

PERSONAL DEATH

By EVA HEYMANN

IN THIS ARTICLE, I AIM TO REFLECT on personal experiences of death in the daily process of living, dying and newness of life. I will draw on events which touched me during early childhood as well as in my current work with people who are HIV+/AIDS. Contrary to popular opinion, people who have the virus proclaim that they are living with AIDS, not dying with AIDS. This is not a denial of death but an affirmation that death and life are interlinked. This statement has echoes in many of my experiences of death and witnesses to my Christian faith in resurrection. It also resonates for people of other faiths where there is a belief that death is not the final act of our living and loving here on earth, each in his or her own uniqueness and in our shared brokenness. Although I will be focusing mainly on physical death, I will also include the wider range of death experiences and explore how our attitudes and responses to death are affected by the value system of our society.

Birth and death

One experience which is common to all of us is the fact that we were born. I believe it is also our first experience of personal death, for in order to be born, we have to leave the security of life in the womb, enter a dark journey into the unknown, and experience the shock of arrival into a very different dimension of life. Theoretically speaking, that could be described as a pattern of our living and dying, as we embrace the constant challenge of what hinders us in our journey, leaving behind what can enslave us, so that we can move forward towards the greater freedom of eternal life. But in practice, we live in a society conditioned to deny death.

It may be for this reason that many at the time of their dying feel so confused and guilty. Like sex, death has been whispered about behind closed doors. We feel guilty for dying, not knowing how to live.¹

A consumer society encourages striving for wealth and success in this world, rather than prioritizing values which enable us to view this life as a preparation for eternity. In our materialistic culture, death is not easily recognized as a birth process. It is more often regarded as failure and feared accordingly. Fear inhibits life and that was my first experience of contact with death.

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Darkness was upon the face of the deep

I was born and lived in Germany for the first twelve years of my life. My parents were Jewish, so we experienced the full effects of Jewish persecution. The predominant feelings this provoked were fear, anger and a sense of helplessness. These are common reactions to death and dying, but in the context of sadistic pogroms against individuals and a whole section of society, the struggle for survival is costly and the effects are likely to be long-term. At the time, I could make no sense of the experience. Why being Jewish were we made the target of such persistent hatred? The systematic diminishment of our lives, partly through exclusion and isolation, was a prolonged experience of dying with the very real expectation that violent death could be the end of that process for any one or all of us. The undeniable message promulgated by Hitler and his followers, reinforced especially by the secret police, was that Jews were a source of pollution which needed to be eradicated. People 'disappeared' and the fear of torture became a reality, especially when those who had been tortured were returned to their families as a sign of warning. Placards outside food stores, other shops and public places proclaimed: 'Jews forbidden'. After the events of *Kristallnacht*² Jews in each town were herded into cattle trucks, stoned, jeered and driven to synagogues. There they were locked in and the buildings were set alight.

I am writing this article at the moment in time when the events in Bosnia and other parts of the world point to the fact that the unleashed forces of hatred which led to the Holocaust are as alive now as they have been throughout human history. For many people the fear of death is deeply embedded in their personal experiences of daily struggles to combat oppression through a variety of different forms of abuse. The wide range of sexual and physical abuse highlights this.

Many years after the events which we experienced in Germany, my mother, sister and I shared some of our feelings, including our subsequent impressions of being refugees in England during the war, when we were classified as enemy aliens. My mother's response amazed me: 'Nothing in life is wasted'. Each one of us left Germany on our own and, given the fact that she was the last one to come out and had endured the anguish of uncertainty whether we would ever meet again, such a remark speaks of immense courage and signifies that the human spirit of hope and love can triumph even over the death-dealing forces of evil.

I have referred to these personal experiences because I believe that they shed light on some aspects of our deeply ingrained fear of death and dying. Commonly, death is perceived as a force of destruction which

overpowers us and, however we struggle against it, we fear the reality that we cannot escape it. Hitler's ideology was to create a super-race, pure and powerful. In this fantasy, the elect would be without blemish and they would live, dominate and thrive. The designated impure, the Jews, gypsies, homosexuals, physically and mentally handicapped were doomed to death. Is it perhaps our fantasy that 'we' would not do what 'they' did? Yet in our place and time, can we ignore the divisions created in our society between those who are powerful and thriving and those who are marginalized, diminished and struggling to survive? The fear of death and dying is often related to fantasy as well as reality. The fantasy of the powerful, financially and socially secure, can be that death is only a remote possibility, far enough removed not to be addressed. The actuality of the powerless is that death is an ever present shadow. Is there a reality which bridges the polarization of these attitudes to death? I think there is.

To thine own self be true

Father Bill Kirkpatrick reflects:

The awareness of death can become one of the most creative and encouraging spurs of life. The denial of death is partially responsible for people living empty unfulfilled lives . . . Our growth into our own personal dying reminds us quite forcibly that one can only be fully oneself if one is no one else.³

If we allow ourselves to become the label others project on us, then we stunt our own growth. Paradoxically, it is often those who are dying who point the way to those of us who will outlive them, to be true to ourselves, accepting who we are and with joy accepting others in their uniqueness, aiming to do so with the same unconditional love which Christ offers to each of us. This involves us in our daily dying and our own inner healing of past hurts and resentments. I have often heard people say: 'It has taken this to bring us together'. When someone we love faces death, there is an urgency to be reconciled and to allow mutual healing to take place. I have been privileged to be part of such a process many times and owe much of my own inner healing to the power of love which such moments generate. Sadly, that is not always the case and there are times when, for a variety of reasons, there cannot be that movement of letting go in order to move to a new relationship of deeper love. Yet we need to enable each other to discover the truth that 'Love is the link between life and death and between death and life. Love is the invisible fabric of the whole of creation.'⁴ When we recognize that truth, then the fullness of

Christ's redemptive love can touch us in our brokenness and enable us to let go of our defences. It was Danny who shattered some of my defences and my spiritual complacency. He reminded me of the reality that strength is found in weakness and that love is the transforming power in both life and death. In the recognition of that truth, we are set free and can move forward with new confidence into the journey of dying which leads to eternal life.

I met Danny in hospital. He was in a side room on his own, lying on his bed. One of his legs was heavily bandaged, but what caught my attention was the laughter in his eyes. Danny exuded life and joy, which certainly did not match the stereotype of a man who was dying. I was taken aback by his first question: 'Does it smell?' I told a white lie, for there was a faint musty smell in the room. Danny explained that he had Kaposi Sarcoma, a form of skin cancer which affects people who have the AIDS virus. In his case, the lesions had fungated and the whole of his leg was an oozing mass of fungus. Hence the unusually large bandage and Danny's concern about a bad smell.

Later, Danny told me his story. When he was first diagnosed HIV+, he decided to share that information with members of his parish, for he needed their support at this time of crisis. Sadly, their response was death-dealing, not life-giving, as he had hoped. They made it clear that he would no longer be welcome as a member of the church community. So Danny not only left his local church, but he turned away from God and discarded his Christian faith. He said: 'From then on, my legs took me to all sorts of places where I should not have gone. The light had gone out of my life and I lost all sense of direction.' That changed when he was admitted to hospital. He was amazed at the love and care shown by the nurses and doctors. 'I felt accepted here and began to realise that God accepts me as I am and that includes the virus and this leg. So I have to learn to accept myself and that means I have to learn to love my leg.' His words touched me like an electric shock! Could I learn to accept the unacceptable parts of myself and learn to love them with the compassion that this requires? I believe that it is difficult to reach that point on our own. Danny's vision of life and love grew out of his experience of rejection, which can diminish life, and the contrasting experience of acceptance which is linked to unconditional love. He recognized that he had the power to make conscious choices in his responses to God, to others and to himself. He died a few days after our meeting, leaving me with the awareness that my life had changed direction because I had met a man who learned to love his wounded self in the light of God's compassionate love. He was at home in himself and could travel unburdened into his eternal home.

Danny exemplified another truth: God meets us where we are, each in our uniqueness, and communicates himself to us in unexpected ways. Initially for me, the beauty and wonder of nature led to an awareness of God's presence in the world and that, too, was the experience of one of my relatives who spent three years in a concentration camp. She had no faith, but she told me that seeing a wild cherry tree in blossom each spring, beyond the barbed wire, evoked for her the hope and truth that God did exist and that there was a life beyond the camp.

There are times in our lives when the choice between life and death is not clear cut. Brigid came to see me at a point when her daughter was coming to the end of her life's journey. She had several AIDS-related illnesses and her quality of life was diminished through blindness caused by the virus. She had asked her mother to help her end her life. One of the painful facts for parents whose sons or daughters have AIDS is the realization that the young people will die before their parents. It is not unusual to hear relatives, lovers and friends say, 'I wish I could take his or her place'. Love can motivate a sacrificial response, but the request made by Anne, Brigid's daughter, posed a question to which no parent can respond without pain. Eventually, Brigid was able to tell her daughter that she would do everything to enable her to die with dignity and without pain, but that she would not take active steps to end her life. Anne wanted to die at home and was well supported by her doctor and care teams. Initially she was able to control her own flow of morphine under the guidance of her doctor, but eventually she was no longer able to do this. Her mother felt that she must keep her promise that she would enable her daughter to die with dignity and with the pain control needed, and she agreed to administer the controlled amounts of morphine. Her daughter died peacefully, but in the pain of grief and bereavement, Brigid is now struggling with the haunting thought that she may have killed her daughter.

Brigid was very clear in her initial response to her daughter's request to aid her in ending her life. She did not wish to engage in euthanasia. But her subsequent confusion indicates that there is an increasing need of pastoral catechesis to help people to distinguish between the euthanasia which in Christian belief is wrong, and the responsible decisions which doctors and nurses sometimes have to take to end artificial prolongation of life which never again can become true life.

It is likely to be a long journey for Brigid to work her way through the confusion of her inner darkness and the sadness that her relationship with her daughter had not always been an easy one. It is at times such as these that, as a companion of another person's life journey, it is

important to be there, even though it is with a sense of helplessness. I realize increasingly it is through our weakness that God's power is at work and that it is in our choice to be there that we dare to believe that we can share in his passion, death and resurrection. There is a line from a modern version of the *Anima Christi* which exemplifies this for me: 'On each of my dyings, shed your light and your love'.

Let your truth and your light lead us

How do we enable those we love to move on from this life into the fulfilment promised by Christ, or those who do not have that faith to move into the next phase of their life after death? In the area of AIDS we are now beginning to work with families spanning three generations, of grandparents whose adult children are dying and grandchildren who have the virus and need to be cared for once they are orphaned. Multiple death in a family presents us with challenges which have not previously been part of our life and death experiences. 'How can I bury my daughter and prepare to mourn for my son-in-law and for my grandson?' That was how one grandmother expressed her dilemma. In a social climate where fear, stigma and ignorance still isolate people who have AIDS, there are no easy answers to this problem. But there is no doubt that in the face of such tragedies, people are discovering new truths in their lives about dying, living and loving.

The hospice movement has transformed our understanding of the care of the dying, particularly by enabling people to be in an environment where unconditional care can be offered to those who are dying and to their immediate carers. For many this has been supportive and enabled them to come to terms with the reality of physical death and at the same time with spiritual realities in their lives. But inevitably, there are many people who have no access to a hospice or may not wish to use this resource. So there is a need to provide alternative support systems which allow for individual needs to be met.

Working with the dying and their families has highlighted for me the tragic fact that at a point when we would wish tranquillity and peace for a dying person, there is often stress and turmoil. Commonly this is caused by unresolved personal relationships between the nuclear family and the partner or chosen family of the dying person. In an attempt to recognize and respond to such difficulties, a project has recently been launched, enabling people to make a Living Will. The Terrence Higgins Trust, together with King's College, London, has produced a format which has the approval of the Medical Association. There are four sections covering the following points:

a) A person can be designated to be at the bedside of the one who is dying.

b) Wishes about the use of the particular treatments and investigations can be expressed.

c) A health care proxy can be named to carry out the wishes of the dying person, who may no longer be able to express these for himself or herself.

d) Statements can be made regarding a person's wish to be kept alive through medical intervention or alternatively to have treatment limited to pain control.

The Living Will is a formal document, though at present it does not have legal status. The response to this document has been widespread and favourable. It has been welcomed as an ethical statement regarding an individual's right to make responsible decisions about the most important event in life: the moment of death.

I have recently had a practical experience of working with a family where a man had made a Living Will, designating a close friend to be the person by his bedside. It was a most painful and in some ways humiliating experience for family members to be publicly excluded. They waited many anxious hours, angry that their assumed rights as family members to make decisions for the dying person had been taken from them. But in that process, the mother of the family began to accept that in respecting her son's wishes, she could show her love for him more effectively than in any other way. She said to me later: 'Had I sat by his bedside, I would have satisfied my needs more than his'. She became aware that she had always tended to impose her views on him, and that there had been little opportunity to listen to each other. Sharing that awareness with other members of the family enabled them to enter more deeply into the death experience as it touched each one of them. When each one was called to the dying man's bedside, they could use their time with him in a far more meaningful awareness, and say goodbye with deeper love than might otherwise have been possible. In the shared experience of living, loving and dying, the family bonds were strengthened. Often the dying person is the enabler for those who are living to enter into their own experience of daily dying in such areas as the need to be in control and to exercise power over others.

To be sensitive to the needs and wishes of those who are dying and to empower them to express those needs enables the dying person to travel lightly without bearing the burden of concern and anxiety about those who are left behind.

There is a poignant example of this in the story of Ben, an eight-year-old boy with haemophilia. His parents and younger brothers were fully

involved in his journey towards light, which is also the title of the book describing his journey and theirs from the time of diagnosis until his death.⁵ When Ben was clearly at the end of his journey, his father asked him if he knew what was meant by making a will. Subsequently, Ben designated each of his possessions to particular people he loved. He was enabled to let go and dispose of his precious belongings in a dignified way. He also chose when and how to say goodbye to his grandparents, friends and his immediate family. In his final hours, his mother was able to be there with him and with the strength of her love, encourage him to 'go towards the light'.

Over and over again, we are shown that it is love which releases a dying person to go forward through death into life beyond death. Sadly, within our human brokenness there are often barriers which prevent that process. To seek forgiveness, to accept forgiveness and to forgive ourselves is the gift of Christ's redemptive love for each of us, but it requires of us a dying to false energies in our lives and a readiness to live in faith and trust allowing God's power of love to supersede our own limited agendas of our responses to life and death. The anguish this can cause is expressed in an anonymous prayer, longing for reconciliation:

AIDS has separated me from my family. God help me and them to realise that I haven't changed. I'm still their child, our love for each other is your love for us. Help them overcome their fear, embarrassment, guilt . . . Their love brought me into this world . . . help them share as much as possible with me.⁶

We need to hear that cry and respond to it. To do so, we need one another so that Christ's compassion, patience and non-judgemental understanding of our weakness can be shared in the giving and receiving of love. We need a community of family and friends who will accompany us and enable us to live in the truth of our own uniqueness. We need to pray for this.

AIDS has caused a separation between me and my Church. Help the Church to restore its ministry to 'the least of these' by reaching out to me and others. Help them to suspend their judgements and love me as they have before. Help me and them to realise that the Church is the Body of Christ and that separation and alienation wound the body.

God of my birth and God of my death, help me know you have been, you are, and you are to come. Amen.⁷

In my end is my beginning

As the title of this article requires that it should be a personal reflection on death, it seems appropriate to end on a personal note.

From my early years in Germany, I learnt that it is possible to experience both life and death within oneself. Physically I had survived the Holocaust, but I had experienced the death of ordinary childhood at an emotional and social level. The gift of faith in later years led to a gradual awareness that death can be transformed through the power of God's love in the pattern of Christ's life, passion, death and resurrection. The unfolding of that faith and the growing recognition of the recurring pattern of living and dying in my own and other people's daily lives, is leading me to see life and death, not as separate events, but as interwoven threads of the tapestry of our lives. Nevertheless, the mystery and wonder of our uniqueness and our common humanity leave many unanswered questions about living and dying. Some of these stem from the appalling effects of injustice which confront us in the power struggles which are manifested in so many different parts of the world, but which I also need to recognize within myself. Working with people who have AIDS and with their families has made me aware of our need to share our common brokenness and our common need of God's redemptive love. It is people like Danny who have highlighted for me that it is through reconciliation with God, with others and with ourselves, that death leads us into a new dimension of life.

The powers of evil which are expressed through the age-old methods of the persecution of minority groups are felt through fear, stigma and isolation. The most death-dealing of these three elements is fear. But the contrary powers, generated by many of those whose life journey I have been privileged to accompany, witness to the fact that faith, hope and love are not vanquished and the greatest of these is love. We may not know the actual hour of our physical death, but in the meantime we have the power to make choices which affect our own and other people's daily living and dying. When these choices are made in a spirit of faith, hope and love, then we can echo T. S. Eliot: 'In my end is my beginning'.⁸

NOTES

¹ Stephen Levine, *Who dies?* (Bath: Gateway Books, 1988), p 2.

² *Kristallnacht* 9–10 November 1938: the night all synagogues were burnt in Germany.

³ Bill Kirkpatrick from his chapter, 'Life in death—death in life' in *Embracing the mystery*, edited by Sebastian Sandys (SPCK, 1992), p 58.

⁴ *Ibid.*, p 70.

⁵ Chris Oyler, *Go toward the light* (Harper & Row, 1988), p 237.

⁶ 'A litany of reconciliation', by an anonymous writer, in *Embracing the mystery*, p 70.

⁷ *Ibid.*, p 70.

⁸ T. S. Eliot, *East Coker*.