

UNDERSTANDING DEATH AND DYING

By FRANCES DOMINICA

Dying is like being born backwards. (Philip, aged eight)

AS IN LIFE, SO IN DEATH, spirituality cannot be isolated from all that makes a person the unique individual God is creating. Body, mind and spirit are woven together intricately and inextricably. Constantly being made aware of this by the children who have taught me so much and of whom I now write, I would be untrue to them if, in attempting to describe their understanding of death and dying, I focused on anything other than the whole person.

Of all the children who have stayed in Helen House in the fourteen years it has been open, 70 per cent have suffered intellectual impairment as a consequence of their illness. The fact that these children are not articulate in no way indicates that their spirit is imperfect. Indeed, again and again we are aware that they exude a spirituality which defies description but which affects all those with whom they come in contact.

Statistics pointing to longer life expectancy and a significant drop in infant mortality make no difference to the child who knows that he or she is dying, or to that child's family – except in so far as they may well feel isolated and lonely because they are different. Their very difference provokes feelings of embarrassment, inadequacy and fear in others.

We are constantly reminded that, unlike our Victorian forebears, we treat death as a taboo subject. (Unlike our sisters and brothers in developing countries too, where death is treated as a natural and important part of life and where between three and four million children under the age of five die each year of gastro-enteritis alone.) So adults protect children from the reality of death by not talking with them about it, consciously or subconsciously hoping that their children will not need to worry themselves with it.

But children always have been aware of death as a part of life, if not through close personal encounters with it then through books, stories,

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nursery rhymes, games, films and today, of course, through the omnipresent, influential medium of the small screen. Fictional representations of death, fantastic (i.e. based on fantasy) or realistic or – worse – a mixture of the two, may be scary or gory or exciting, but they fall into a different category from the face of death captured by the cameras for a news programme or a documentary. Yet both fictional and factual are at one remove, a safe distance from everyday personal experience of life.

A child's initial firsthand encounter with death may well be an insect lying upside down on the window-sill or a mouse the cat has brought in. The death of a pet may be a cause of real grief. But this is frequently resolved in the child's thinking by the suggestion, often the child's own, of a new kitten, rabbit, goldfish or other suitable replacement. There is also a certain matter-of-factness about the situation shown by many small children, exemplified by a five-year-old: 'Mummy didn't want me to see Sammy [the family gerbil] but I sneaked in and I poked him. His eyes were open but it's all right 'cos he's really dead.' Three little girls, four, six and eight, engaged the services of their clergyman father to conduct a funeral service and burial for their hamster. The four-year-old was tearful, the eight-year-old suitably solemn, while the six-year-old busied herself with ensuring that everything was done according to the book. Just as the burial began, the corpse got up and started to walk away. Totally devoid of sentiment, the six-year-old took command: 'Quick, daddy, hit it on the head so it's properly dead and we can finish the funeral'.

Anthropologists and psychologists in recent years have made detailed studies of children's perceptions of death. Twenty-five or thirty years ago the commonly held assumptions were that, by and large, children were not much aware of the reality or the personal risk of death; or, if they were, they had a built-in resilience which enabled them to cope at the time and soon to forget it. We now realize that this is not true. In recent studies considerable attention has been paid to the age at which children grasp the essential components of the concept of death. It is unlikely, for example, that a two-year-old will be able to grasp any of the components, but most eight-year-olds of normal intelligence will have a fully developed idea.

The nine most frequently quoted components (Barbara Kane, 1979) are shown below:

<i>Component</i>		<i>Average age attained (in years)</i>
realization	the awareness of death	3
separation	the location of the dead – where are they?	5
immobility	the child's notions – are the dead alive or inactive?	5
irrevocability	permanent and irreversible or temporary and reversible?	6
causality	what brought about the death? violence, old age, sickness?	6
dysfunctionality	ideas of bodily functions other than the senses	6
universality	the child's ideas of mortality – everybody, nobody, some exceptions?	7
insensitivity	does the dead person dream, feel, think, hear?	8
appearance	does the dead person look different or the same?	12

Much of our knowledge on the subject is drawn from western Judaeo-Christian tradition and so is only partial. A child's cultural and religious background is highly relevant to his or her perception. The greatest influences arise, however, from actual experience, such as the death of a grandparent or sometimes, tragically, the early death of a parent or brother, sister or friend. It is often hard for children to articulate their thoughts and feelings about death, not least because adults tend actively or passively to discourage them from doing so. When young children do *speak* of death they will often mirror their parents' views and attempted explanations – 'She was very ill and the doctors and nurses couldn't make her better so Jesus took her to heaven to be with him'. But the familiar story ending, 'and they all lived (died?) happily ever after', implied here is an unhelpful stance for children – as indeed it is for adults – struggling with strong emotions of anger, guilt, confusion and the out-and-out grief and hell of separation from someone they love and ache for. Besides which, not all children think heaven is a good place to be. Some think it may be boring or even frightening – and the known is preferable to the unknown. Some children do not believe in life after death anyway.

If, in good times, family members communicate openly and honestly with each other, then it is likely that they will do so in difficult times. Unfortunately the converse is also true. A death in the family will not suddenly enable private, reticent people to bare their souls to one another, at least not for long. Children may choose not to talk about death – their own or anyone else's. 'It helps me to talk about it but I don't see why a child or a person should be forced into having to talk about it, not if they don't want to,' commented a ten-year-old. Sometimes children find it easier to talk to someone they trust outside the immediate family. This may well be one symptom of their strong desire to protect their parents from further pain: 'If I talk about it with them they either get cross or cry'. In this, as in many ways, we see children reversing roles and assuming parental concerns and responsibilities for their mothers and fathers.

Paul was twelve when he first visited Helen House. He suffered with cystic fibrosis but, his parents told us, he knew little about the disease or the prognosis. On his first two visits to us for respite care his parents chose to stay with him. Then one day he telephoned from home. 'Sorry to bother you but I'm bored at home and I'm fed up with my parents. Please can you book me into the Snoopy bedroom next week – and they won't be coming with me.' His parents took a good deal of persuading, but he was determined. Having elicited a promise from us that we would not initiate a discussion with Paul about his illness or its outcome, and having reluctantly accepted our proviso that if *he* initiated the discussion we could not break our rule about never deceiving or lying to a child, his parents left him with us. He said goodbye, transparently triumphant, and they had scarcely driven out through our gates before he turned to one of the team and said, 'I got cystic fibrosis real bad. I'll probably be dead this time next year. What's it like?' I do not know what answer she gave, but had it been other than brief and to the point he would have been the other side of the garden kicking a football around, or heavily into the Super-Nintendo.

It is never easy knowing how to respond to such questions. We have not ourselves died. We do not know what it is like to die, nor do we have tangible evidence of what life the other side of death is like. We may have faith to rely on, but we do not have proof or experience. It is acceptable to say, 'I do not know' or 'We do not understand' when these are the honest answers. We must not say anything we do not believe. Children will accept honesty, however frustrating, but they will not accept perceived pretence, humbug or deception.

Paul resumed the conversation several times more, at intervals of days or months, when he felt like it. Our role, as we understood it, was

to be open and ready to enter into dialogue and to follow his lead. Paul's parents did not want to believe that he knew he would die in the foreseeable future, and even when they did accept the fact I do not think that either they or Paul talked about it much together.

We subsequently learnt from the paediatrician looking after him that once when Paul was being admitted to hospital, a case conference was planned. As the doctor walked past him carrying Paul's medical notes and accompanied by other members of the ward team, Paul stopped him. 'Are you going to have a meeting about me?' The consultant said they were, but what made him ask? 'When no one was looking I made a yellow mark on the cover of my notes so I would know which were mine,' came the reply. And then, 'Can I come to the meeting?' He did, and this was the start of much more open communication between patient and professionals.

Increasingly, enlightened and sensitive paediatricians look for opportunities to involve their child patients in discussion and decision-making. It takes courage but is almost always helpful to all concerned. It is a little easier, though still deeply distressing, to discuss with the parents the probable death of their child than it is with the child concerned. Similarly, research has shown that parents more often talk to their healthy children about the death of their brother or sister than they do to the dying child. It is desperately hard to tell a child that he or she will soon go on to a future which we have not ourselves experienced and cannot accurately describe or measure, and that we cannot go with them – they must travel alone. 'I wish all four of us could die at the same moment so nobody need be sad,' was the comment of an eleven-year-old girl who knew her own death was not far off.

John came to stay with us a number of times in the last eighteen months of his life. Intelligent, ten years old going on sixty, meticulously polite, his emotions tightly controlled, it was difficult to know what went on inside him as he wrestled with an inoperable brain tumour. Then he came on an unaccompanied stay of a week or so and a little boy of four died in Helen House. Suddenly John's anger was unleashed and he railed against the injustice of life and death. 'I hate sunshine and green grass and flowers and trees and all the things that remind me of football and my bicycle and the things my brother can do and I can't any more.' A few weeks later he wrote:

Dear Mother Frances,

Thank you for your letter, other people's letters are always much more interesting than your own. Nothing interesting happened here – nor ever will. I only have my next visit to you to look forward to in life,

and I always think of you all when I'm depressed. I'm not always sure whose side God is on. I do hope he is on mine . . . Sorry it was such a dreary letter.

John

In another letter he wrote: 'I know God is there but he never seems to be there when you need him. Will he be there if I fall over? or if I fell down stairs?' This from a child who suffered with chronic vertigo.

Ann Goldman, paediatric oncologist, and Deborah Christie, clinical psychologist, undertook a study, published in 1993, of thirty-one children between the ages of three years and sixteen years, dying from progressive malignant diseases, to see whether the child's impending death was discussed between the child and the family. Twenty-six of the thirty-one children had been told that their disease had recurred. Twenty-eight of the families had another child over three years old; twenty-one (75 per cent) of these had told the siblings that their brother or sister was going to die. The twenty-two senior staff in the department where the children were treated were unanimous in advocating an open, honest approach in talking with children about their own death. In the light of these facts it is perhaps surprising to learn that of the thirty-one children:

the approach of death was mutually acknowledged by 6 of their families (19%);

7 children were felt to know but chose not to discuss death (23%);
in 2 families discussion with the child was blocked by the family (6%);

9 died unaware (29%);

in 7 families what the children felt was unknown (23%).

The mother of a child who died at the age of seven as a result of neuroblastoma is convinced that he was aware for some time of the probability that he would die, but most of the time he was intent upon a simple examination of the facts of his illness and treatment and on the task of living. His mother overheard a conversation between him and his five-year-old sister when they discussed where they would each like to be buried. Hamish was in no doubt that he would like to be buried in a churchyard not far from home where several relatives were already buried. 'Then we would all come out at night and have lovely spooky parties.' His mother felt strongly that it was important for him that they should be open with each other about his death, and a few days before he died he gave her the opening. 'Yes,' she said, 'you probably will die.' He reacted as if she had asked him to go for a very long walk on a stormy day. 'I'd really rather not,' was all he said.

Of the families who have stayed at Helen House since it opened in 1982, 12 per cent have two or more children affected with the same genetic illness. For children such as these who do not suffer progressive intellectual impairment as part of their illness, the distress of the longer surviving of the children in each family is unimaginable. Children with life-threatening or life-limiting illness who are able to observe and to reason are usually very well-informed about the course their illness will take, not least through noticing what happens to other children with the same condition. How much more so if it is your brother or your sister who is at a more advanced stage of the same illness as you!

A very articulate five-year-old with spinal muscular atrophy lived eleven months after her sister died. She often spoke of Zoë being in heaven and would ask to see photographs of her or to watch a video of them together when they were both bridesmaids shortly before Zoë died – 'to remind me what she looks like so I'll recognize her when I get there'. In the months before Leanne died she often put on her child's make-up before she went to bed at night – 'so I'll look really pretty when I meet Jesus'. But mostly she was very busy living and was totally occupied with the present moment. She became critically ill about four months after her sister's death but said clearly that she didn't want to go and find Zoë yet. Through what seemed to be sheer will-power, she survived another seven months.

Leanne clearly knew that she was going to die and said so, but she also had elaborate plans for when she was grown-up. She knew just what kind of man she was going to marry and she planned to have lots of babies. Indeed she practised being pregnant, persuading her mother to make her a maternity dress and stuffing a cushion up her front!

Holding on to two contradictory ideas at once is not only seen in young children. A seventeen-year-old boy in the advanced stages of muscular dystrophy spoke of his approaching death and, almost in the next sentence, of planning to work in computers. 'I know I'll be dead before I'm twenty-two . . . but that's all right.' 'Are you afraid?' After quite a long pause he said, 'No, but, you know, I don't really think too much about it, I just get on with living'. Told that his cheerful attitude to life had helped another muscular dystrophy sufferer, Peter said that although he knew what might happen to him, 'You can decide to be miserable or you can decide to be happy and being miserable only makes things worse and worse'.

A nineteen-year-old, also living with muscular dystrophy, was very anxious, angry and deeply depressed. He was a man of few words,

although he did express some of his feelings through drawing and painting. He was staying in Helen House when another teenager died. With a little encouragement he soon made a card for the other boy's parents, and joined them and several members of the team sitting at the round dining-table planning the funeral. He asked to come to the funeral. He bought flowers and placed them on the coffin and stayed for the funeral service. Afterwards he expressed the wish that his funeral could be 'lovely just like that'. He said it had taken all his fear away, and although he knew the fear would return he would always be able to think of the funeral he had attended and remind himself not to be afraid. For a taciturn young man this openness was remarkable.

A visit to the Ashmolean Museum was the trigger for a nine-year-old to release some of his feelings about his inevitable death. Fascinated by the Egyptian mummies, their tombs and artefacts, he asked why they put 'all those things in their tombs'.

'Because they thought they would need them in the next life.'

'Why were they wrapped in bandages?'

'Because they wanted to take their bodies with them.'

'Yes, I want to take mine.'

Fifty-year-old accompanying him: 'I'm not sure. As I get older and more worn out I think I'd rather like a new one.'

Pause.

'Yes, Maybe I could have one that worked . . . Anyway I know what heaven is like. It's like a lovely pub. You have a drink and forget all about the things that make you sad. My uncle does anyway.'

An eight-year-old whose twin, Beth, had died had a contrasting concept. 'Heaven is different for everyone. Heaven is where there are all your favourite things and favourite people. My heaven will be a huge gymnasium with trampolines and ropes and bars. All my friends will be there and Beth and Jenni.'

Just as children who believe in heaven picture it differently, so they have different ways of describing the transition from here to there – and what part of you it is that goes and why you don't come back. Kelly was three when children asked her where Jamie was. 'In heaven with Jesus.' 'And why can't he come back?' 'Cos he likes it there.' But Elizabeth, aged five, was angry with God: 'Dear Lord Jesus, you've had our Katie long enough now; we need her back please.'

Helping his mother to set a coal fire, a four-year-old reflected, 'He's gone somewhere else like the coal. Just the ashes left behind'; and a seven-year-old mourning the death of his dog said, 'He's left his skin behind'. But Jane was puzzled when she saw her sister's body. Playing

with the doll's house an hour or two later she asked, 'But how can she be in heaven with Jesus if she's in that little room?' And later: 'I thought when you were dead there was only your head. I thought all your skin peeled off.'

Many children who know that they will die soon are wise way beyond their years, with a maturity many of us will never attain. Occasionally, in the presence of one such, we sense that we can only, with Moses, put off our shoes from our feet, for the place on which we are standing is holy ground. Wheelchair-bound, spirit housed in diseased and handicapped body, such a child does not wait for heaven but seems to walk and jump and leap with God here and now. Those of us who stumble along beside can never be the same again. Two such have left an indelible mark on my soul. Jane and Garvan were both ten when I first met them. Jane died when she was thirteen, Garvan when he was twelve.

Jane tried to take her own life when she was ten. The burden of guilt she carried was too heavy. She and her one-year-old sister both had spinal muscular atrophy. Their parents' marriage was breaking up and Jane believed the demands her illness made on them were the major cause of the friction.

Jane's relationship with God had to be concealed from her father who became very angry at the mere mention of God or Christianity. But she was strong in her faith and her praying was part of her living.

Dear Lord, please look after everyone in the world, especially my friends and family. Most of all look after my sister Laura as she has the same thing as me but worse. She has a tube down her nose to be fed through and she is sucked out often. Please look after her and pray that one day she may be healed of her ulcer. Also Lord, please look after my mum. Please pray that she will win the court case. Pray that she will be able to cope with Laura and I and that she will no longer have migraines. Also Lord please look after me and pray that one day I will be able to walk too. Please look after my dad. Please look after all the handicapped and sick people in the world and pray that they will be able to cope. Please look after everyone. Pray that we all become closer to you and forgive us all for our sins. Amen.

Her mother did win custody of the children. After Jane's death I found a note in her handwriting on a small scrap of paper:

Why do I feel like this? We've won the court case. My mum has got custody of my sister and I. Oh why why why! All I have to do now is win my life. And I don't know how.

Yet through all this she busied herself with living, often proving to be an accurate observer of other people's ways of carrying on. 'When you're in a wheelchair people either treat you like a baby, or deaf or stupid. I'm not any of those. My body is handicapped but inside I'm just ordinary and I like people to treat me ordinary and do ordinary things with me.' With all her adult cares and concerns she loved to play and delighted in being a little girl again.

She openly talked of her illness and death. She was angry with her mother for agreeing to new treatment, still experimental. She refused it for herself and did not approve of Laura having it. 'God made me like this for a reason. You shouldn't interfere.' She was even more angry about an occasion when she had been visiting Laura in hospital and had watched while Laura stopped breathing and was resuscitated. 'Don't ever do that to me.'

With a sense of urgency, Jane asked to be confirmed in our Anglican chapel so that she could receive holy communion in the Roman Catholic Church when she attended with her grandmother. She made it clear that she wanted to have a headstone after she was dead. Her mother would need somewhere to visit.

We went to London on 20 December to see Bonnie Langford in *Peter Pan*. We were caught up in that wonderful make-believe world. Bonnie even gave us gold dust – and some to take home to Laura – so that when the grown-ups were asleep in bed we could learn to fly.

On Christmas Day Jane developed a lethal chest infection. The television played quietly in the corner of her bedroom and we saw Bonnie Langford flying again. Then we saw Jane herself in Helen House, talking with her beloved friend, the Duchess of Kent, with whom she had had countless early morning telephone conversations between personal encounters.

Jane died the following morning. Laura, now four years old, said 'But I wanted to die first', and five days later she died. They lay together in the 'little room' at Helen House until their funeral, Jane's arms enfolding her sister.

Garvan, from a wonderful Christian family where God is talked about as often and as naturally as the rest of us talk about what we have done at work or who is going to win the Cup Final, must speak for himself:

As I'm sitting here, I'm Garvan, right – but this isn't really me, my body is just a reflection. When I die I will leave my body behind and that reflection will fade. But the real me won't die. My real self will leave my body and will go up to God. At the moment when I die, I

believe Jesus will be standing right beside me with his arms outstretched, ready to take me to his father. Imagine the sheer excitement of meeting him for the first time!

I think of God as friend and guardian and the person who loves me. And of course He *is* the Father, He is not just any father, He's the Father of all of us, every one of us, me, you.

Jesus said, 'Don't be afraid, I am the light', and He is the Light; He shines, but we can't see it, but in the end we will see it. You see, God has the answers, we have the questions, and only in the end, when we come to the end of our life, He will tell us the answers. He'll have the answers.

Dying isn't really dying. It's just like opening an old door into a new room, coming from an old room into a new room, which is the place where you're going to live; Heaven, where you came from. Where you came from you have to go back to. That's your real home. I mean, we will all have to go one day, where it will be the happiest life of all. I mean, this earth is very happy but there are riots and things! But when we go into the other life, no sickness, no pain, no tears, just full of happiness and joy. I'm looking forward to that day. Heaven is so beautiful God can't describe it to us. We'll only know what it is like when we get there. I'm glad really that Jesus kept it a secret, because it will give us a surprise, it will give us such a big surprise.

And when I die, I do believe that Christ will look after my family and whatever they need He will provide for them. I shall always look down on them if I go before them. I will be there in the midst of my family. They might not see me, but I'll be there, watching them, looking after them, all the time.

On Easter Day, nine days before he died, I visited him and his family at home. He was sitting in a large armchair, wrapped up in a duvet, his face radiant and transfixed as he watched Alec McCowan recite St Mark's Gospel on television. 'I've always loved the gospels,' he said, 'but I've never seen anything as wonderful as this!'

I returned four days later. He was very sick and death did not seem far off. 'Do I have to die now?' he asked. Foolishly I reminded him of all that he so genuinely and fervently believed. 'Yes,' he said, 'but I love my family and my home and life so much, I don't want to go yet.' The next days were not easy. The transfusions he had referred to as his 'life-line' were no longer possible. He refused the medication prescribed to ease his physical distress in the belief that to accept it would be to hasten the end. To the last he was concerned about everyone else's well-being. 'Are *you* all right, Frances?'

Garvan never lost consciousness. His struggle at the end and his agony of parting in no way denied his faith; indeed it made it the more

real, for in the torment of a death not so unlike his Lord's he was united with the One who had been his friend and his example in life, the One whom he so loved.

Some of the names used are pseudonyms.