

Christians on Ageing Annual Conference

‘What on earth should we do about dying and death?’

Wednesday September 25th 2024, by Zoom, 10am-4pm

Welcome and introduction to the day

CoA’s chairman, Revd Dr Keith Albans welcomed everybody and invited a short self-introduction from participants.

In the morning session, we heard from **Revd Dr Joanna Collicutt**, Anglican Priest, Theologian and Clinical Psychologist, and one of the authors of the recent BRF publication *Death & Life: A church’s guide to exploring mortality*. Her presentation (below) was followed by discussion groups and feedback, ensuring a chance to exchange views with others.

Death and Life: Exploring Mortality

Why don’t we talk properly about death and mortality as a society?

First, it’s hard for us to get our heads around it – research shows we can’t conceive of the idea of non-existence even if we understand material decay. Second, it’s existentially and physically threatening for many reasons. Death is fundamentally unpredictable, uncontrollable and reminds us of our ultimate impotence. It involves unknown and possibly extreme degrees of physical discomfort and pain. It means (perhaps final) separation from those we love and, at the end, is undergone alone. It puts an end to our plans and projects, including chances of redemption, salvation, reconciliation, and the fulfilment of our responsibilities to others. It seems to annihilate those who undergo it. The mystery of death is that we can only speak about our observation of it, not from experience of it. But we are called to offer hope and encouragement:

Blessed be the God and Father of our Lord Jesus Christ, the Father of mercies and God of all comfort, who comforts us in all our affliction, so that we may be able to comfort those who are in any affliction, with the comfort with which we ourselves are comforted by God. 2 Corinthians 1:3-7 (RSV)

In order to be empowered and resourced to give comfort, we must first feel the comfort ourselves. As people of faith, we draw on what our traditions and faith communities offer us. What of those of no faith, many of whom nonetheless seek meaning and transcendence in life – a desire for something more than rationalist perspectives? Tom Holland¹ suggests:

The future for the churches is to remind people where these ideas come from ---- from the belief that these were taught by a guy who got nailed to a cross and then

¹ Holland, T. (2019) *Dominion*

rose from the dead and offers the promise of eternal glory in life. These are obviously, objectively to a rationalist perspective, mad things. But the madness is precisely what makes them so powerful --- people want the supernatural, they want the strange, they want what they don't get out of a Labour Party manifesto.

Death and loss are right at the heart of the Christian story

The New Testament was written by bereaved communities who had lived through trauma and faced adversity and danger. And yet they had hope because Jesus had been through it (see Luke 16:30-31 and Hebrews 4:14-15) and been tested by undergoing suffering and death. However, because he died young, violently and quickly, he does not offer us a model for death in later life, which may be anticipated or slow. But we can learn from his experience if we view the Passion as a kind of 'compressed ageing'. We can see how Jesus starts being the passive rather than the active character in his 'handing over'. He becomes depleted, marginalised, objectified, as those who have power in the situation take over. We may be able to see modern-day parallels, such as patients in end-of-life care.

Following Jesus in his approach to death

I'm proposing four ways in which we can learn from Jesus' example and experience.

First, **in Jesus' attitude to the bereaved** before his death: He often *saw with compassion* the suffering of others concerning death, such as in the story of the widow of Nain (Luke 7:13). He also *saw with empathy and came alongside*, as with Mary of Bethany at the death of Lazarus (John 11:33-35). He *saw ahead to the needs* of the bereaved, as he did whilst dying, concerning his mother and his best friend John (John 19:26-27). Today, the messages of the dying will often include 'I love you' and 'Look after the others'.

Second, **in Jesus' preparation for his own death**, we see him *facing it* (Luke 9:51 and 13:33, and Matthew 8:31-36) but *not seeking it* (Matthew 26:37-39). The Gospel of John also records the *gifts that Jesus offered* in his 'farewell discourses' in chapters 13 to 16. These included the service of the washing of the disciples' feet (13:3); the promise of the Holy Spirit (14:16); and the ongoing attachment shown by the 'true vine' (15:1). Primarily, of course, the last supper (Luke 22:19) offers a *re-remembrance* – a kind of putting back together – foreshadowing his death. Last in his preparation we see Jesus seeking and accepting the *ministry of others* as he moves alone into the last part of his journey (Mark 14:3-9 and 32-34).

Third, **in Jesus' final approach to death**, we see him *crying out* – over Jerusalem, as he enters the city, and in lament as he faces what is to come (Luke 19:41 and Hebrews 5:7). Thereafter he begins the *move from active to passive*, letting the events take him. This was because the time was right (the 'kairos' moment), that passivity (dependency, as we might see it today) was the only response, and that opposing action was irrelevant (no means of 'saving yourself').

Fourth, **at the moment of Jesus' death**, then, we see that he is under the *control of others* and the physical process involved. He is in physical agony and experiences *separation* from his Father. He undergoes this alone, as most of his followers have run away. He remains faithful, however, even as he *undergoes doubt and questioning*, and draws on scripture (see

Psalms 22). The outcome is annihilation for over 24 hours; the *emptiness and fact* of Holy Saturday is significant: he actually died.

Jesus as a 'creative worker' in his death

Jesus gives us examples of what death can achieve. As just discussed, this will often need attention and focus beforehand. John reports a key statement of Jesus about a grain of wheat falling and dying in order to bear much fruit (John 12:24) and his final cry that 'it is finished' (19:30). But the work of Jesus continues in raising us up: we will be remembered (Luke 23:42) and will be among the 'fruits' of the resurrection (1 Corinthians 15:20-22).

The call to follow Christ in his death can be found in the following ways:

- In his active life of compassionate action and empathetic solidarity with those who suffer
- In his careful preparation for death
- In his timely move into his passion and gracious receipt of help from others
- In his creative death and hence his glorious resurrection.

Ageing and resurrection – how we view people near the end of their lives

Old people are often seen as past their 'sell-by' date not only today but also through the ages, including in scripture. I want to argue that the New Testament offers a more positive perspective. Some of its older characters are seen as standing on the threshold of a new age even whilst they are living in the last days of their own lifespan. Their vision from 'over the hill' is the clearer for it – think of Simeon and Anna. Such older people can see vistas ahead that those behind cannot see. Older people can 'dream dreams' perhaps because they have laid down the less important concerns of earlier life. Their voices and visions need to be appreciated by today's church.

How to respond?

First, we need to be prepared to explore more about death. We should learn, and encourage others to learn, about mortality and its meaning for our lives. Such conversations need to be across generations. We need to work out what it means to be resurrection people here and now.

Second, preparation for death involves living well in the light of mortality. Who can be involved in such preparation? How can planning for our last years and days be facilitated?

Older people can be visionaries about mortality and the end of life that we all face. With a sense of mission and purpose and a direction of travel, they can 'set their face to Jerusalem' but do a lot else on the way! That is, they can envisage the end but enjoy the journey. We all need to grasp the times and seasons, and create safe spaces, to think about these things.

Talking with people near the end of their lives (whatever their age) yields stories and insights. We need to avoid treating such people as 'other' or objects. They may present us with

dilemmas but they are not 'problems to be solved'. Listening can involve hearing and joining the lament that needs expressing. Most people remain very much themselves, not wholly identified by sickness or disability. Living in the light of mortality raises issues that are lifelong, not just for the end of life.

Joanna was able to recommend a new resource from **Bible Reading Fellowship**, which she had co-authored, entitled: *The Churches guide to exploring death and life*. This consisted of a workbook and associated resources that would enable a church to learn much more on this topic but also put on a six-session course for others. There was an accompanying set of reflection cards that could be used as discussion starters. Visit www.brfoonline.org.uk

Feedback from morning groups

Dr Collicutt had suggested some questions for groups to discuss. Participants were allocated randomly to groups/questions.

Group 1 was facilitated by Revd Dr Joseph Cortis.

Q: How do I think about death?

- Some people welcome the opportunity to reflect on this question
- The proposals offered for consideration (in the session) were all valid and real
- Happy that death is not seen as the end but the way to die may be off putting: protracted, in pain, remorse etc.
- The context in which death happens is very important and influences what the individual thinks about death
- Role of culture is very important e.g. western cultures are perhaps not as open as others to talking about death
- We as human beings are very bad at not being in control
- What does the often-heard phrase 'Far too young to die' mean?
- If the concept of death is not real it will stop us living
- How do we deal with the transition from one stage of our lives to another - reference to the Book of Ezekiel
- Our own personality has a bearing on how we respond to the question posed
- We need to suffer but how do we process its meaning? Reference was made here to the classic writing of Pope (Saint) John Paul II
- Importance of real memories, perhaps recorded, for those left behind.

Group 2 was facilitated by Sister Maureen Murphy

Q: What item we would like put in our coffin?

- A sewing needle to represent a life of creativity
- Bible showing the values and way of life the person tried her best to live
- Father's Bible because it had loose-leaf notes which were precious
- Pair of running shoes because someone was always trying to do better and to catch up
- A book *Letters and Papers from Prison* by Dietrich Bonhoeffer because of the immense hope it offers.

Q: What advice would we give to a young person?

- Before the end of the day forgive others and yourself for any hurt/wrong-doing
- Wait a while before you respond to a letter/email or situation in order to think about the best or right thing to do or say
- Look into yourself and then be that person; follow that path.
- There comes a time when we have to make crucial decisions about who we are and where we want to be – do not delay too long to decide but be brave and courageous and do not worry about what others will think.
- One person had already said goodbye to her grandchildren in Australia because she will not go again and she told them as she left "Be kind, work hard and love Jesus".

Group 3 was facilitated by Dr Joanna Walker

Q: What hymns/songs do I want at my funeral or memorial service?

- The choice of sung items rather depended on the extent to which the service was for you (the departed) or for the congregation. We agreed it should be a balance of the two but it was important to 'complete your story', which could be done very well through music.
- Little-known musical items should be avoided (which led to 'awkward mumblings'). Alternatives included listen-only recorded hymns/songs to aid reflection, or sung recordings that gave a good vocal lead.
- We all recognised the fast-pace of changes in funeral/thanksgiving practice. The focus, even in more traditional settings, was very much on the unique life of the individual concerned rather than liturgy. The menu of music was therefore much larger than church service fare.
- Current trends meant that ministers needed to be open to new forms of memorialising – such as online celebrations or even no service / direct cremation. However, group members who were involved with funerals/thanksgivings felt that it was an honour and privilege to be involved with families at this time, ie. the human

aspects of conducting services. They observed that grief is the most complex emotion.

Group 4 was facilitated by Marion Shoard

Q: What form would I like my remains to take, and why, and where would I like my remains to rest, and why? Or am I bothered?!

- Anyone who imagines Christians would be uninterested in the form and location of their remains will be confounded by this discussion. In these environmentally aware times, the fact that a single cremation generates releases 160–190 kg of carbon dioxide, which is similar to driving a car 470 miles, was a cause for concern. Burial too has some environmental impact – for instance, chemicals from traditional coffins leach into ground-water.
- We discussed briefly the option of donating one's body to medical research or student teaching – this can be considered commendable, but one has to bear in mind that no corpse is present at the time of a funeral held soon after death, as the person's remains are usually returned to the family at a later date for cremation or burial. This can affect the nature of the funeral service and the way in which mourners think of the deceased person.
- Several members of the discussion wished to be buried, for various reasons: the Catholic Church considered cremation a sin until 1963; burial seemed more natural; Jesus had been buried. We observed that while some people like to see an open coffin at the funeral or the body of the deceased beforehand, others find the presence of any coffin at the funeral uncomfortable.
- We noted the Jewish tradition of families visiting graves in the fortnight before the Jewish New Year to pay respect to the memory of loved ones. The Christian equivalent is All Souls Day.
- One member of the group said he would like his body to be received into church the night before his funeral, followed by a full requiem mass at the funeral. Cremation could follow.
- Natural burial, in which the body is dressed in biodegradable cloth, laid in a biodegradable coffin and buried at 3 rather than 6 feet (where the body decomposes more quickly) appealed to some. One problem was later finding the spot where a loved one had been buried, as woodland often grows up over the site of the burial. Could a memorial stone be placed above?
- What should any memorial stone say? We wondered whether one should go against the grain and rather than simply recording the esteem in which the family hold the departed announce instead or in addition their contribution to society, say 'poet and seamstress'.
- Stronger views were held on where to seek burial. For many Irish Catholics, this should be back in Ireland. However, for the many who die in London, the cost of repatriation is usually prohibitive. To make matters worse, it is difficult to find an inexpensive burial plot in or close to the capital, often leading to cremation.
- We were told that the majority of people in Zimbabwe oppose cremation, as the body is viewed as the sacred symbol of the person who has died. Funeral directors there

provide schemes enabling Zimbabweans to contribute to a fund to pay for the repatriation of their body after death and its burial in Zimbabwe.

Music as a support for those approaching death

The lunchtime 'creative practice' slot that has become part of our recent conference programmes was led this year by Music Therapist, Brigitte Schwartling. She had worked in hospitals, hospices and the L'Arche Community and was a pianist, organist and choral director, with 30 years' experience in the UK. She engages with individuals and groups, children and adults, and people living with learning difficulties and with dementia.

Brigitte felt that music was important in life for reaching and relating to people. Music can reach parts of us that are difficult to express. She asked us to reflect on ever feeling 'taken out' ourselves through music. We all learned and joined in a simple four-line song with actions to denote positive states of mind: awareness, presence, calmness, freedom, feeling loved, strong and healed.

Brigitte shared three brief cameos of the effect of music therapy in end-of-life situations.

- A child, around eight years old, in the last phase of life needed her heart rate lowering. This was achieved by gentle singing to a sounding bowl, during which her breathing regulated.
- Phone conversations with lonely older people during Covid (offered by a Manchester charity) featured singing with a keyboard and an encouragement to compose simple songs about their lives.
- In a child oncology setting, a grandfather rang to say that his grandchild's death had been peaceful and they had been comforted by a song that she had written during music therapy. He felt that the song was a gift and legacy for the family.

Brigitte proposed a number of music therapy 'truths' or principles:

- Our responsiveness to music is human.
- Music enables connection on several levels – personal (within a person) and interpersonal. It can help a mind to heal.
- Active involvement in music (including listening) activates all areas of the brain.
- The social components of music open doors to social relations.
- Psychological benefits include confidence and sense of identity.
- Musical taste is very personal – different music will have different effects on different people.
- Musical pulse and tonality can be reassuring, as it activates the parasympathetic nervous system.
- Music can also be a stimulus, as the brain will latch on to it.
- The quality of connection with music will depend on many factors, eg. its familiarity, likeability.

- Live music adds a further dimension because it includes relationship – connection to others.

Brigitte gave us some questions to take away for further reflection:

- What kinds of music do you like?
- Do you use it to improve your mood?
- What is your experience of making music?
- Are you able to share your tastes in music, and know/ appreciate the tastes of others?
- What part could music play in a period leading up to death?
- How could music be used in preparing for death or planning a funeral or thanksgiving? For instance, could you talk to loved ones about music, or even create a play-list for yourself or others?

In the afternoon session, we heard from **Gerry Burke** on his new edition of *Dying and Death*, and heard two perspectives on the current debate about assisted dying from **Rabbi Jonathan Romain** of the Religious Alliance for Dignity in Dying and **Revd Katie Tupling** of St Hugh's College Oxford and Disability Adviser for Oxford Diocese.

Dying and death – Faith perspectives in a secular society

Dr Keith Albans introduced Gerry Burke, CoA's honorary Vice-President and previous chair. Gerry had extensively updated his 2010 publication '*Dying and Death: Faith perspectives in a secular society*' and was pleased to launch the revised publication today. Conference attendees will be sent a complimentary e-version of the new booklet. He recalled an early professional experience concerning death, whilst in ministry as a chaplain, for which he had had no preparation. Furthermore, since then, the social and cultural changes of secular society had been immense.

Most recently, Covid had brought an experience of death close to many, despite a general culture of avoidance. So, Gerry had found himself pondering again the question of what difference a Christian perspective made to the human propensity to wonder about death and after death. Persons of no-faith would also have concerns about the how and when of death and its legacy. Christianity could offer the game-changing idea of resurrection and, in practice, the comfort and consolation that is part of learning to walk with God and being with him, in life and through death.

The Assisted Dying Debate

Keith Albans, as chair, introduced the next part of the afternoon, noting the current prominence of this debate in public discourse. Whereas it had used to be understood that all

people of faith would oppose any kind of assisted dying, this was no longer the case. The debate is now more focused on what faith might advise about levels and types of mitigation or safeguards. Legislation to provide for some form of assisted dying has now been envisaged and was actively being developed. Rabbi Jonathan Romain and Revd Katie Tupling had been involved in such a debate on an edition of Radio 4's *Beyond Belief*. We were delighted that they were both able to join us today. Each would provide a brief introduction to the topic, from their perspective, and a few minutes of Q&A would follow for matters of fact/clarification only.

Rabbi Jonathan distinguished between some of the terms often used and heard: Assisted suicide was the taking of a life in cooperation with the person concerned, at any age or state of health. Euthanasia was a killing of someone by an individual or the state. Assisted dying is proposed for the terminally ill only (thus not applying to persons with disabilities, who are not dying) especially if dying is painful or difficult. Mental capacity is required at the time of the request for assistance; a pre-written request, for example in a 'living will', is not adequate. Assisted dying is not about shortening life but about shortening dying that is already in progress.

Rabbi Jonathan stated that he was just as much in favour of palliative care, but had seen too many of his congregants dying in pain. This was not a big leap into the unknown, since such services have been running in other countries, whose experiences we can assess. Assisted dying had been available in Oregon for 25 years, which system was regarded as 'safe' and had not required changing since it was introduced.

The alternatives for terminally-ill patients in pain or distress were to suffer on, to commit suicide, or visit Dignitas (expensive and therefore exclusive). Jonathan believed they should have a right to choose a better death and that others should not stand in the way of this, since avoiding a bad death is compassionate. The book of Ecclesiastes reminds us that there is a time for all things under heaven, and a compassionate, modern reading of this supports the idea of a time to die as being a time of our choosing. A Bill is likely to be presented in this Parliament and to have positive political and social momentum. The aim for people of faith should be to help make it happen well, and in the best form, by working positively with the questions and doubts that surround the whole issue. He urged people not to deny what they themselves might come to want, later or in other circumstances.

In answer to a question about whether palliative care can be failing, inadequate or missing in some situations, Rabbi Jonathan felt that it could be. Medical situations may not allow /enable it to take place; some conditions are impervious to eradication of pain.

Revd Katie drew on her experience of disability and disability rights. She was against legal changes regarding assisted dying from a sense that all legislation sends a wider message. It would alter society's view of people who were elderly, sick or disabled, seeing them as having a lesser quality of life and as burdens on society and others. The obligation to 'shuffle off' could turn to covert or even overt coercion, on individuals or their families.

Another version of the 'thin end of the wedge' argument was the widening of criteria for assisted dying that had been seen in some countries' experience of it. For instance, initial

criteria required doctors' confirmation of a terminal condition leading to death within 6 months. Over the years, in some places, this had widened to other chronic conditions that were life-limiting and distressing, but not immediately terminal.

We should invest in palliative care widely and consistently, to improve the current 'post-code lottery' of patchwork provision. The issue of involving doctors to confirm access to assisted dying needed looking at. Were 'disinterested' medics better (more objective) than doctors who had known the patient?

Allowing doctors to prescribe lethal drugs crosses the rubicon of 'do no harm'. The circumstances of how and when to end a life are difficult to legislate for and then change if necessary. It involves a breach of bodily integrity and does not contribute to healing – unless death is viewed as a form of healing. Historically, we need to be wary of wiping out a group or class of persons deemed to be a burden. Keeping legislation fully accountable (and up to date) for the criteria it identifies is difficult, especially where such nuance is involved. Loopholes and unintended consequences will abound.

The House of Lords in a report of 1994 said that it was impossible for all acts of assisted dying to be guaranteed as free of coercion, and this conclusion still stands. Disabled and other marginalised groups already die earlier than other groups, simply because of issues in access to health care. Are we to be in the business of helping marginalised people to die? Katie feared the gradual move from assisted dying for the terminally ill, to the chronically ill, to the disabled.

A question from the floor speculated whether money and cost could become a major source of coercion, not so much for inheritance but to avoid costly care / nursing fees?

Group discussion followed, in four different groupings, for the afternoon on the question: *What can we do or say regarding safeguards around legislation for assisted dying, for older people in particular?*

Group 1: facilitated by Joe Cortis

- On the topic of coercion, the group had discussed the issue of organ donation as an example of a procedure that could be chosen without pressure.
- The group also discussed how the circumstances of dying in peace could be (made) possible.

Group 2: facilitated by Maureen Murphy

Given that a change in the law will probably come soon how can we influence what will happen?

- Most of the group felt it was right to support a change in law because it was the compassionate response to the needs of people who are suffering.

- We felt we should be able to protect people at the present time but the difficulty will come in the future if the wording is changed from “Terminal illness” to “Chronic illness” because future generations may think very differently to our own time.
- As Christians, we have our own beliefs and values but we cannot impose these on the wider secular society.
- Many doctors are now afraid of being sued if they prescribe enough morphine to keep someone pain free and we heard of several examples of people even in hospice dying in pain.
- The Play “Unspeakable Conversations” was recommended.

Group 3: facilitated by Joanna Walker

- The group considered what would make *us* feel safe, regarding the option of assisted dying?
- Does having professionals ‘sign off’ on the proposed choice provide reassurance? How many professionals, and with what knowledge of the patient? Do greater numbers of professionals required give greater confidence?
- Living Wills may assist with the background to a person’s intention but they are guidelines only, and timing is an issue if they were drafted some time previous to the current decision.
- The current draft Bill is a private members’ bill and not to be introduced by Government.
- Doctors’ ethics have historically included that their actions should not unnecessarily prolong life. Perhaps this could be more fully recognised in the current debate, as an option in ensuring that people are not surviving in pain and distress due to unnecessary treatment.
- Faith communities could play a part in talking more openly about death and dying.

Group 4: facilitated by Marion Shoard

- We considered that the provision of safeguards was extremely important in any law to legalise assisted dying, not only for the reasons commonly advanced, such as that someone might later change their mind, but also because of the potential financial factor in any coercion. Older people, in particular those who need substantial amounts of care including in a care home, can quickly get through a large amount of the money their heirs might be very keen to inherit.
- In care homes, their own home or perhaps in a granny flat, older people may live isolated lives, cut off from outside society, perhaps without easy access to a phone or computer. They may lose a sense of their own self-worth and might be more easily persuaded or enticed by an heir to agree to sign the form, even against their better judgment.
- Lord Falconer’s Bill requires a witness (who must not be a relative, nor involved in the person’s care nor likely to have a pecuniary interest in the person’s death) and two doctors to be persuaded that the person proposing to take the poison should not be acting under duress or coercion, but we considered more robust safeguards to be necessary.

- In the limited time available, we focused mainly on wondering whether there could be a requirement that the state should ensure that an independent person spend time with the person proposing to sign an assisted dying form to get to know them, their background and motives and to discuss the matter fully with them.
- This might be done through a legal requirement that in these circumstances the state must provide an advocate, as happens in certain other circumstances. For instance, the mental capacity legislation requires a health or social care body to make arrangements to enable an independent mental capacity advocate (or IMCA) to represent and support somebody who lacks mental capacity when they face major decisions such as whether to agree to major surgery or to relocate to a care home. Advocates go through a vetting and training process and work within rules and guidelines.

Our two afternoon speakers were invited to make some closing observations

Revd Katie Tupling:

Changes to the law regarding assisted dying were neither easy to discuss or enact. Any law will have loopholes where vulnerable people could be coerced, or coached to give appropriate responses. We need to re-state that the vulnerable are not un-valuable. Thanks very much for wrestling with this topic today.

Rabbi Jonathan Romain:

Society and its understanding of such matters has changed enormously, which should be recognised. All major declarations and policies continue to support medics to act in the best interest of their patients. Changes in practice may alter doctor-patient relationships, but maybe for the better. Coercion around the end of life already exists, and new legal arrangements could introduce checks and balances.

Final reflections from Conference Chair, Dr Keith Albans:

Challenges remained to further define what safeguards are needed to prevent coercion or widening of scope for assisted dying. Examples from other countries showed mixed experiences. Some had changed and broadened their scope in ways that some may fear; others had not evolved but preserved their original purposes. We seek safeguards that guarantee people have the best options and the best possible law to protect them.