not be parted from you. May your servant, set free from the bondage of earth, be changed into your likeness, from glory to glory.

As in life he/she glorified your name, so beyond death may he/she serve you still.

May death bring him/her comfort, rest and peace and open the way to life with you forever.

*Revised Funeral Rites 1987, ‘The Service in Church, Commendation and Prayers’*

Funeral liturgies also reflect the changed religious, cultural and social context of countries like Scotland. Fuller provision is made for the funerals of children; the practice of cremation is acknowledged; prayers at the interment of ashes have been added. The SEC’s ‘Revised Funeral Rites, 1987’ (RFR87) are an example of the attempt to take on board a new awareness of the psychology of grief and the emotional needs of mourners. Positive images of journey and mystery are often used.

As this our brother/sister goes from us, may your love be with him/her in the shadows and lead him/her to your presence where the life that began with you is sustained for ever.

*RFR87 ‘Prayers with the relatives at the time of bereavement’*

Your servant has begun his/her journey to the place which you have made ready for him/her. Hallow all the memories we have of him/her in this house which no longer is his/her home.

*RFR87 ‘Prayer on leaving the house’*

May the prayers of your whole Church uphold him/her and support us in face of death’s mystery.

*RFR87 ‘Reception of the coffin in church’*
Sometimes the reality of difficult or painful dying is recognised,

Your servant has come
by a hard and painful road
into the valley of death.
Lead him/her now into the place
where there is no more pain.

*RFR87 ‘The Service in Church, After a Difficult Death’*

Although RFR87 provides liturgical resources for a wide range of pastoral situations, it does not include suicide. The Church of England’s Common Worship does provide material for this, however, such as,

Let not the manner of *his/her* death
cloud the good memories of *his/her* life.
For *N* the trials of this world are over and death is past.
Accept from us all that we feel even when words fail.

*Common Worship, Prayers with the Dying and at Funeral Services (2000)*

*Pastoral Liturgies for the Dying*

Liturgy also deals directly with death and dying in pastoral services and prayers for people who are dying, their carers and relatives. Many churches now make substantial provision of such liturgies, provision which the SEC is now proposing to develop. RFR87 (following the Prayer Book) already provides some prayers for the time of death, but very few. They are only suitable for the actual time of death, and not for someone preparing for death. They include the traditional words,

Go forth upon your journey from this world, dear child of God, …
… may peace be yours this day, and the heavenly city your home.

*RFR87 ‘Commendation at the time of death’*

Common Worship provides a greater range of similar traditional prayers, with in addition a provision for Reconciliation (Confession), Communion and Anointing of the dying person. But the Episcopal Church (USA) has produced a much greater variety of liturgical texts and services for use in situations of dying and death. Many of these texts use different language and imagery from the traditional prayers found so far in British
Anglican churches, such as this Prayer of Commendation for the dying person,

Look kindly on N. as death comes near.
Release him/her, and set him/her free by your grace
to enter into the company of the saints in light.
Be with us as we watch and wait, and keep us in the assurance of
your love.

And this prayer for release in death,

Blessed Jesus, Living Water, Solid Rock: Uphold your child N.;
loose the fetters of sickness, break her/his yoke of pain,
and from this land of affliction, lead her/him home.
*Episcopal Church USA, Enriching our Worship 2,
Commendation of the Dying (2000)*

Liturgical texts like these are trying to form in Christians a more
positive approach to death and dying, where they are not simply the result
of tragedy or evil. They do this not least by the fact that using them with
people is an explicit acknowledgement that they are dying, and will soon
die, and because they are a continuation of the normal spiritual practices
of the Church’s daily life and, as such, support everyone, both those who
are dying and those who care for them.

This is not just a naive view of death and dying, but one which,
through many of the texts themselves, attempts to deal with the
ambiguous and ethically difficult questions which arise in contemporary
experience of dying, such as those created by medical technology. For
example, ‘Enriching our Worship’ includes prayers ‘When Life-Sustaining
Treatment is Withheld or Discontinued.’

There is an ‘Act of Commitment’ which family members and friends
may make to the dying person,

N., may Christ comfort you as you follow him on the path now set
before you.
With God’s help, I will journey beside you.
With God’s help, I will watch and wait with you, and with God’s
help,
I will witness the love of Christ by my presence and prayers with
you.
And prayer for the one who is dying,

Free N. from all earthly cares, pardon his/her sins, release him/her from pain, and grant that he/she may come to dwell with all your saints in everlasting glory.

There is a Litany, which asks,

That our actions may proceed from love, blessed God: Holy One, help us!
That our best judgments may accord with your will, blessed God: Holy One, help us!
That you will hold N. and us in the palm of your hand this day, blessed God: Holy One, help us!

And ends with one of these prayers,

Give us grace now to accept the limits of human healing as we commend N. to your merciful care. Strengthen us, we pray, in this time of trial and help us to continue to serve and care for one another.

Bless the decisions we have made in hope, in sorrow, and in love; that as we place our whole trust in you, our choices and our actions may be encompassed by your perfecting will.

Episcopal Church USA, Enriching our Worship 2, Form of Prayer When Life-Sustaining Treatment Is Withheld or Discontinued (2000)

These texts are examples, in one particular situation related to death and dying, of the need to develop liturgical resources which try to echo the positive and trusting approach to death and dying of some traditional texts, yet also try to place these hopes firmly in the contemporary Western context. I hope that whatever liturgical provision we will make in the SEC will address ambiguous and uneasy realities of death and dying such as these, and not only the ideal of a prepared and peaceful Christian death.
Funeral styles: a proposal

The funeral liturgies of the Scottish Episcopal Church have gone through a process of considerable evolution.

The service in the 1929 *Scottish Prayer Book* (called ‘The Order for the Burial of the Dead’) is clearly related to the very traditional burial service found in 1662 *Book of Common Prayer* of the Church of England, but the 1929 service contains substantially more scope for variety in the choice of psalms, readings, and prayers than the 1662 service. Consequently, the 1929 service can be made less stark than the 1662 service, and it allows for a reduced emphasis on the impersonal finality of death, even including prayers of compassion for those who mourn, something the 1662 service resolutely excludes. The modern language service (*Funeral Rites*, 1987; revised 1998) takes this process even further, explicitly explaining in the opening introduction that, ‘The various rites set out in this book are not designed to be followed slavishly. Every death is different...Where the words provided do not meet the situation, other forms may be devised.’ There is a clear pastoral dimension: if there was any doubt in earlier years whether the funeral service was principally intended for the benefit of the mourners or the mourned, it is the needs of the mourners who now come to the fore. An interesting direction included in the 1987 service is that of the ‘Sermon’; never required in the earlier services, but now considered essential. It is no longer enough simply to proclaim the stringent gospel of death and resurrection in the traditional 1929 words immediately before the burial (which, incidentally, are not included in the 1987 service): ‘Man that is born of a woman hath but a short time to live, and is full of misery...O holy and most merciful Saviour, deliver us not into the bitter pains of eternal death.’ Now the minister must explain the gospel of mercy and resurrection in her own words. Almost universally, this has become the opportunity for the ‘eulogy’ or family reflections, whether or not the minister delivers a sermon as well.

If we ask what the ‘art of dying’ means from a liturgical angle, the answers given over the years have changed considerably, especially in recent decades. If it was ever considered appropriate to offer one liturgy (‘one size fits all’), then that is no longer the case. In 1662, the inflexibility of the liturgy reflected the fact that death is totally inflexible for all alike, and that we must therefore all alike hope in God’s mercy alone. The modern tendency to amplify the particularities of the dead person (along with the particular pastoral needs of the mourners) runs the danger of putting across exactly the opposite message: that we can no longer hope
in God, so let us celebrate what made N unique while (s)he was alive, in the hope that we can prolong it for a little longer.

While we vary liturgy these days, the church would still retain what is good in the principle of burying prince and pauper alike. It seems that, if we cannot face up to the finality of death (for all alike) liturgically, then we cannot face up to death, and we cannot face up to an important aspect of our life. If grief can be expressed publicly only through a celebration, perhaps something important about life in general is lost, something that is captured by the words from the 1929 service (also left out of the 1987 service), ‘In the midst of life we are in death’. It is, of course, a truism that a life is only complete in its death. But if we wish to understand such enigmatic statements more deeply, the key is provided by the example of Christ who, while dying a death none of us would choose, showed an awareness of it and of its significance which informed the entire art of his living. And liturgically, he chose to celebrate such a death with a symbolic meal, which has become the central Christian liturgical act proclaiming the art of his living and dying. There is a strong case to be made for upholding the Eucharist as the heart of every Christian funeral. It is our most basic form of liturgical celebration, and not of the individual but of the whole community gathered at the messianic banquet.

The cult of the individual is now replacing the individual at the heart of the cult (Christ). A Christian liturgy is able to offer a hope that no celebration of an individual's worth or merits – however substantial they may be – can hope to offer, namely hope for inclusion within the communion of saints. The individual is not effaced from the celebration: the lives of the saints can be seen as the gospel story in miniature, worked out in countless particularities. In such a way, the life of the deceased can be presented as framed within the context of the gospel of hope for resurrection and eternal communion.

Practically then, there is certainly scope for espousing the contemporary tradition of reflecting extensively in the funeral liturgy on the life of the dead individual. But this can be done most constructively in a setting where the community that embraces the individual (on earth and in heaven) is also emphasised. There can be no better way of doing this than in the Eucharist. Addresses, sermon, intercessions, and choice of music can all reflect the idiosyncrasies of the person who is being mourned, but the fact that they are not the central liturgical act – which is instead the taking, the breaking, and the sharing of the bread and wine – places a completely different perspective on the art of dying as celebrated
liturgically. In such a way, the individual is seen placed within the community, gathered in communion, and one of those who even now might be celebrating the Individual.
Mourning, some changing practices

Both Old and New Testament witness to how in Jewish culture professional mourners were used to help make the shedding of tears around death easier and more acceptable. Today, we give time to the internal processes of bereavement, but engage little in external mourning practices; hence the growing trend for swift and private committals followed directly by a celebration of the life of the deceased. So far as mourning is concerned, of all periods of human history it is our own time and culture that is the least sympathetic overt or extended shows of mourning. If Queen Victoria’s practice of wearing mourning in honour of her beloved Albert for the rest of her life (1861-1901) seems extreme, as does the insistence of peasant cultures in southern Europe requiring much the same of more ordinary widows, the graded signs that characterized Victorian England did allow time for those grieving to come to terms with their loss. Indeed, the Church acknowledged the wisdom of pagan practice in this matter in initially copying the notion of the refrigerium or meal at the grave repeated over a period of time; at the very least at burial, nine days later, and with an annual remembrance. We will see below how the refrigerium is today a contested practice in certain parts of the world, where Christian authorities either assimilate or resist it.

Liturgy may or may not help. The 1662 Book of Common Prayer assumed both the faith of the individual and certainty of their resurrection. Prayers for the dead formed no part of the liturgy and it was only gradually over the course of the twentieth century that most of the Anglican Communion, including the Church of England, moved in a different direction. This was in part aided by agnostic formulae that commended the individual to God’s care without specifying why that might be appropriate. For the more Catholic-minded, purgatory had once more assumed a significant role, not now as a place of punishment but of purgation, of a gradual process whereby individuals come to a fuller understanding of themselves as perceived in God’s eyes and so prepared for the full light of his presence in heaven. For those who doubt the difficulty of adequate self-perception, it is perhaps appropriate to quote a prayer from the national bard:

O wad some Pow’r the giftie gie us
To see oursels as others see us!
(Robert Burns: To a Louse)
Such a more open context also of course makes it easier to handle the deceased’s possible own lack of firm conviction. The prayers of the living can then be seen as making their own significant contribution.

Equally, the 1987 Scottish burial service explicitly sought to provide comfort to the bereaved in a way that was lacking in 1929 where, though the resurrection was preached, it was set in a context that seemed rather severely judgmental. Not that judgment should be absent from the Christian message, but care needs to be exercised in avoiding any appearance of hitting a captive audience when they are at their most vulnerable. Sadly, that is certainly what the Church did in the past with those who committed suicide. Their burial outside consecrated ground was supposed to indicate the ultimate dereliction of their duty to remain at the post God had assigned them till a divine summons indicated otherwise. Now we know differently: that, more often than not, the minds of such individuals are temporarily unbalanced and are deserving more of compassion than of judgment. Indeed, the term ‘committed suicide’ relates to a time when suicide was a crime, such that those who failed in the attempt could be prosecuted. Suicide was decriminalised in England and Wales in the Suicide Act of 1961. This Act did not apply to Scotland, because suicide was not an offence against Scot’s Law (although assisting a suicide can lead to charges of murder or culpable homicide). At least in the Church’s favour it may be noted that one of the earliest advocates of change in attitudes towards suicide was an Anglican priest, Chad Varah (d. 2007), the founder of the Samaritans.

As already noted, in the twentieth century cremation has become the most common form of committal, ironically reverting to a practice which had largely died out in the Roman Empire by the second century BC. The Church thus did not need to argue for burial, but it did reinforce the practice through the very literal view that was taken of the connection between the old body that had died and the new one that would eventually be given (see, for example, Article Four of the Thirty-Nine Articles). Christians are in general no longer quite so unimaginative in their views, but with cremation now the norm it is important that space still be allowed for physical rituals of letting go, such as the final sight and touch of the corpse. Fortunately, many undertakers do show real pastoral concern for their customers, and indeed some can offer Christians truly profound insights, such as the American undertaker, poet and writer, Thomas Lynch with his best-seller The Undertaking: Life Studies from the Dismal Trade (1998). Like Victoria Sweet’s more recent God’s Hotel: A Doctor, A Hospital and a Pilgrimage to the Heart of Medicine (2012), the
book recognizes that care for those *in extremis* is not so much a matter of technology as relatively simple indicators of care.

Cremation may allow for a greater sense of equality in death, with the demand for elaborate tombs or memorial tablets now reduced. Even so, it is worth recording that before the introduction of coffins there would have been an even greater levelling in the use of a shroud that could be used repeatedly for dispatch to a common grave. However, the positioning of crematoria on the outskirts of towns and cities has introduced one further irony, in a return to the placing of the dead in locations that antedate Christianity. For pagans the dead were a potential source of pollution and so must be excluded from places of population, whereas Christians wanted their dead close by where they worshipped, to intercede for them (hence graveyards beside churches). Of course, the explanation for the modern placement is quite different, but it has introduced a significant new feature to Christian liturgy, the huge rise in the popularity of All Souls services at which the dead are remembered, often now the next most popular service after Christmas and Easter. In fact, having said that we do not sympathise with extended periods of mourning, the popularity of All Souls services in some ways proves us wrong, and commends a particular, and communal pattern of sharing and supporting one another in our grief.
Funerals as part of a Good Death – a cross-cultural perspective

In 1980s South Australia, some older men paid the church-tax (*pastorgehalt*) for their married sons to ensure the latter will get a church burial, even if the son had ceased to pay his dues as a statement of separation from the church: married daughters are not so paid for, being the responsibility of their husband. In a rural community in Sabah, Malaysia, the refusal of the Anglican priest to bury Dungap and Marukin in the village-owned church-yard, on the grounds that one had not attended church within a year of his death and the other had two wives, is still talked about bitterly some five years on, although the ruling was not his decision but that of his Bishop. And in Scotland, where an increasing number of funerals are ostensibly humanist, at least some of the bereaved families expect that Christian prayers will be said and hymns sung, that being the appropriate ritual to deal with the dead - just as many UK soldiers in Afghanistan who do not tick the 'religion' box nonetheless expect that hymns and prayers will be said should they die in service. Hence, there is an accompanying trend of people having sought out a humanist service, then requesting a minister or priest on discovering that some favourite music, if it is deemed religious, such as Fauré’s Requiem, or a favourite hymn, is not permitted in services taken by humanist celebrants.

These examples are less about similarities within the variety of attitudes to dying and death across the world, than about the problem of dissonance between theological and ecclesial assumptions about dying held by ‘the church’ and those who identify with church in some way. Regular church attendees may be assumed to share ‘church’ assumptions –but may well not do so, as we will see later in relation to anxieties carried by rural Australian Lutherans. As for the Sabah village in Malaysia, people from each household there attend church weekly, but are involved in such a covert tussle with the priest as representative of ‘the church’ that almost no funeral is free from tension. Therefore, no dying of older people brought up in the local tradition is free from tension. The art of dying well may be thought to be separate from the skill of being dealt with properly afterwards: but it is not. While segments of the total rite of passage are separable into their own separation-transition-incorporation, dying rites, funeral rites, and so on, the whole must be seen as one rite, each segment of which affects the others, and all being embedded in life as the dying and the bereaved understand it.
The common strand in the examples above is that ‘ordinary people’ are not being listened to by those they identify as ‘authoritative church people.’ Anxious Lutherans do not express certain fears lest they be thought to be ‘false followers’, even though their fears relate to beliefs that are not owned by their church; anxious Anglicans in Borneo do not express the tension between local and Christian practice, as they know they will be excluded if their attempts at mediation come to light; and peripheral, cultural Christians in Scotland fear expressing their wish for Christian links lest they be judged as not true Christians. How do we minister well to people where they are, especially those who feel rejected by ‘the church they don’t attend’?

Taking ‘Food, Friends and Funerals’ as the base line rather than ‘Faith and Doctrine,’ offers a suitably grounded approach. Lived religion concerns what food people eat or reject and with whom, what friends they make and marry, and how they bury their dead. A good death for the dying is one which leaves those living in as good a state as possible, while assisting the dead to ‘move on,’ however that is understood. It does not follow that faith and doctrine are irrelevant to the study of lived religion or indeed its practice. Far from it, for grasping the memories, internalised assumptions and the variously understood meaning of discussants is as vital for the researcher and the pastor as living it, or living with it, may be for those identifying as adherents. Yet food, friendship and death, are always relevant, and it should be recognised that, especially with death and funerals, people’s understanding may be affected by practices and teaching from one or two centuries ago, so long is the cultural lag.

As it is so often easier to see the issue by looking elsewhere, we turn to Borneo, and outline death and life for rural Kadazan Anglicans, and the problems which can ensue when ‘the church’ makes decisions for people based on ecclesial assumptions about them.

For Kadazan, a good death is one attended by family members; one of the most serious insults and threats being ‘I will not sit with you when you die!’ The customary pattern is to go to the dying person’s house to sit with them, and if death is clearly immanent, to start assembling the necessary goods to make the temporary kitchen needed to cook for up to two or three hundred guests for three or four days and nights: only where death is through drowning does the burial occur as quickly as possible. Both before and after death, visitors will talk to the focus of attention, stroking their head and arms, telling of their deeds and their memories: only rarely is there any weeping. It is an intensely sociable time, both for
the dying/dead person and those attending, for while the point of death is noted, and usually very exactly, the process of death means that for several hours afterwards, the person is seen as ‘not quite dead:’ ignoring them would therefore be unkind, and even rude. The burial usually takes place two to four days after death, although if distant family members are held up, it may be delayed for up to a week.

Even after the burial, social and spiritual support for the bereaved does not stop. Every evening for seven nights, the candle is kept lit so the departing spirit knows where they belonged. Were it to be upset by a sudden rejection from the erstwhile family, who knows what disturbance might ensue. Visitors also come to support the bereaved, especially those loosing a child or spouse, for they are judged most at risk of suicide while the mind is disturbed.

A solitary or unquiet death is one filled with danger, for the angered or sad spirit may fail to leave the community in the correct way. Shades of the dead are not malevolent by nature but rather neutral, though those who died by suicide or in childbirth, who were not buried properly, or who hold resentment still unresolved at death, are liable to be used as the medium for one badly-intentioned villager to hurt another. One of the two souls, the ginavo which enlivened the body, goes to the highest mountain in Sabah, Kinabalu, while the other, the tatod - in life, actually seven souls in the head, chest and joints - stays in the surrounding woodland. The departed ginavo of the dead is of no interest to the living, unlike the resident tatod, although if a ginavo fails to make the journey, hovering around the village, it will cause problems. While one aim of post-death ritual was to enable a calm time for the dead (tatod) until they had truly become part of the amorphous collective dead, the category engaged with, in what uncomprehending Christians may scathingly call ancestor-worship, was in no way the individual dead in themselves, but rather the ‘local ancestral force’, which is why any interaction needed to be done collectively.

In the past, the annual cleaning of the graves at the end of the harvest cycle (now usually moved to 31st December) was done by villagers, shared by the dead. A small table made of short sticks and swiftly interlaced leaves was made before each cluster of graves, on which were placed seven ritually significant items, none in daily use. Nothing was said to the dead, unless a newcomer came to the ritual who must be properly introduced to the graveyard’s residents as would be the case with living hosts: people did sometimes chat to each other about
various forebears without naming them. The journey, and the ritual, was done to reciprocate what had been done for and passed on to the living by the dead when alive encapsulated in the tradition (adat) around which all daily life and thought was oriented. A respectful balance (mi-timbang) was thereby maintained between all spiritual existences, because that is proper and, as a corollary, because not to do so can cause resentment. Insulting the ancestors (envisaged both as grandmothers and grandfathers, odu-aki and rogon, neutral easily offended emanations) is unwise.

Recent years have seen a change in the items placed before the graves of those dying before 1958, and of those who did not convert before dying after that date, all of whom are buried in the far-distant pagan graveyard, which is visited annually by those village Christians who still honour all the village dead. Now there may be a few ‘correct’ items on the table but the wrong number, or spectacles, indicating a visually challenged table-maker. It is thus no longer a purely collective interaction, but expresses the individuality of the giver. This change is further marked by the fact that the dead are talked to in detail, their life being rehearsed and – a very new addition - their intercession with God sought for the health of the speaker. Another change is that while a roof still decks the grave of some who had had children and thus died as fully adult, other graves of adults have no roof but a stone Christian cross. Before, as now, the giving of food or ritual items to the dead is accompanied by much eating and drinking of cold rice, snacks, beer, brandy; unused remnants being left on the grave. Concrete or stone graves make good seats for the party fully to share the feast with the dead, as in the refugerium rites of Early Christians, in the same way as anyone bringing home a haunch of wild pig shares it with neighbours lest they be accused of uncivilised dog-like behaviour. Sharing food is also done after a quarrel, to signify the end of anger and of all reference to a quarrel. Sharing human food with the tiny foot-high ‘people of the jungle’ is enough to turn them into humans.

At the Christian graveyard cleaning, food and drink is also brought, although since 1993 alcoholic drink has been forbidden by the resident priest, despite the bitter but ‘cooling’ beer being a valued antidote in spiritually ‘hot’ situations. No one brings the seven ritually prescribed items or their modernised equivalents to the grave, for it would be inappropriate for items from the local system to be brought into the Christian context, a caution deriving less from Christian wishes than from local law in which mixing categories entails danger. Since 1999, the only food allowed in the graveyard is for immediate consumption by those
attending in person: enabling the dead to share thus becomes impossible. Yet the wish to maintain the reciprocal respect between the living and the dead, who taught so much by acknowledging the less visible in the visible world, leads some villagers to ignore the priest’s ruling that only cut flowers brought from the distant town can be left: they either place food items after the evangelist or priest has said prayers and gone, or they return later in order to leave food items. Those who wish to retain their public social status as totally Christian and yet still honour their dead are in a quandary, one not shared by those who abjure such behaviour as archaic and unchristian.

The church reasoning is that belief in the ability of the dead to respond to the living is wrong, as are offerings assumedly done for benefits which can only come from God. Grave-side interaction, with its implication of an opening to that which is beyond accessed not through acceptable Christian prayer but non-Christian ritual action, is likewise anathema, for the dead have no power. Any act other than cleaning graves and laying flowers improperly elevates the ancestors, ‘worship’ being reserved for God or Christ. Were graveyard visitors’ intentions heeded, however, distant church officials would know that the dead are not expected to have power to act or to come to the living. Indeed, one aim and outcome of the rite is that the departed each stay in their allotted place, having been honoured, reverenced and remembered in the hospitable and inclusive graveside feast. Respectfully honouring that relationship was an obligation of a similar order to that obtaining between each living villager, for respect is given to age but not to gender or rank. Collective ritual showed respect in the fact of performance if not the manner, no ritual outside church being especially orderly, and affirmed the shared past and present for the benefit of all members, visible and less visible. Ancestors were not worshipped, nor was or is relating to them ‘of the devil,’ despite the current views of church leaders there.

This clash between the villagers and the central administration of the church concerning funerals affects the dying and thus the living; a good many people are now anxious that should they fail to come to church for a year for whatever reason (serious illness or extreme age is a valid excuse), they may be ‘tossed into a garden like a dog.’ They could, of course, attend church sufficiently. But Dungap’s actual and mental age did not allow proper burial, and while Marukin’s money was acceptable to the church, his dead body was not. The church threatens to excommunicate those who fulfil vows to long-dead grandparents, who
died before Christianity arrived in 1958. Therefore, Christian villagers are face problems about their own deaths and so too about their lives.

Such problems are not restricted to Borneo, and nor are they new. Consider the early Church, where the cemetery, the place of the dead, was equally the place of the living: where prayers were addressed to the dead on behalf of the living, various eating and drinking acclamations were made to the deceased, and the meal was eaten in honour of the birthday or death day of the departed. The shared Eucharistic food in the building used as a church, and the shared spirit food at the grave, were part of the same unity.

Earlier, the Roman grave of a special person was believed to house his advising spirit (daemon), which could assist still-living kith and kin. The early Church cared about the heaven or Hades-bound dead in part because many of the dead in a period of religious upheaval died under the previous regime: in both Borneo and the Graeco-Roman world, they were kaffir, pagan. And in the same way that Christ was believed by some Church Fathers to have gone to Hades to rescue precisely those pagan dead who had not had the chance to know him, sharing with the dead in the graveyard was also a way of reaching out and including them. Macculloch notes that the Irish missionary Clement taught that Christ released all detained in the Underworld, believers and unbelievers, worshippers of the true God and idolaters. ‘As a missionary,’ says Macculloch, ‘his opinion was perhaps due to some consideration for the fate of those who died ignorant of the Gospel’.57

As Leclerq explains, the refrigerium, defined as an agape liturgy with refreshment in spiritual but also liquid and solid form, ‘is an ancient custom tolerated by the church essentially lest by excessive austerity they discourage those trying to become part of the church.’58 True, he notes that neither Ambrose nor Augustine were happy about the practice: but it did last at least another 1000 years; the scathing view of the ‘tolerating’ church contrasting with the feisty attitude of the people performing it or similar rites.

Rural Lutherans of German origin in South Australia struggle with the dissonance of being terrified at the approach of death, knowing that they are (officially) saved by grace through faith, and therefore hiding their fear because it seems improper.
Sitting over an excellent glass of red wine that his sons had made, Wilf fell silent, and then said: ‘I don’t know that I believe in predestination.’ Given that Old Lutherans rejected the idea of a Union Church in Prussia after 1850, finally leaving the region in 1839 for America, South Africa and Australia, because of theological difference over both the Eucharist and the ‘Will of God’ expressed in predestination, I [Elizabeth Koepping, reporting on fieldwork] suggested that Wilf certainly did not need to accept predestination. In exploring a little further what he understood by the term, we learned that he had been taught double predestination, which is a Calvinist doctrine teaching that some are predestined for heaven and others predestined for hell. Wilf was seriously worried that when he died, he would go to hell if God had so decided, irrespective of his faith; an especially likely outcome if he was sinning at the point of death. And hell was a very clearly conceived place.

The local pastors insisted that no one in their communities believed that God predestined people to hell, unless they had picked up such beliefs from Calvinists or perhaps Pentecostals – the catch-all for odd theology! Given that people rarely talked to pastors about faith, one wonders how pastors knew what parishioners actually believed and feared. I explored the issue further within that congregation and in three others in the area. The view of death and judgement was indeed alive (though hardly well) in older members of Wilf’s congregation, and in others who, like Wilf, had been confirmed by Pastor R, an incumbent for over fifty years and trained in the very conservative Ohio Lutheran Synod after initial training in Germany.

This teaching about death and therefore life stemmed from late nineteenth-century theology of a particular strand. It was overlaid by different, more life-affirming versions, but it was not negated. Therefore the predestination teaching, imbibed by confirmands, survived for a century. Failure to understand underlying fears, or to explore in a non-judgemental way, and to listen to the awkward silence of anxious members, means that Wilf and others in his congregation live with a black cloud over their heads: waiting for a death that on the one hand they should rejoice to claim, but on the other are terrified of finding is a passage to hell.

Amongst these rural Lutherans of South Australia, the divide between clergy and people is based on status (which in the nineteenth and early twentieth centuries was conceived in terms of peasants and their pastor), and on the almost theocratic control exerted by the pastor
over his flock in an almost entirely Lutheran village. There was some resentment among the peasants - called ‘das Poebel’, the rabble, by a 1930s pastor – but an acceptance of necessity of his rule. Such a rule, however, did not involve listening to the words, much less the silences, of his people. How could he know what the villagers actually thought of death and therefore of life, if it diverged from the correct Lutheran version? Divergence is deemed sinful, not unlike the way in which ‘residual superstitions’ and ‘folk religion’ are dismissed in other contexts.

In Sabah, division experienced by villagers is between the new, mobile, foreign religions of Islam and Christianity, and the local, grandparental traditions that are impossible to practice in town. For so many ordained people, any inkling of non-Christian practice associated with death is sinful. Consequently, life as lived by those embedded in one system, even if happily cleaving to the new, is also being rejected by clergy. The necessity for a good death for the dying is not merely to ease the passing of one person, but rather to assist the living of all left behind.

If food, friends and funerals are markers of religion in life, experiences around death and funerals are the experiences held onto the longest. We might think that a problem with a particular dying relates just to the particular family and event. Yet, as indicated in these examples from Borneo and Australia, death in anger, and life in anxiety may refer to long-past dyings and deaths, unspoken but not forgotten. Pastors, priests and ministers seem especially guilty of ignoring the distant, seeing themselves as a new broom rather than just one more holder of an adequately-maintained besom.

All over the world, dying rites, funerals rites, mourning rites, are part of life; life being anchored not in this moment, this century, or even the last, but in the multi-stranded past of this region and of many other regions of the world. Assisting a good death means fully honouring the life of the departed and those left behind. One cannot honestly (as opposed to patronisingly) honour what one does not know. The only way to know what that life-way is and was is to listen to the scraps, and the silences, of all involved. As ever, the role of minister for all, lay and ordained, means open ears comes before an open mouth!
Postscript

Christian ministry is needing to adapt to cultural trends around dying and death, for example, to funerals which are barely funerals, and to spiritual care which is not religious. Health-care Chaplain and Church of Scotland minister, Ewan Kelly, describes creating a funeral with a bereaved family, in which there was no mention of God, afterlife or any other religious belief or affiliation. The funeral director asked Kelly: ‘Do you find it hard not to mention the Lord?’ But Kelly believes that ‘the Lord was implicitly a large part of…the funeral’ because of the way that Kelly served the family in responding to their needs. He made himself vulnerable and let go of his professional tools, and so embodied ‘Christ’s life and teaching’. Bruce Rumbold, an Australian hospital chaplain, talks about ‘running the risk not just of professional inadequacy but of personal helplessness in order that change may come about’. The proper balance, Kelly explains, is between vulnerability and appropriate use of authority.

The art of dying is full of the paradoxes of giving things up only to find we get them back in a new way. Christian ministers themselves practice the art of dying as they support and accompany others. We will end with two stories from Christian accompaniers who felt themselves die to their professional knowledge and training and plunge into feelings of helplessness, and in that dying found their Christian ministry returned to them.

A hospital chaplain was asked to administer the last rites to a man who was greatly distressed, but who could not speak. Not being able to hear his confession, the chaplain had to find another way. He asked the man to offer his distress to God, so that God could transform it. The man became calm, and he and the nurses anointed him with oil. This occasion brought peace to the dying man, insight to the chaplain, and returned something to the nurses – their sense of vocation, as they developed ways of attending to patients bodily that went beyond the basic functions of applying drips and toileting.

The final story is from Jane Millard, a former Vice-Provost of Edinburgh, who had a ministry amongst the many AIDS sufferers in Edinburgh in the 1980s and 90s. She would clean and shop for them, and watch with them when they were dying. As she waited with them she would jot down thoughts and things they had said that would help her to construct their funerals. She called these jottings ‘fragments of the
Watch’. The then Bishop of Edinburgh, Richard Holloway, has encouraged her to let him publish some of these fragments. One concerns a young woman who was very afraid of dying. ‘I don’t want to die’, she said. ‘Him upstairs will get a big stick and shout at me, tell me to go to hell. I’m frightened. I don’t want to be shouted at’.

And I hugged her [Jane Millard wrote], bereft of anything theological to say that sounded real, and she snuggled in.

‘Talk to me,’ she whimpered.

‘There was a man who had two sons…’ and I told her the story of the prodigal son and loving father.

‘Will you be with me when I die? Be sure and tell me that story.’

So I did, about an hour ago, now we are waiting for the undertakers.\(^{62}\)
Appendix 1

END OF LIFE ASSISTANCE (SCOTLAND) BILL

Submission to the End of Life Assistance (Scotland) Committee  
by the College of Bishops of the Scottish Episcopal Church

The College of Bishops of the Scottish Episcopal Church welcomes the opportunity to provide input to current thinking concerning end of life issues facing the Scottish Parliament.

The Scottish Episcopal Church is part of the world-wide Anglican Communion. The Bishops of this Communion meet regularly at the International Gathering of the Lambeth Conference. While the Archbishop of Canterbury has no jurisdiction or formal authority within Scotland, his pronouncements on matters are generally taken seriously by the Churches of the Communion.

The Scottish bishops would wish to comment as follows.

At a meeting of the Lambeth Conference in 1998, the following resolutions were passed by the Bishops gathered there.

*In the light of current debate and proposals for the legislation of euthanasia in several countries, this Conference:*

a) affirms that life is God-given and has intrinsic sanctity, significance and worth;

b) defines euthanasia as the act by which one person intentionally causes or assists in causing the death of another who is terminally or seriously ill in order to end the other’s pain and suffering;

c) resolves that euthanasia, as precisely defined, is neither compatible with the Christian faith nor should be permitted in civil legislation;

d) distinguishes between euthanasia and withholding, withdrawing, declining or terminating excessive medical treatment and intervention, all of which may be consonant with Christian faith in enabling a person to die with dignity. When a person is in a permanent vegetative state,
to sustain him or her with artificial nutrition and hydration may be seen as constituting medical intervention; and

e) commends the Section Report on euthanasia as a suitable introduction for study of such matters in all Provinces of the Communion.

In addition, the Archbishop of Canterbury spoke in the House of Lords on 12 May 2006. This speech will be known to Scottish Parliamentarians. He had earlier written on this matter in The Times on 20 January 2005.

Two points are worth extracting from the Archbishop’s comments. The first is that in talking about legislation guaranteeing to people a right to die, we can quite soon move to finding ourselves in the position where others are thereby deemed to have a responsibility to enable the person concerned to exercise that right. In addition, we might add that in talking of someone having a right to end their life, this can also swiftly move to talk of a person having a duty to end their life under particular circumstances. We are well aware of this move in other areas of legislation. ‘Your fathers fought for the right to vote in elections, you therefore have duty to exercise that right!’ Rights, responsibilities and duties intertwine in our consciousness in many ways, and important as it is to articulate rights, once these have been enshrined in legislation, and put formally into the public domain, the language of responsibility, and the language of duty can come swiftly in its wake.

The Bishops of the Scottish Episcopal Church are conscious that seriously held differing views exist within our church, but in general they would be reluctant to see moves to enshrine the right to die through assisted suicide formally enshrined in legislation. However, we would wish to recognise that etymologically ‘euthanasia’ means ‘dying well’, and the Church would wish to see itself thoroughly committed to enabling people to have a ‘good death’.

Accordingly the Church is committed to supporting the hospice movement, where death can be achieved with minimum pain and with dignity. The Church would also see itself as committed to focussing thoroughly on questions of dementia and the spiritual and pastoral issues faced by those suffering from it. To this end, within the church many are involved in projects looking seriously at the spiritual issues that face people when health deteriorates and the end of life approaches.
would also wish to say that through Chaplaincy and other provision, our commitment to the hospice movement is assured.

In formulating their response to the current consultation, the Bishops were grateful to have received comments from the Church’s Doctrine Committee. A copy of the views expressed by that Committee is set out in the appendix below.

The College of Bishops
Scottish Episcopal Church
May 2010
It should be emphasized first of all that the Doctrine Committee of the Scottish Episcopal Church are not able to offer a dogmatic position on this issue, but would nevertheless agree on certain fundamental assertions:

**That**, humanity is created in the image of God and that therefore every human life is sacred.

**That** we would endorse the statement made by the Church of Scotland in its document *End of Life Issues*: ‘The Church stands resolutely against the idea that human life is made less dignified or worthy by limitations in capacity.’

**But** that we could not agree unanimously on the following statement in that document, affirming ‘opposition to legislation which seeks to bring about deliberate ending of life.’ However, we would wish to draw attention to a distinction which lies at the heart of Christian medical tradition, and has been observed in medical practice in general, between ‘doing’ harm and ‘not doing good officiously’.

We are extremely concerned clearly to define the category of people ‘who judge their lives to be intolerable.’ The danger is that the provision could be close to conferring a right to aided suicide on anybody and everybody, including those suffering from diagnosable clinical depression.

We would point out that it is unlikely that most people will have ready access to someone who is trained to assist dying. The ‘regular physician’, who ought to be someone senior and who has cared for the patient for at least one year should, at the patient’s request, consider referring them to an assisted dying specialist team. But there is an issue of the physician who in conscience cannot be on the register of those prepared to assist in dying, and who has a duty to refer to someone who is on the register at the request of the patient, regardless of his or her own judgement of the case.
We are aware that there is no public consensus on the issue and certainly no majority view in favour of assisted suicide. (We are conscious that Ms. MacDonald is keen to distinguish between ‘suicide’ and ‘assisted death’.)

We need to be aware that the issue is not so much about death itself as about how death occurs.
RESPONSE FROM THE FAITH AND ORDER BOARD AND DOCTRINE COMMITTEE OF THE SCOTTISH EPISCOPAL CHURCH TO THE ASSISTED SUICIDE (SCOTLAND) BILL CONSULTATION QUESTIONS APRIL 2012

We affirm the absolute sanctity of all human life and its creation by God as a gift which is in our care. As creatures made in the image and likeness of God we recognise our responsibility for ourselves and to enhance the lives of our fellow human beings, especially in circumstances of suffering, through the exercise of love which is ultimately of God.

QUESTIONS

Q1. Do you support the general aim of the proposed Bill (as outlined above)? Please indicate “yes/no/undecided” and explain the reasons for your response.

We do not support the general aim as too many problematic and specific questions are raised which are insufficiently addressed in the proposal. In particular the issue of the facilitator is highly problematic.

Q2. What do you see as the main practical advantages of the legislation proposed? What (if any) would be the disadvantages?

The practical advantage is that it might have the effect of reducing the stress of the person who is wishing to die, particularly if they are assured
that their nearest and dearest would not be prosecuted as a result of assisting them to die.

The “licensed facilitator” we see as a disadvantage because the role is not clearly defined, it is too open to potential abuse and the qualifications for the role are unclear. Furthermore we see no reason for a non-medically trained person to be involved.

Q3. Do you consider that these suggested eligibility requirements are appropriate? If not, please explain which criterion or criteria you would like to see altered, in what ways, and why.

“Find their life intolerable” cannot be given an absolute status. It is particular to circumstances which can change, such that peoples’ state of mind and feeling about their life also changes.

There is an anxiety about the potential breadth of the criteria described and how that breadth could lead to compromised practice.

Q4. What is your general view on the merits of pre-registration (as described above)? Do you have any comments on what pre-registration should consist of, and on whether it should be valid for a set period of time?

Optimum process and time period for registration would be circumstantial. If one, as in the previous clause, is deemed “capable” at the time of the event itself, then pre-registration is redundant.

The proposed practice is too open to abuse at each stage, such as forms of external pressure. How can you decide on action in circumstances which have not been experienced?

Q5. Do you have any comment on the process proposed for the first and second formal requests (for example in terms of timings and safeguards)?

None
Q6. Do you think a time-limit of 28 days (or some other period) is an appropriate safeguard against any deterioration of capacity?

This would seem to be dependent on medical issues which would be peculiar to each case. In that sense this period of 28 days seems arbitrary.

Q7. Do you agree that the presence of a disinterested, trained facilitator should be required at the time the medication is taken? Do you have any comments on the system outlined for training and licensing facilitators?

We think that it could be difficult for someone to remain “disinterested” – and are unclear as to what “disinterested” means in such contexts?

Would the facilitator be medically trained? We worry about circumstances in which something goes wrong with the administration of the drugs or their effects, and no medically trained professional is at hand.

The scope of the training is unspecified.

We wonder what the effects would be in practice, on society and on the individuals concerned, to create a post or office of licensed facilitator.

What would constitute an unsatisfactory process?

Q8. What sort of documentation and evidence is likely to be required? In particular, how important is it that the process is filmed?

The concept of filming is disturbing, and open to possible abuse and use.

The only finally satisfactory evidence would have to be from a medical practitioner.
Q9. What is your assessment of the likely financial implications of the proposed Bill to your organisation? Do you consider that any other financial implications could arise?

Who would pay for the services of the facilitator?

There are no financial implications for the SEC as far as we can see. There will be other financial implications as a new area of work has been created, which will tend to spawn more work and support mechanisms.

Q10. Is the proposed Bill likely to have any substantial positive or negative implications for equality? If it is likely to have a substantial negative implication, how might this be minimised or avoided?

Some may be deemed “suitable” but otherwise not “capable” (e.g. because of their mental capacity) – would this come up against disability legislation?

The most vulnerable could be persuaded to register.

There would appear to be no positive implications for equality but only negative ones.
Some questions for reflection

1. What might it mean to die well?
2. How does contemplating your own mortality help you to live this life?
3. What are your experiences of accompanying friends or relations in dying?
4. Why are people anxious about making a Will?
5. What has been helpful or unhelpful in the funerals you have attended?
6. How would you like your own funeral to be? Have you made any requests about your funeral?
7. What are your attitudes towards legalising assisted suicide?
8. Is it ever right to say 'I've had my life'?
Some suggested reading


Christine Bryden, *Who will I be when I die?*, Jessica Kingsley Publications (2012), an autobiography of someone living with dementia.


Ewan Kelly, *Meaningful Funerals: Meeting the Theological and Pastoral Challenge in a Postmodern Era*, Mowbray (2008), by a Church of Scotland health-care chaplain and former medical practitioner.


Some useful websites

http://www.palliativecare.scotland.org.uk/content/living_dying_well/

http://www.goodlifedeathgrief.org.uk/

http://www.bath.ac.uk/cdas/ - a website of resources and information from the 'Centre of Death and Society' at the University of Bath.

http://webcampus.drexelmed.edu/religion/death/research.asp - this religion and spirituality in medicine website provides perspectives from multiple faiths.

Medical References

Austad SN (1999) Why We Age; What Science is Discovering about the Body’s Journey through Life, John Wiley and Sons.


John Swinton, Dementia: Living in the memories of God, SCM (2013).
Endnotes

1 For some overviews, see Julia Neuberger, *Dying Well: a guide to enabling a good death*, 2nd edn (Oxford and San Francisco: Radcliffe Publishing, 2004); The Religion and Spirituality in Medicine website, which provides resources from different traditions, for coping with death, [http://webcampus.drexelmed.edu/religion/death/research.asp](http://webcampus.drexelmed.edu/religion/death/research.asp)


8 Schweitzer, p. 75.


12 As well as through other rites that are counted as sacraments in parts of the Church: confirmation in which we are strengthened on our baptismal path; reconciliation in which we die to our sins; anointing of the sick (formerly known as Extreme Unction and performed at the Last Rites); marriage, in which couples make their vows ‘til death us do part’ (formerly ‘depart’); and Holy Orders of those administer the Sacraments.
15 Based on I Corinthians 15.51-2, Common Worship Pastoral Services, p. 236.
16 Cf Henry L. Novello, Death as Transformation: A Contemporary Theology of Death (Farnham; Burlington, VT: Ashgate, 2011).
21 The ensuing slide comes from a talk, ‘Spiritual Wellbeing and Physical Decline: serial in depth interviews in the last year of life’ by Scott A Murray, St Columba’s Hospice Chair of Primary Palliative Care, University of Edinburgh, UK, given in Glasgow on 13 March 2012.
22 quoted in Evans, p. 279.
24 Viktor E. Frankl, Man’s Search for Meaning: The Classic Tribute to Hope from the Holocaust, quoted by many including Evans, p. 341; and Grant, Murray and Sheikh.
25 E.g. see http://www.stchristophers.org.uk/healthcareprofessionals/arts.
29 Frank, p. xi.
30 Grant, Murray, Sheikh.
Bryden, *Who will I be when I die?*, Dedication page, pp. 153 and 158.

E.g. http://www.ageuk.org.uk/health-wellbeing/conditions-illnesses/dementia-and-music/;

Bryden, pp. 62-3.


In conversation with Rev Ali Newell.

Physician assisted suicide became legal in the Netherlands in 2002, though is a less popular option there than euthanasia, which has been made possible there since the 1970s and 80s through a series of decisions not to prosecute, and processes of formalising criteria.

12% opposed it and the remainder were unsure, http://www.bbc.co.uk/news/uk-scotland-11821324, still live 18 April 2013.

For some discussion of the bill as it was proposed in 2012, see http://www.palliativecarescotland.org.uk/news/news/proposed_assisted_suicide_scotland_bill/, last accessed 25 April 2013.


guardian.co.uk, Tuesday 7 July 2009, ‘Assisted dying: not in our name’.

The full Submission appears in an Appendix at the end of this Essay.

Conversations with Marie Curie nurses.


In conversation with Marie Curie nurses.

Based on findings in the Netherlands, Oregon and Washington State, Evans, pp. 128-30.


Kelly, Meaningful Funerals, pp. 118-9.

Bruce Rumbold, quoted in Kelly, p. 121.

Beau Stevenson, Pastoral Care Advisor to the Diocese of Oxford; conversation with the author, 2012.