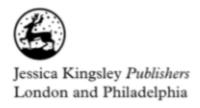
Helping Children and Adolescents Think about Death, Dying and Bereavement

Marian Carter



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Introduction

Working in schools, hospitals, hospices and a parish I have been challenged and inspired by the insights from and conversations with children and young people. It is an amazing privilege. I have always been a teacher in primary and secondary schools and trained teachers and clergy while working throughout in a voluntary capacity with children and adolescents. Bereavement has been a significant area of conversations. For nine months, I lived with a family whose young mother had died leaving three children and learnt rapidly the understandings and needs of each of them. More recently, I have been alongside my teenage niece, an only child, in the terminal illness and death of my sister, her mother. I have worked in a hospital with responsibility as a chaplain for the Special Care Baby Unit; then as a full-time hospice chaplain I was involved with the children and grandchildren of patients, leading funerals with children present and running courses for teachers and social workers on bereavement care.

The book is concerned with how children and adolescents understand death, their own mortality and the death of someone they love, including pets; how children deal with bereavement and funerals; and how they can be supported in continuing care. It is intended to be used by parents and professionals, children and youth workers, health professionals, social workers, funeral directors, teachers and ministers of religion – both those in training and qualified in all these professions – who face children's grief and their questions about death.

This is a theoretical and practical resource, since there is no comprehensive book available, and this is a growing concern with the recognition that learning about death is part of a child's 'primary socialisation' without which the child is likely, subsequently through adult life, to suffer psychological problems such as depression when faced with mortality. I have experienced that children have a freshness and openness in attitudes to death and can be a model from which adults

can learn; adolescents are more thought-provoking! The examples in this book are from my own experience (the names have been changed to honour confidentiality). Although most of my experience is from a UK perspective, research indicates and includes North American perspectives.

Since this book is significant as a resource for those who do not have faith, the material on faiths will be with a light touch. Children do ask questions about death such as, 'Where is granny now?' We need to be open in exploring these with children. These are questions common to those of different religious faiths, and those with none.

Each chapter has a pattern beginning with an illustrative diagram – the hermeneutical circle (see below) – since it begins with experience and leads finally to practical responses. At times, I refer back to the original experience: this is an example of the 'spiral curriculum', since when we return we will have a deeper understanding of a situation.



Each chapter also includes activities to elicit the reader's experience.

Chapter overview

Chapter 1: What is Death?

Children suffer losses, and death is the ultimate loss. Death is experienced in many ways — on the TV news, children playing 'dead' in the playground or the death of someone close, for example

a parent, grandparent, favourite teacher or sibling. The development of the stages of understanding in children come from insights in the psychological and social sciences and listening to the experience of children's voices and questions. Both those of faith and those with none wrestle with the meaning and significance of death.

Chapter 2: Grief and Bereavement

Children experience a range of emotions and express their grief in related behaviour. Grief may seem like jumping in and out of puddles, one minute sobbing the next asking what is for tea. Adolescent grief is more hidden. The grief of an adult is more consistent and is often hidden, a taboo in UK culture. World faiths have rituals and customs of grieving which are distinctive to each faith.

Chapter 3: Challenging Factors Influencing Grief

Grief and the behaviours associated with it depend on the nature of the relationship. Each person responds in their own way. Grief is unique. Different types of death are explored — a miscarriage, terminal illness of a child and parent, a sudden death and a suicide. Each bereavement is unique.

Chapter 4: What Should We Tell Children and Adolescents?

As adults we need to listen to the child; children are very realistic and 'down to earth'. This listening will give us clues to the approach to use to comfort and reassure children. Euphemisms such as 'Gran has gone away for a holiday' and 'Grandad is a star in the sky' are examined. Anticipatory grief and actual grief raise questions about how much a child should be told about a situation. Adolescents need listening to rather than telling. World faiths explore understandings of a life beyond death. How is this handled with children? Is it possible to live on beyond death?

Chapter 5: Schools Coping with Bereavement and Death

Bereaved and grieving children and young people attend school. Should schools respond? An exploration of response is through the significance and practice of pastoral care and through the curriculum. Models of these two responses are suggested. A large proportion of schools are faith schools and reflect each of the different world faiths. Their contribution and the criticism of them are examined.

Chapter 6: Funerals: The Attendance and Participation of Children and Adolescents

Should children be encouraged to attend a funeral? We look at preparing a child for what will happen at a funeral. Can a funeral be child friendly? What arrangements need to be made for a child or adolescent to attend a funeral? Can a child play a role in the funeral? What are the alternatives, if we are taking grief in a child or adolescent seriously? The rituals of each of the world faiths are examined.

Chapter 7: Continuing Care of Children and Adolescents

What form might this take and who might be responsible? As adults we sometimes forget that a child or adolescent needs to revisit a significant loss. However, the continuing remembrance of a loss may become pathological and need professional help. There are public occasions when those who have died are remembered, such as at the Cenotaph. Practical suggestions are given in the chapter to help children and adolescents positively to grieve.

Chapter 8: Care of the Carers Including Ourselves

Parents and professionals are asked to recognise their own losses and remember how they coped; these losses might well be ignited again in working with bereaved children and adolescents. Resources for 'stress busting' are examined and spiritual resources are also looked at.

Chapter 9: Weaving the Threads Together

This chapter is a summary of the important points in regard to the care of bereaved children and adolescents including how, as adults, we can learn from them as well as responding to their grief and distress.

The methodology used in this book

I have attempted to use the methods of Paulo Freire (1921-1997), so that as a reader you may make links with your own professional

experience and relate new insights to your existing life experience and knowledge. Paulo Freire challenged traditional education methods in his book Pedagogy of the Oppressed. His emphasis was on dialogue signifying respect in the pupil-teacher relationship, in contrast to what he describes as the 'banking' type of education, where the educator 'deposits' knowledge into the mind of the listener or reader. Freire believed that the educator had to forget himself, to die in order to be born again and to educate alongside, to teach and learn from the person being taught. Education was about praxis; it deepened understanding and made a difference to building community, leading to actions for justice and human flourishing. His is a pedagogy of hope. He wrote of conscientisation, of developing a consciousness in people that has the power to transform their thinking and attitudes. Freire's learning used personal experience, narrative, the senses, the imagination, life stories, experience and exploring together. I have attempted to follow his example.

The method to be used in this book is one of lifelong learning. In current adult education individuals are encouraged to have a 'buddy' or a 'mentor'. The invitation is for the reader to find someone with whom to share. You will be invited to engage with this book through activities, questions and reflection in the section of each chapter headed 'Activities to elicit the reader's experience'. My hope is that you and your 'work' in supporting bereaved children and adolescents will be enriched. If you would like to enter into a more personal dialogue, then that is possible. I have set up a website (dyingtolive.org.uk) for conversations and comments.

What is Death?

If you never get born you never have to die, but you miss a lot. (Alison in Marshall 2003, p.86)



A child's experience

Stephanie, a three-year-old, lived in a rural village. She and her mother came across a dead pheasant while walking across a field. Stephanie was rather surprised that it did not seem to move. Her mother explained that it was dead. 'If I breathe on it, will it come alive?' she asked. Later Stephanie asked her mother, 'Will you die, Mummy?' 'One day,' her mother replied, 'but when you are much older.'

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Reflection on experience

We each have a need to make meaning from our experiences of life. Children have a drive to make sense of the world in which they live and Stephanie was doing just that. She knew that living things like pheasants move and breathe; if she breathed on the pheasant, it might live. Early humans noted the importance of the breath. The breath was the life, the spirit of a person. When the breath ceased, so did life and death resulted. Children need their questions answered honestly. Her question, 'Will you die, mummy?' needed the truthful answer, 'One day' and the reassuring words, 'but when you are much older' that her mother would be present for her now and for years to come.

An adolescent's experience

The major event of 11 September 2001 shook the world. Many people can recall where they were when the attack on the twin towers of the World Trade Center in New York City happened. Regular television and radio programmes were suddenly interrupted, and American TV took over. We watched in horror. Was this a film or reality? On a clear Tuesday morning an American Airlines Boeing 767 with passengers on board was hijacked and crashed in the North Tower leaving a gaping, burning hole near the 89th floor of the 110-storey skyscraper, instantly killing hundreds and trapping hundreds more in upper floors.

Eighteen minutes later a second Boeing 767 United Airlines Flight 175 turned sharply and sliced into the south tower near the 60th floor. Debris was showered over surrounding buildings. Fifteen minutes later the South Tower collapsed, followed later by the North Tower. Three thousand died in the World Trade Center and its vicinity, including 343 firefighters and paramedics, 23 police and 37 Port Authority police. The event dominated the news for several days. A year later a group of secondary school pupils in the UK were asked to recall the event. Natalie, aged 15, said:

It was like something you saw in a film, but this was real, and that shook me up inside...I kept asking myself, how can any human being treat another with no care at all? No care about whether they live or die, no care about how many families they destroy. (Natalie, quoted in Duffy 2008, p.46)

Reflection on experience

We live in a world where communication can be almost instantaneous. Acts of terrorism continue, fear of further threats of death lie at the door. We are all involved. It may seem as Natalie said, at first like 'a film', but death is a reality, its presence and immanence unknown to us.

Linking adult, child and adolescent experience

In the UK, there is a taboo among adults about talking of death, but this is beginning to change. Groups like the Dying Matters Coalition are beginning to develop, and there are 'Death Cafes': the first in Britain took place in September 2011, organised by Jon Underwood, 'to create an environment where talking about death is natural and comfortable...death is a catalyst to think about important things in life' (Battersby 2012). Underwood mentions that we 'out-source' death to hospitals, behind closed doors, but gradually death is being brought out of the shadows (Battersby 2012). There are websites to be found on the internet through which you can find death cafes near you. Funeral festivals are advertised in national newspapers. They are organised by funeral directors concerned that people should know the choices of prepayment funeral plans, wills and advanced directives. In the USA, 'Death over Dinner' is encouraged as a way to talk in an informal way over a meal with friends and strangers about personal experiences with life and death. One hostess, a former hospice volunteer, said:

We want to talk in an informal way about personal experiences with death. How do people want to die? Have you shared that with anyone? What deaths have you experienced? We don't want to be distasteful, or uncomfortable, but an uplifting atmosphere. (Hafiz 2013)

There are published accounts of dying such as those of *The Guardian* columnist John Diamond (Diamond 1998), Philip Gould (Gould 2012) and Christopher Hitchens (Hitchens 2012). There are guides to dying well, for example that by Rabbi Julia Neuberger (Neuberger 1999) and other factual and fiction books about death (Albom 2003; De Hennezel 1997; Levine 1986; Reoch 1997; Schwartz 1998). An online search will find 'training and life coaching classes' and one of the tasks on such a course is to write your obituary. This is a reality check to ask the questions 'why am I here?' and 'what do I want to be

able to say about my life at the end?' In the USA, Legacy.com publishes self-written obituaries each month; the UK equivalent is ObitKit.com.

There have been reality type films such as the documentary *Life Before Death* (2002) about pain relief for dying patients, *Shadowlands* (1993) the story of C.S. Lewis's wife's dying, *Dying Young* (1991) about a nurse working with a dying young man, *I Didn't Want That* (2012), *The Bucket List — Time to Start Living* (2007) where two terminally ill men fulfil dreams before death and *The Fault in Our Stars* (2014), which tells the story of two teenage cancer patients beginning a life affirming journey. There have also been fantasy films such as *Death Becomes Her* (1992) where an immortality treatment replaces death, *Sixth Sense* (1999) in which a young man communes with spirits of the dead and *Lonely Bones* (2009), in which a murdered girl comes to visit her family. In the UK, the Wellcome Institute had a display from autumn 2012 to spring 2013: 'Death: A Self-Portrait, the Richard Harris Collection'. A newspaper stated:

Death in a secular and medicalized world has been made into something to be put off. All credit to the Wellcome Foundation for holding a show that reminds us that death has been an intrinsic part of life through most of human history. (Hamilton 2012)

In contrast to an adult obsession, young children in particular are fascinated by death and talk about it naturally, though their concept development is different from that of adults. The American psychologist J.A. Graham believes that children's comprehension of death depends on both experience and developmental level:

Children's experiences with death (i.e. actual experience and what they have been told about death) are critical to their understanding, they also do not have enough life experience to realize that death is inevitable for all living things. Children may not understand that death is permanent and that it cannot be 'fixed' or reversed. (Graham 2013)

Death is a loss – the ultimate loss – and is experienced by children and adolescents. In 2012 in the UK over 3000 babies died before their first birthday – for reasons ranging from preterm underweight birth, poor prenatal care, poverty, social inequality and abuse – and over 2000 children and young people died between the ages of one and nineteen. One in five deaths is of those between 15 and 19 years as a

result of road accidents, risk-taking behaviour, poisoning and cancer (Wolfe et al. 2014).

Every day more than a hundred children in the UK are bereaved of a parent, 24,000 every year; 6 per cent of 5–16-year-olds – 537,450 in the UK – have experienced the death of a close friend of the family; and the incidence of memories of childhood bereavement undealt with in youth offenders can be up to ten times higher – 41 per cent – than the national average of 4 per cent. These facts and figures come from the charity Winston's Wish which is the major provider of care for the bereaved child in the UK.

Children and adolescents, in common with everyone, experience loss across a wide range of experience. Physical losses may be the security of the womb at birth, health through infections, a tooth, the hormonal change of puberty or an illness resulting in a loss of freedom which may be temporary or permanent. The ultimate loss is the death of a person – a grandparent, parent, sibling or peer-group friend - or a terminal illness of the child or adolescent himself. Social loss might include moving house and school through changed family circumstances with the ensuing break of friendship groups. Emotional loss is felt with the separation or divorce of parents, parents changing partners, the ending of a peer friendship and the breaking down of a relationship. A loss of self-esteem may result from poor marks in school, failing an important exam or parents' divorce. Loss can be spiritual loss, a feeling of being alone; a lack of self-worth; feeling unloved; or feeling life has no purpose. Loss can be vicarious through television dramas, 'soaps' and from adverts and computer games.

Sociological, psychological and historical insights

What is death? How is death historically defined? In 77–79 CE, the Roman author Pliny the Elder wrote in his *Historia Naturalis*, 'so uncertain is men's judgment that they cannot determine even death itself'. In 1768, the first edition of the *Encyclopaedia Britannica* defined death as, 'the separation of the soul and the body', reflecting the context of a predominantly religious society. In 1974, in the fifteenth edition of the *Encyclopaedia*, the definition was 30 times longer and solely from a biological standpoint. One reason for this is that medical advances make it more difficult to determine if a person is dead. The